

**Adult Cancer Survivorship:
An Evaluation of Survivorship Care Planning and Follow-Up**

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ABSTRACT

Over 1 million Americans are diagnosed with cancer in a given year and currently there are approximately 12 million cancer survivors in the United States. With improved detection strategies and medical advances, the number of cancer survivors continues to rise, making survivorship care an increasingly important phase along the continuum of cancer care. The purpose of the current study was to investigate the emerging field of survivorship care, including care planning and follow-up, in survivors of different types of cancer. We quantitatively evaluated the post-treatment care received by 123 cancer survivors, including the use of survivorship care plans and the impact of these care plans and subsequent follow-up on a variety of behavioral health outcomes. We qualitatively assessed survivorship care providers' ($n = 8$) perspectives on comprehensive survivorship care and experiences delivering post-treatment services. The majority of participants (54%) are receiving a moderate level of survivorship care, including minimal receipt of a written care plan (31%) and some amount of referrals for mental health, diet, and physical activity (28%). Results suggest significantly lower general psychological distress ($F [1, 104] = 8.316, p = .005$) and higher coping self-efficacy ($F [1, 104] = 6.627, p = .011$) for those who received some form of written care plan versus those who did not. These results imply that written care plan documents have the potential to lead to higher psychosocial functioning for survivors of cancer. The qualitative data provide initial evidence supporting the value of SCPs for patients *and* providers. Critical barriers to implementation of comprehensive survivorship care and SCPs, from the providers' perspective, include the fragmented healthcare system and resources. The current study is an important step toward

increasing knowledge of and potential intervention targets to improve cancer survivorship experiences – from both the patients’ and providers’ perspectives. Future directions include developing a standardized system for delivering survivorship care and SCPs, and increasing the evidence base to examine the impact of SCPs on short- and long-term patient-reported and clinical outcomes, increase the focus on patient-centered care, and explore the impact of SCPs delivered to vulnerable groups of survivors.

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Chapter 1. Introduction and Aims

"Getting cancer can become the beginning of living. The search for one's own being, the discovery of the life one needs to live, can be one of the strongest weapons against disease."

Lawrence Leshan, Ph.D., *Cancer As a Turning Point*

A diagnosis of cancer is not only potentially life-threatening, it often comes with significant physical and psychological burden. Cancer and its treatment impacts an individual's health and well-being from the day of diagnosis through long-term survival. The overall prevalence of cancer is quite high and thus, attention to disease prevention efforts are paramount. Many people diagnosed with cancer (68%) survive their disease at least five years, placing importance on efforts to improve treatment and management (American Cancer Society [ACS], 2011; US Department of Health and Human Services [US DHHS], 2010). These elements – prevention, treatment and on-going management during cancer survivorship – encompass the cancer control continuum. A primary goal of survivorship research is to improve our understanding and management of the physical and psychological sequelae associated with a cancer diagnosis and treatment. Delivery and continual assessment of quality care to patients and survivors is critical to reduce the overall impact of cancer. Cancer care for the whole patient has the potential to improve short- and long-term health outcomes and thus maximize quality of life and longevity in individuals surviving cancer (Institute of Medicine [IOM], 2008).

As detailed in a 2006 IOM report, follow-up care and surveillance are important elements in the survivorship care research domain (Hewitt, Greenfield & Stovall, 2006). We do not yet know whether specific clinics or programs devoted to follow-up care are effective in detecting cancer recurrence, new primary diagnoses or preventing/reducing the late effects of the disease and its treatment (Hewitt, Greenfield & Stovall, 2006). The IOM report called for development of a standardized service delivery model for follow-up care, noting the need for consistency

across types of treatment centers, from large cancer centers to smaller community oncology practices (Hewitt, Greenfield & Stovall, 2006).

Interestingly, despite the new priority of cancer survivorship, there is a dearth of research on the actual care provided to survivors of cancer – including the effectiveness of different survivorship care approaches. Thus, empirical evaluation of the type, content, quality, and quantity of care provided to survivors is an important next step (Aziz, 2007; Jacobs et al., 2009). This, along with recent recommendations that comprehensive care should specifically include survivorship care plans (SCP) and the contrasting lack of consensus on the best approach to care, serves as the impetus for the current study design. An improved understanding of the current state of survivorship care is needed to guide and improve the development and implementation of effective comprehensive care models, potentially reduce recurrent and new primary diagnoses, and optimize adjustment, health and well-being.

The aims and hypotheses of the present exploratory study are to:

Aim 1. Assess the current status of survivorship care planning and follow-up.

H1: Survivors will report inadequate referrals and follow-up care regardless of whether they received a SCP.

Aim 2. Assess the strengths and weaknesses of the current models of care.

H2: Survivors with SCPs will report that these plans are specific about how to manage treatment-related side effects and cancer surveillance, but most ($\geq 75\%$) SCPs will lack specific recommendations for health behaviors such as healthy nutrition and exercise.

Aim 3. Weigh the evidence supporting or not supporting comprehensive survivorship care.

H3: Survivors who report receiving SCPs will report better outcomes (e.g., lower distress, higher quality of life, self-efficacy/activation, and satisfaction with care, and healthier lifestyles) compared to those who report not receiving SCPs.

Aim 4. Assess healthcare providers' experiences and perspectives on comprehensive survivorship care and SCP implementation.

H4: Healthcare providers will report low levels of systematic delivery of comprehensive survivorship care, including little experience using SCPs and lack of a formal system for providing and tracking referrals or communicating with providers across specialties. The providers are expected to have strong opinions about existing barriers to implementing SCPs and differing opinions on which provider should be in charge of developing SCPs.

Results of the current study will contribute to the conceptualization and design of comprehensive survivorship care interventions, including integration into the current models of care. The ultimate goal of this line of research is to reduce the overall burden of a cancer diagnosis and treatment.

Chapter 2. Background

2.1 Cancer Survivorship

Impact and Innovation. Over 1 million Americans are diagnosed with cancer in a given year (ACS, 2012). Currently, there are approximately 12 million cancer survivors in the United States and scientists estimate this number will grow to 18 million over the next decade (de Moor et al., 2013; National Cancer Institute [NCI], 2012; Siegel et al., 2012). As defined by the National Cancer Institute, “an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life”, and survivorship care typically refers to the post-treatment phase of the cancer care trajectory that entails the prevention and management of long-term and late effects of cancer and its treatment (NCI, 2012; US DHHS, 2010). In response to the growing rate with which individuals are surviving a cancer diagnosis, and the co-morbid health risks associated with cancer/its treatment, survivorship care has become increasingly important.

In addition to future efforts to evaluate and standardize models of survivorship care delivery, organizations such as the IOM and the American Society of Clinical Oncology (ASCO) have endorsed use of SCPs as part of comprehensive, quality care. SCPs include: a summary of treatment, health behavior prescriptions, psychosocial support referrals, wellness education, individualized surveillance plans, and information about the management of treatment-related side effects (ASCO, 2010; Hewitt, Greenfield & Stovall, 2006). Although SCPs have the potential to change the face of healthcare following cancer treatment, to understand the impact of SCPs, research is needed to examine their efficacy and effectiveness.

To date, little to no research has been done to measure the posited effects of SCPs on actual survivor outcomes (e.g., survival rates, surveillance adherence, health promotion,

decreased dysfunction resulting from adverse sequelae). Research is also needed to examine the utility, feasibility, implementation, and dissemination of SCPs if these plans will ultimately serve to improve survivors' short- and long-term health and well-being. The current study is innovative because it is one of the first to empirically assess the type, content, quality, and quantity of care provided to survivors of cancer. The proposed work uniquely seeks to explore associations between survivorship care planning/follow-up and psychosocial, quality of life, and health behavior outcomes. In addition to quantifying survivors' perspectives of their post-treatment care, our approach includes a novel in-depth assessment of survivorship specialists' and providers' perspectives on the utility, feasibility, and implementation of comprehensive survivorship care.

Transition in care. Transition from active treatment to more routine follow up is emotionally and physically complicated for patients. For cancer survivors, returning to a normal personal and professional life following treatment is considered a difficult “re-entry” due to a decrease in the amount of hospital visits and ongoing physician support and an increase in personal responsibility for the follow-up care associated with life-long recovery. Short-term follow-up care typically entails the monitoring of recovery, side-effects of treatment, and surveillance for recurrent and new primary cancers. Long-term care includes the same medical monitoring, in addition to screening for treatment-induced diseases and late effects, as well as co-morbidities such as heart conditions and neuropathy. The overwhelming, challenging and stressful nature of this transitional phase underscores the importance of comprehensive and continuous care in minimizing negative physical and emotional effects.

2.2 Impact of Cancer and Treatment

Cancer-related sequelae. Because survivors of cancer are living longer given improved treatment, concerns regarding the long-term and late health consequences of a diagnosis and treatment have increased. Despite recent progress in the long-term management of pain, fatigue and nausea, cancer patients still commonly experience physical and psychosocial effects from surgery and adjuvant therapy. ASCO's guidelines convey the importance of preventing and controlling side effects as a significant focus of a patient's healthcare team and the transition to survivorship care (2010). Patients remain at risk for experiencing a variety of deteriorations related to mental and physical health and well-being (ASCO, 2010; Bultz et al., 2006; Jacobsen et al., 2005; NCI, 2010; Zabora et al., 2001). These deteriorations may be exacerbated by a cancer survivors' experience of significant and recurrent stressors, including for example, undergoing cancer treatments, frequent hospital visits, undergoing invasive and recurrent medical procedures, dealing with side-effects of treatments and pain, isolation from work and friends, and monitoring the status of the cancer and its possible return (Deimling et al., 2002; IOM, 2008).

Physical health. Cancer patients often experience numerous physical sequelae that negatively impact their health and quality of life. Common short- and long-term side effects that may result from the cancer itself or cancer treatment (i.e., surgery and radiation/chemotherapy) include: pain, decreased energy, chronic fatigue, nausea, vomiting, skin sensitivity, scars, menopausal symptoms, infertility, sexual impairment/dysfunction, heart/liver failure, nerve damage/neuropathy, impaired cognitive functioning, and sleep disturbance (Pearce et al., 2008). Each of these side-effects can develop during treatment and linger for months or years following completion of treatment. The late effects of cancer/treatment can include: osteoporosis, cataracts,

lymphedema, lung disease, hypothyroidism, memory problems, liver and heart problems, and secondary cancers (Stein et al., 2008). Survivors' increased risk for other chronic diseases are exacerbated by unhealthy lifestyle behaviors, including risks for cardiovascular disease, type 2 diabetes, hypertension, and other cancers (Irwin & Mayne, 2008; Winzer et al., 2010). Based on the multitude of negative effects associated with a cancer diagnosis/treatment as well as the increased risk for other illnesses, and consistent with the goals of *Healthy People 2020*, comprehensive survivorship care aimed at preventing, minimizing, and managing these effects in cancer survivors is of critical importance.

Mental health and quality of life. Although most survivors of cancer successfully adjust to their pre-diagnosis lifestyles and routines, including reintegration into the workplace and familial roles and responsibilities, many experience psychosocial and emotional sequelae post-treatment (Hoffman et al., 2009; Kornblith, 1998; Stanton, 2006). Short- and long-term side effects from the cancer or cancer treatment often include: cognitive impairment, anxiety, depression, post-traumatic stress disorder (PTSD), diminished quality of life, decreased self-esteem, poor body image, and social isolation (Stein et al., 2008). The prevalence of psychological problems varies significantly by a number of clinical factors, including type and stage of the disease, time since diagnosis, level of impairment (i.e., physical and role impairment), experience of pain, and prognosis (IOM, 2008; van't Spijker, et al., 1997).

Cancer survivors may experience a broad range of significant anxiety, distress, and depressive symptoms (Costanzo et al., 2007; Deimling et al., 2002; 2006; IOM, 2008; Thomas et al., 1997). Emotional and psychological distress occurs in survivors of all cancer types and can persist for years (Burstein et al., 1992). Psychological distress is not only related to the invasive medical procedures and negative side-effects of treatment, but also worries and concerns about

disease relapse (Mehnert et al., 2009; Skaali et al., 2009). Continued monitoring for recurrence and late effects from treatment is stressful (Mullens et al., 2004). Adjustment disorder is the most common psychological diagnosis among individuals with cancer, with prevalence rates of approximately 30% (Derogatis et al., 1983; Miovic & Block, 2007). Just over 20% of cancer patients have been found to experience clinically significant anxiety, with over 40% reporting some level of anxiety (Breitbart, 1995; Schag & Heinrich, 1989; Stark et al., 2003). Nearly 25% of people with cancer experience major depressive disorders, a rate significantly higher than that of the general population (AHRQ, 2002; Miovic & Block, 2007).

Cancer survivors may also experience post-traumatic stress or PTSD. A cancer diagnosis represents a life-threatening event and several studies indicate that cancer survivors and their family members experience post-traumatic symptoms (Smith et al., 1999). PTSD incidence rates vary from 3-4% in patients newly diagnosed with early-stage disease, to 35% in cancer survivors assessed post-treatment (Gurevich et al., 2002). The rates are higher when evaluating PTSD-like symptoms (not full diagnostic criteria), ranging from 20% in patients with early-stage cancer to 80% in those with recurrent cancer (Gurevich et al., 2002).

In sum, many survivors experience mental health issues related to their cancer diagnosis and concern about relapse, including a decrease in quality of life and an increase in anxiety, depression, and PTSD symptomatology (Deimling et al., 2002; 2006; Derogatis et al., 1983; Gurevich et al., 2002; Hoffman et al., 2009; Kornblith, 1998; Mehnert et al., 2009; Miovic & Block, 2007; Skaali et al., 2009; Smith et al., 1999; Stanton, 2006; Thomas et al., 1997). Given these decrements in functioning, comprehensive care designed to augment the quality of life and mental health of cancer survivors is of critical importance (Hewitt, Greenfield & Stovall, 2006; IOM, 2008). Providing coordinated, continuous survivorship care for the whole patient has the

potential to transform the quality of care delivered – including patient-physician communication, patient satisfaction and survivors’ overall quality and longevity of life (Arora et al., 2011; Hewitt, Greenfield & Stovall, 2006; IOM, 2008).

2.3 Risk Reduction

In the general adult population, health behaviors are linked to cancer deaths such that approximately one-third of the greater than one half million cancer-related deaths in the U.S. each year are attributed to suboptimal dietary and physical activity practices (Demark-Wahnefried et al., 2008). Furthermore, growing evidence suggests a link between lifestyle and health behaviors and cancer recurrence and death. Specifically, maladaptive health behaviors (e.g., a sedentary lifestyle, unhealthy eating) have been found to lead to poor health-related outcomes in cancer survivors (e.g., increased rates of secondary and new primary cancers, cardiovascular disease, diabetes, cognitive impairment, fatigue; Irwin, 2008). Cancer survivors are already considered an at-risk population based on the nature and treatment of their disease; however, maladaptive or substandard health practices can further exacerbate their increased risk of disease and even death (Irwin, 2008). Due to the life-threatening nature of the disease, a cancer diagnosis commonly represents a “teachable moment,” during which healthcare providers have the opportunity to intervene and help survivors make necessary health behavior changes to improve their long-term health and well-being (Demark-Wahnefried et al., 2005; McBride et al., 2000; Pinto et al., 2013; Pollack et al., 2005).

Health behaviors, modifiable risk factors.

Health guidelines. Notably absent from standard cancer treatment protocols are specific health behavior recommendations or prescriptions. These types of lifestyle prescriptions also appear to be lacking in the care delivered to survivors of cancer. According to ASCO, cancer

patients are encouraged to follow established health guidelines, which include maintaining a healthy weight, not smoking and eating a balanced diet (2010). However, these general guidelines have proven difficult for the average adult, and are likely to be more challenging for adults post-cancer treatment (Demark-Wahnefried, 2005; Schmitz et al., 2005). To ensure cancer survivors are feasibly and successfully able to make necessary health behavior changes, survivorship care is expanding to include more specific and individually tailored prescriptions, based on empirical guidelines (Hewitt & Ganz, 2006; Jacobs et al., 2009; Rowland et al., 2006). Building upon these guidelines, researchers recommend specific diet and exercise regimens for cancer survivors as alternative goals for long-term survivorship (Demark-Wahnefried, 2008; Irwin, 2009; Pekmezi & Demark-Wahnefried, 2011). Physical activity among cancer survivors is safe and has a positive impact on overall physical and psychological functioning (e.g., energy and fitness levels, strength, fatigue, quality of life, anxiety, and depression; Demark-Wahnefried, 2005; Schmitz et al., 2005).

The American College of Sports Medicine (ACSM) recently released a consensus report based on a roundtable panel evaluating the evidence for physical activity during cancer survivorship and existing recommendations for exercise from the ACSM, the American Heart Association, the ACS, and the recent 2008 US DHHS Physical Activity Guidelines for Americans (Schmitz, 2011; Schmitz et al., 2010). Overall, the ACSM report documented the numerous benefits of exercise on daily physical functioning and quality of life and its relevance to cancer prevention and control. The report also documented the various injury risks (e.g., skeletal fractures due to bone metastases, changes in arm/shoulder symptoms in patients with breast cancer, increased risk of infection for those currently undergoing treatment) and moderating factors (e.g., cancer site and stage, treatment types, pre-diagnosis factors [e.g., age,

gender, fitness level, co-morbidities]) for healthcare providers to consider when making exercise referrals and prescriptions (Schmitz et al., 2010). Synthesis of consistent research evidence led the ACSM roundtable consensus to support the safety and efficacy of routine exercise in the general cancer survivor population (Schmitz et al., 2010). Broadly, the expert ACSM panel recommends that cancer survivors should follow the US DHHS “2008 Physical Activity Guidelines for Americans” while pursuing exercise programs that are specifically modified based on cancer site-specific factors and treatment-related side effects (Schmitz et al., 2010). These guidelines include aerobic activity (weekly activity of 150 min of moderate-intensity exercise or 75 min of vigorous-intensity exercise, or an equivalent combination); strength training (perform two to three weekly sessions that include exercises for major muscle groups); and flexibility (stretch major muscle groups and tendons on days that other exercises are performed). The ACSM roundtable report provides clear and evidence-based recommendations in the areas of physical activity and cancer survivorship.

In a study assessing survivors’ perspectives of survivorship care, Arora and colleagues (2011) found that quality perceptions were among the lowest with regard to discussions about health promotion. A pilot study with a sample of colorectal cancer survivors at high risk for developing a second colorectal cancer found that 60% received recommendations from their oncologist regarding physical activity practices, 30% received dietary recommendations, and only 20% received both (Kelleher et al., 2011). With regard to specificity, survivors reported their oncologists made general recommendations to “stay fit” and many reported that their oncologists were “not specific” in their recommendations (Kelleher et al., 2011).

Overall, these findings suggest a weakness in the quantity and quality of survivorship care with regard to the physicians’ role in broaching the topic of health behavior guidelines and

recommendations with survivor patients. Although it is not expected that oncologists and primary care physicians will conduct comprehensive health behavior interventions, cancer survivorship experts assert the importance of oncologists and primary care physicians, among other care providers, discussing health behaviors with their patients and subsequently providing prescriptive referrals as needed (Hausman et al., 2011; Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008). Therefore, researchers suggest that physicians and/or members of healthcare teams become aware of the benefits of healthy lifestyle behaviors and current health guidelines. Improved awareness will facilitate provision of appropriate and effective prescriptions, referrals and high-quality comprehensive survivorship care (Irwin, 2009; Irwin & Mayne, 2008).

Fortunately, cancer survivors look to their oncologists and primary care physicians for guidance with regard to changes needed to improve quality and longevity of life (Aziz, 2007; Pollack et al., 2005). As this guidance includes health behavior change, survivorship care providers will play a vital role in health promotion efforts during this “teachable moment” (McBride et al., 2000; Pollack et al., 2005). Patient education and counseling can impact a broad range of health outcomes by addressing adherence to key health guidelines (Aziz, 2007; McBride et al., 2000; Pinto et al., 2013; Pollack et al., 2005). Data from a randomized trial conducted by Pinto and colleagues show that oncology healthcare provider advice for physical activity combined with 3-months of telephone counseling led to significant improvements in physical activity among breast cancer survivors at a 6-month follow-up compared to the standard contact control group (2013). These findings provide empirical support for the potential to promote health behavior change during the survivorship phase of care (Pinto et al., 2013).

Adherence to health guidelines among survivors. Despite the documented effects of a healthful lifestyle and evidence-based health guidelines, only a minority of cancer survivors adheres to physical activity guidelines (less than 30%; Schmitz et al., 2005). Furthermore, only 25%-42% of survivors consume adequate amounts of fruits and vegetables (Demark-Wahnefried, 2005). The aforementioned findings detailing the benefits of engaging in healthy behaviors, the safety of physical activity for cancer survivors, and the low rates of adherence have major implications for survivorship care. Health behavior referrals and prescriptions should become a standardized component of survivorship care.

Empirical support for health behavior interventions. The burgeoning evidence base pertaining to health behavior interventions during cancer survivorship demonstrates the safety, efficacy, and feasibility of adoption and maintenance of healthy behaviors (i.e., exercise, healthful diet) in people surviving cancer (Pekmezi & Demark-Wahnefried, 2011). Results of a thorough review of the extant literature indicate that, for cancer survivors, physical activity interventions improve fitness, strength, physical function, and cancer-related psychosocial variables, and dietary interventions produce improvements in diet quality, nutrition-related biomarkers, body weight, and psychosocial health (Courneya & Friedenreich, 1999; Doyle et al., 2006; Ferrer et al., 2011; Pekmezi & Demark-Wahnefried, 2011; Schmitz et al., 2010). The critical role of good nutrition and routine exercise in cancer prevention and control continues to emerge with a growing body of evidence that suggests both health behaviors can decrease the risk of many cancers and even extend survival for survivors of some cancers (American Institute for Cancer Research [AICR], 2007; Courneya & Friedenreich, 2001; 2007; 2011; Demark-Wahnefried et al., 2006; 2008; Holmes et al., 2005; Irwin et al., 2008; Meyerhardt et al., 2006; 2006; Pekmezi & Demark-Wahnefried, 2011; US DHHS, 2008).

2.4 Comprehensive Survivorship Care

The National Comprehensive Cancer Network (NCCN) has released new clinical practice guidelines for cancer survivorship (2014). Although these guidelines include, among other things, information about the management of side effects and detection strategies, health promotion recommendations, and support resources, they have yet to be formally integrated into current survivorship care practice (Arora et al., 2011; Centers for Disease Control & Prevention [CDC], 2011; Hewitt & Ganz, 2006; Hewitt, Greenfield & Stovall, 2006; IOM, 2008). From the patient's perspective, physicians' information exchange and coordination of care are often associated with lower ratings of care (Arora et al., 2011). These findings reveal a deficit in our current survivorship care paradigm and highlight the need for systematic integration of comprehensive, coordinated care for the whole patient. This integration could include education, prescriptive health behavior referrals, mental health resources, and sustained behavioral follow-up procedures for cancer patients. Improving our understanding of how different survivorship care efforts impact health outcomes, quality of life, costs, and survivor perceptions and satisfaction with care is an important next step in the evolution of comprehensive survivorship care.

Continuity and coordination of care.

Barriers. Early research in the field of survivorship care has revealed several barriers to providing high quality, continuous, coordinated care. In addition to funding and resources (e.g., time, staff), primary barriers involve a lack of preparedness (inadequate knowledge of survivorship care guidelines), considerable differences between oncologists and primary care physicians regarding knowledge, attitudes, and practices related to adequate care for survivors, as well as a lack of communication among survivorship care providers (Bober et al., 2009; Faul

et al., 2010; Irwin et al., 2011; Potosky et al., 2011; Snyder et al., 2009). In a study of primary care physicians, those responsible for the majority of long-term survivorship care, only about 25% of physicians met criteria for providing comprehensive post-treatment care (Bober et al., 2009). Moreover, nearly half (47%) of these primary care physicians reported inadequate preparation and a lack of formal survivorship care training as a significant barrier to delivery of survivorship care (Bober et al., 2009).

Research comparing oncologists' and primary care physicians' knowledge and attitudes regarding the delivery of survivorship care indicates that primary care physicians were more likely to endorse routine use of non-recommended tests for detecting cancer recurrence (Potosky et al., 2011). Both oncologists and primary care physicians stray significantly from survivorship care guidelines when delivering care to adult cancer survivors (Potosky et al., 2011). Among nurses in the first five years of their oncology practice, almost half reported insufficient knowledge, while about 35% of nurses with five or more years of oncology experience reporting the same (Irwin et al., 2011). Across delivery mode and provider type, improvements are critically needed in evidence-based survivorship care models and provider education and training (Bober et al., 2009; Gage et al., 2011; Gamble et al., 2011; Hewitt, Greenfield & Stovall, 2006; Irwin et al., 2011; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006).

Overcoming the barriers. Consonant with the IOM's survivorship care agenda, researchers are identifying ways to begin addressing barriers to effective care delivery and have named overall preparedness and coordinated care and communication as targets for improving the quality, continuity, and coordination of care (Cheung et al., 2009; 2010; Faul et al., 2010; Gamble et al., 2011; Hausman et al., 2011; Hewitt & Ganz, 2007; Hewitt, Greenfield & Stovall, 2006; Hudson et al., 2009; Snyder et al., 2009). Specifically, work must begin with the

healthcare providers (namely oncologists and primary care physicians) with a focus on preparedness to ensure those on the front lines of healthcare delivery are adequately prepared to treat survivors (Bober et al., 2009; Gage et al., 2011; Klabunde et al., 2009; Snyder et al., 2009). Improvements in preparedness are most feasibly done via improved education and training programs (Gamble et al., 2011; Irwin et al., 2011; Papagrigoriadis et al., 2001). Once the healthcare providers have the foundational knowledge to adequately care for their survivor patients, communication between the multidisciplinary team of specialists and primary care physicians becomes of utmost importance to facilitating continuity and coordination of care (Gamble et al., 2011; Potosky et al., 2011; Snyder et al., 2009). Physicians perceive that survivors' quality of and satisfaction with care is significantly increased with greater coordination of care between oncologists and primary care physicians (Cheung et al., 2009; 2010; Grunfeld et al., 2006; Grunfeld, 2008; Nekhlyudov & Latosinsky, 2010). Thus, there is a critical need for healthcare providers to agree on how to effectively provide and communicate about comprehensive survivorship care, including management of long-term and late medical effects of cancer treatment, guidelines for health behaviors, and assessment of psychosocial support needs (Grunfeld, 2008).

Survivor-reported needs. Cancer survivors report dissatisfaction with the limited information received as well as the timing of when they receive it (IOM, 2008). Survivors' report of needing more information from their physicians reveals another gap in the quality of survivorship care (Burke Beckjord et al., 2008; Royak-Schaler et al., 2008). As effective physician-patient communication is positively associated with patients' health outcomes, cancer survivors' reports of poor communication is of significant concern (Engel & Kerr, 2003; IOM, 2008; Kaplan et al., 1989; Maliski et al., 2004). Although survivors of cancer have diverse

information needs, the general survivor population is not receiving adequate information related to long-term survivorship (Burke Beckjord et al., 2008). Therefore, the lack of adequate, effective patient-physician communication has implications for the long-term health and quality of life of adult cancer survivors (Arora, 2003; 2011).

In a sample of 1,040 adult cancer survivors between two to five years post-diagnosis, survivors reported needing *more* information related to maintaining good health outcomes, although information needs varied based on age, ethnicity, gender, type of cancer, and comorbidities (Burke Beckjord et al., 2008). Specifically, survivors of cancer indicated the need for more information about tests and treatments, insurance, health promotion and side effects and symptoms (interpersonal, emotional, and sexual function and fertility; Burke Beckjord et al., 2008). With regard to the health promotion category, about 68% of the adult survivor sample reported needing more information about decreasing the risk of having cancer again, nutrition and diet, and staying physically fit (Burke Beckjord et al., 2008). Furthermore, those who indicated more information needs were also more likely to report poorer mental and physical function (Burke Beckjord et al., 2008). Royak-Schaler and colleagues examined survivorship care and patient-physician communication from the patient's perspective, and identified differences in the information, or lack thereof, provided to patients by their physicians (2008). Specifically, there was "strong interest" among a sample of breast cancer survivors in receiving specific health behavior recommendations, with approximately 90% of the sample indicating never receiving such lifestyle prescriptions (Royak-Schaler et al., 2008).

In a study examining survivorship care in a sample of Australian breast cancer survivors, researchers found that following treatment, women reported concerns about communication between a multidisciplinary team of physicians as well as information needs regarding follow-up

care (Brennan et al., 2011). The sample expressed enthusiasm for a written document, such as a SCP, to organize survivorship care and address these issues (Brennan et al., 2011). Survivors' awareness of the need for primary and secondary prevention is encouraging; however, these findings highlight the increased risk for adverse sequelae resulting from a lack of knowledge and preparation as they transition into the survivorship phase of care (Burke Beckjord et al., 2008). Overall, empirical evidence confirms the IOM's cancer survivorship care agenda – including the focus on patient-centered care for the whole patient – for enhancing care via improvements in coordinated and comprehensive care efforts (Brennan et al., 2011; Burke Beckjord et al., 2008; Royak-Schaler et al., 2008).

Survivorship care models (Table 2). Different strategies for delivering survivorship care have been developed over the previous decades and continue to evolve with our increased knowledge and understanding of the challenges facing survivors of cancer. While there is a pressing need for empirical evaluation of the current types of survivorship care, several care models exist. Due to the identified challenges facing cancer survivors, survivorship care models are designed to formalize the services available to survivors and more systematically treat and control the long-term and late effects of a cancer diagnosis and treatment. Survivorship care models have been designed based on the differences in healthcare settings in the United States (e.g., community practice vs. academic institutions) and the variable needs of the diverse survivor population. Thus, researchers and practitioners have denoted no one “correct” or “best” model, nor have they identified one that will be effective across all settings (McCabe & Jacobs, 2008). Research has also revealed a lack of consensus regarding which healthcare provider (e.g., general practitioner, nurse, oncologist, surgeon) is best suited to coordinate survivorship care (Baravelli et al., 2009; Jefford et al., 2011). Instead, the focus of survivorship care is on the

components and characteristics of each distinct model and the ability for each model to successfully meet the survivorship needs of the patients served, within the capacity of the institutional setting (Oeffinger & McCabe, 2006).

Components critical to the effective delivery of adult survivorship care apply whether the care is delivered in a community oncology office, community hospital, academic medical center, or cancer center (see Table 1; McCabe & Jacobs, 2008). The survivorship care components common across care models and delivery settings include: surveillance guidelines for recurrent and new primary cancers; assessment, treatment, and management of medical and psychosocial effects of the cancer/treatment; health promotion recommendations, and development of a care plan for the patient (Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Although the organization and delivery of these care components differs based on a variety of factors (e.g., setting, patient characteristics, available resources), leaders in the field of survivorship care have identified these components as essential to effective comprehensive survivorship care (Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006).

Currently, there are three unique models for delivery of survivorship care: 1) shared care; 2) nurse-led care programs; and 3) the survivorship clinic model, which includes comprehensive and disease-site specific care clinics (Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Despite the shared goal of meeting the diverse needs of cancer survivors, each of these models differs in focus and organization (McCabe & Jacobs, 2008). Specifically, the coordination and delivery of the essential components of care varies based on the complexity of the care model in conjunction with the resources available in the particular healthcare setting. Irrespective of the differences between models, consistency lies

with the key providers of care being oncology nurses and nurse practitioners (McCabe & Jacobs, 2008).

Shared care. First, the shared care model, based in a community setting, refers to a shared responsibility for patient care between at least two healthcare providers from different specialties (Hewitt, Greenfield & Stovall, 2006; Oeffinger & McCabe, 2006). This approach to cancer survivorship care is designed after the well-established shared care model for the treatment and management of chronic disease (McCabe & Jacobs, 2008). Thus, it is particularly beneficial for the management of patients with chronic and co-morbid diseases, as it facilitates periodic communication between physicians with disease-specific specialization (Oeffinger & McCabe, 2006). This model is also especially promising for survivors of adult cancer since adults (especially older adults) are more likely to experience co-morbidities, or at least increased risk for co-morbid disease (McCabe & Jacobs, 2008). Despite the presumed benefits of the shared care model, it is not well established with respect to the adult cancer survivor population and therefore is not without fault. Because significant work is yet to be done to further develop this cancer survivorship care model, one weakness of the shared care model entails the lack of differentiation of roles and expectations regarding who is responsible for which issues (McCabe & Jacobs, 2008). Thus, improvements in this shared care approach to cancer survivorship will involve more clearly defining and distinguishing the roles of each care provider in addition to establishing ongoing communication between providers.

According to the shared-care model, the primary care clinician is usually considered the point of contact and coordinator of the patient's survivorship care, though some shared-care approaches enlist a nurse as coordinator. Most commonly, the primary care physician is responsible for addressing all of the patient's physical and emotional health needs, or making

referrals as needed to effectively address the health issues that require the attention of a specialized physician (Hewitt, Greenfield & Stovall, 2006). Thus, treatment and management of survivors' medical recovery (i.e., surveillance of recurrent and new primary tumors, identification/treatment of adverse health-related sequelae), psychosocial health, and health promotion efforts can occur 'in-house' and through consultation, classes/support groups, or by referral to an outside specialist or survivorship program. Successful sharing of care between generalist and specialist in this care model requires ongoing communication and consultation, as well as a common understanding and expectation of roles (Hewitt, Greenfield & Stovall, 2006). Ineffective shared care can potentially result in unsuccessful transfer of care, delayed diagnostics, excessive and unnecessary testing, increases in patient anxiety and distress, and decreases in quality of life (Hewitt, Greenfield & Stovall, 2006; Grunfeld et al., 1999b).

Despite ongoing debates about primary care physicians' preparedness and effectiveness in treating cancer survivors over the long term, research findings from shared care initiatives in Europe, Canada, and Australia reveal the feasibility of providing adult cancer survivorship care in a primary care setting (Brennan et al., 2011; Grunfeld et al., 1996; 1999a,b). Specifically, results of a randomized controlled trial comparing breast cancer survivorship care in a primary versus specialty care setting suggest that, compared to specialists, primary care physicians provide adult cancer survivorship care at a lower cost, with higher levels of patient satisfaction (Grunfeld et al., 1996; 1999a,b). A randomized controlled trial assessed for recurrent tumors, 'serious clinical events,' health-related quality of life, and death in survivors cared for by a primary care physician versus survivors cared for by a specialty physician, and found no statistically significant differences in outcomes (Grunfeld et al., 2006). Overall, these findings

suggest that primary care physicians can be key providers of survivorship care, without compromising patients' disease-free survival and quality of life.

Nurse-led care. Second, the nurse-led model of survivorship care, a good fit for community hospitals and hospital outpatient departments, is one of the more well understood models with similarities to the pediatric oncology model of survivorship care (Hewitt, Greenfield & Stovall, 2006). Although nurse-led cancer survivorship care is not yet as widely implemented in the United States as it is in other countries (e.g., Australia), nurses have historically played a central role in interdisciplinary healthcare efforts in the United States and have also been successfully providing care for childhood survivors of cancer for many years (Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). What's more, nurse-led cancer survivorship care has the potential to extend delivery of quality care to individuals of low income and in rural areas (Desch et al., 1999; Hewitt, Greenfield & Stovall, 2006; White et al., 1996). Nurses receive comprehensive training in the assessment, treatment, and management of a broad range of disease symptomatology, psychosocial care and care planning, and are also known for their role as liaison between the physician and patient (Ferrell et al., 1995; 1997; 1998; 2006). This background and expertise makes nurses an ideal choice for facilitating continuity and coordination of ongoing patient care in various geographic and clinical settings (Hewitt, Greenfield & Stovall, 2006).

Given their increased presence in academic and research-oriented healthcare settings, oncology nurses are playing key roles in cancer control programs and cancer survivorship research (Dow et al., 1999; Ferrell et al., 1998; 2003a, b; Ritz et al., 2000). The nurse-led model of care could take on various forms, including one or several of the following options: a nurse acting as coordinator of care working in collaboration with the treating physician (i.e., oncologist

and/or primary care physician); a nurse acting as coordinator of a multidisciplinary team providing survivorship care; a nurse engaging in regular in-person or telephone follow-up consultations with survivors. As a result of the various nurse-led approaches, treatment and management of survivors' medical recovery and psychosocial health, in addition to health promotion efforts, can occur 'in-house' and through consultation, or by referral to an outside specialist or survivorship program.

Research comparing nurse-led versus standard doctor-led care have largely found that nurse-led care has the potential to increase the continuity of care, while also effectively addressing survivors' needs due to an increased amount of time available to provide comprehensive care (Koinberg et al., 2004; Lewis & Hendry, 2009; Lewis et al., 2009). This research also suggests that nurse-led care is either as effective or more effective in providing quality comprehensive care, citing no differences in patients' psychosocial well-being, satisfaction, and timing to recurrence or death (Helgesen et al., 2000; Koinberg et al., 2004; Lewis et al., 2009). Furthermore, results of several studies examining nurse-led models of survivorship care have identified a number of positive outcomes, including a smooth transition into survivorship, needs originally reported as unmet were met during follow-up, improved QoL and higher rates of emotional functioning, increased patient and physician satisfaction with care, and projected three-year cost savings (Grunfeld, 2009; Jefford et al., 2011; Knowles et al., 2007; Lewis & Hendry, 2009; Lewis et al., 2009; Moore et al., 2002). Overall, accumulating evidence suggests nurse specialists managing survivorship care has the potential to enhance the quality of care provided to survivors due to facilitating the continuity and coordination of care as well as patient satisfaction, while affordably and effectively addressing survivors' diverse needs (Beaver

et al., 2009; Hewitt, Greenfield & Stovall, 2006; Grunfeld, 2009; Jefford et al., 2009; Lewis & Hendry, 2009; Lewis et al., 2009; Verschuur et al., 2009).

Survivorship follow-up clinics: Comprehensive and disease-site specific care. Third, survivorship follow-up clinics, most prevalent at comprehensive cancer centers and academic institutions, include comprehensive and disease-site specific care. Broadly, survivorship clinics are multidisciplinary resources with healthcare staff trained in after care and survivorship issues with the primary goal to “empower cancer survivors to take steps to maximize their health, quality of life, and longevity” (Yale Cancer Center, 2010). Survivorship clinics utilize healthcare teams made up of experts from various health disciplines, including oncologists, exercise physiologists, nutritionists, social workers, and psychologists to address survivors’ medical, psychological, social, and educational needs via one-time consults and ongoing risk-based care. These healthcare professionals assist patients in creating SCPs, which include a summary of treatment, specific health behavior prescriptions (e.g., nutrition counseling, exercise and fitness recommendations) and psychosocial support and emotional care (e.g., treatment of post-traumatic stress, sexual health), in addition to wellness education, individualized surveillance plans, and management of treatment side effects (Hewitt, Greenfield & Stovall, 2006; Yale Cancer Center, 2010).

In addition to medical care, survivorship clinics can also include psychosocial and health behavior interventions, health education classes, and support groups. Although there is still significant work to be done (e.g., increasing reach of and examining effectiveness of survivorship clinics), it is extremely important that health scientists and practitioners continue to join forces to create transdisciplinary resources for cancer survivors post-treatment. This

multidisciplinary model of care is believed to significantly benefit survivors' long-term health and quality of life.

Disease-site specific care. Survivorship clinic care can take the form of both disease-specific and comprehensive survivor programs (Hewitt, Greenfield & Stovall, 2006; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Disease-site specific care clinics entail the delivery of multidisciplinary healthcare focused on the post-treatment needs of survivors of one particular form of cancer (e.g., M.D. Anderson Breast Cancer Survivor Clinic, Houston, TX; Hewitt, Greenfield & Stovall, 2006; Oeffinger & McCabe, 2006). The disease-specific approach is considered the first iteration of the survivorship care model, most commonly known for its use in the breast cancer survivor population (McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Although late and long-term consequences of a diagnosis and treatment can be common across tumor sites, many adverse effects are unique to the disease site. As such, multidisciplinary disease-specific initiatives were developed to address and manage the wide-ranging sequelae experienced by a large proportion of survivors of a particular form of cancer (Oeffinger & McCabe, 2006). These single-disease programs can be stand-alone clinics, independent of the larger cancer center services, or integrated into the institution's survivorship services (McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006).

Comprehensive care. Comprehensive survivor programs are multidisciplinary programs with the goal of providing a broad range of healthcare services to a diverse group of cancer survivors (e.g., The Lance Armstrong Foundation, Austin, TX; Hewitt, Greenfield & Stovall, 2006; Oeffinger & McCabe, 2006; INSPIRE; Survivorship Training and Rehab [STAR]). Comprehensive survivor programs can be characterized by three distinct models of healthcare delivery: 1) consultation, 2) nurse practitioner-led survivorship clinic, and 3) specialized,

multidisciplinary survivor program (McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). The specialized, multidisciplinary survivorship clinic program most closely follows the pediatric oncology model of survivorship care. That is, risk-based care is delivered by a multidisciplinary team specialized in survivorship issues (Oeffinger & McCabe, 2006). Although this model is believed to be a good fit for the provision of care to groups with smaller numbers of survivors, survivorship experts and healthcare providers are faced with the challenge of adapting this approach for the care of groups with larger numbers of survivors; thus, because it is so complex and resource intensive, the specialized, comprehensive program is not without limitation (Oeffinger & McCabe, 2006).

As reported by the IOM, well-established survivorship clinics serve approximately 300-400 survivors each year, with newer and smaller programs serving 50-60 annually (Hewitt, Greenfield & Stovall, 2006). Cancer survivors assessed through a survivorship clinic model are typically seen following completion of care – when they are disease free – by their treating oncologist (Hewitt, Greenfield & Stovall, 2006). Thus, survivors seen in the survivorship clinic setting are usually about 2 years removed from the completion of active treatment and/or approximately 3 to 5 years post-diagnosis (Hewitt, Greenfield & Stovall, 2006). As survivorship clinics are still relatively new, they are either autonomous within the medical institution or partially integrated into institution-wide care. Thus, short-term goals have included piloting care programs that will impact the broadest number of cancer survivors, with the long-term goal of becoming an institution-wide program that integrates clinical and research resources (Oeffinger & McCabe, 2006). To ensure long-term success and sustainability, however, survivorship clinics must deliver cost-effective and clinically-relevant care that meets the ongoing medical and psychosocial needs of cancer survivors (Oeffinger & McCabe, 2006).

The need for complex treatment plans and coordinated care efforts in the long-term management of cancer survivorship requires a comprehensive care approach (Horvath et al., 2010). Cancer survivorship care in a multidisciplinary setting leads to improved health outcomes, especially with regard to clinical efficiency and seamless care (Carlson et al., 2008; Horvath et al., 2010). Although physicians have reported dissatisfaction with the referral process related to outpatient survivorship care, survivorship care in a multidisciplinary setting is believed to improve the continuity and coordination of care through facilitating provider communication (Gandhi et al., 2000; Horvath et al., 2010). Additionally, survivors have reported strong preference for a “one-stop diagnostic clinic” rather than a “multiple-visit approach,” in addition to higher rates of satisfaction among those who received multidisciplinary care (Berry et al., 1998). Improvements in patient satisfaction have also been associated with increased comprehensive care and support received in a multidisciplinary setting (Gabel et al., 1997; Walker et al., 2003). These findings further provide support for the delivery of survivorship care in one multidisciplinary setting (Horvath et al., 2010).

Along these lines, researchers and clinicians have proposed use of a patient-centered medical home (PCMH) conceptual framework for cancer survivorship care (Hudson et al., 2012). The PCMH is a model of primary care designed to address the unique needs of the whole patient, improve care quality, and increase patient satisfaction (Arrow et al., 2009; Wise et al., 2011). PCMH is multidisciplinary, coordinated and continuous team-based care that promotes active outreach to and engagement of the patient (Wise et al., 2011). The PCMH approach is likely a good fit for post-treatment cancer care considering survivors’ chronic and co-morbid health concerns (Hudson et al., 2012). Accountable care organizations (ACO) – as denoted in the Patient Protection and Affordable Care Act (PPACA) – is a similar concept as they intend to

provide high-quality integrated care to individuals with chronic illness (Centers for Medicare and Medicaid Services, 2014).

Overall, each of these care models share similar core components and thus demonstrate some degree of overlap (e.g., nurse specialists acting as coordinator of care, inclusion of SCPs in treatment protocol, some level of shared care and/or referral system), while also containing many aspects of the pediatric oncology care model (e.g., nurse specialists acting as coordinator of care, multidisciplinary team, risk-based care). Despite overlap in the characteristics and components between models, each care model can also be considered a unique fit for its designated setting, accounting for the distinct needs of patients served and the resources available. With only an estimated 5% of cancer survivors being treated at academic centers, the vast majority of the cancer survivor population is receiving survivorship care in the community (Wolfson, 2010). Since shared-care and nurse-led approaches are the primary models of care in the community, there is a critical need to increase the accessibility of academic center-type comprehensive survivorship care programs while also enhancing the community-based models of care.

In spite of a dearth of research examining healthcare provider perspectives with regard to cancer survivorship care, Gage and colleagues recently found that oncology clinicians (e.g., oncologists, oncology nurses) prefer a *combination* of survivorship care delivery models (2011). The oncology clinicians assessed reported beliefs that services related to the treatment and management of survivors' medical recovery should be provided in a disease-specific oncology clinic, whereas all other survivorship issues (e.g., psychosocial concerns, health promotion) should be addressed in a comprehensive clinic setting (Gage et al., 2011). While the continued evolution of survivorship care models is more than promising, significantly more research is

needed to evaluate these models of care, including their sustainability and cost-effectiveness, not to mention their effectiveness on health promotion, disease prevention, and survival outcomes.

Funding issues and insurance coverage for comprehensive survivorship care. Despite the obvious appeal of multidisciplinary patient-centered clinics, barriers exist due to a lack of empirical support and funding. One significant barrier includes the frequent denial by health insurers given the lack of empirical evaluation of the effectiveness and value of such programs (Hewitt, Greenfield & Stovall, 2006). Thus, without empirical support, health insurers have argued that such comprehensive long-term care is medically unnecessary (Hewitt, Greenfield & Stovall, 2006). Furthermore, cost analyses have shown that when reimbursement is provided, it is often inadequate and therefore does not cover the time and effort that is required for long-term treatment and management of survivors (Hewitt, Greenfield & Stovall, 2006). Unsurprisingly, until the effectiveness of comprehensive survivorship clinics is demonstrated, funding remains an ongoing challenge (Hewitt, Greenfield & Stovall, 2006).

Health insurance coverage for cancer survivors varies significantly based on the type of plan in which an individual is enrolled in; however, regardless of the healthcare plan, cancer survivors are likely to have high out-of-pocket expenses (mostly accounted for by prescription medications; Hewitt, Greenfield & Stovall, 2006). Researchers reported that for a group of insured cancer survivors who have completed treatment, out-of-pocket, cancer-related costs could range from \$700 to over \$1,000 per month for both medical and non-medical direct expenses (e.g., insurance premiums, co-pays for medications and physician visits, lost wages, and travel to appointments; Pisu et al., 2010). Research also suggests that about 13% of cancer patients spend more than 20% of their annual income on healthcare and insurance premiums (Bernard et al., 2011). Consequently, indebtedness is a significant concern among cancer

survivors. In a sample of colorectal cancer survivors, researchers found that 25% were in debt because of treatment and the average debt totaled over \$25,000 (Shankaran et al., 2012). Considering the higher likelihood of co-morbid disease in the cancer survivor population, these estimates should be considered minimums. In addition, survivors could be refused coverage for some aspects of their care (e.g., out-of-state consultations) or denied access to covered services if the specialist needed to deliver a particular service is considered outside the plan's network of providers (Hewitt, Greenfield & Stovall, 2006).

Healthcare reform and comprehensive survivorship care. Although coverage for most of the healthcare services needed by survivors is regulated by state policies, some types of coverage are mandated by the federal government. For example, The Women's Health and Cancer Rights Act of 1998 requires that insurers who cover mastectomy surgeries must also cover related services (e.g., reconstructive surgery; Hewitt, Greenfield & Stovall, 2006). The passage of the PPACA in 2010 included important provisions for cancer survivors, with increased access to coverage and elimination of pre-existing condition exclusions among the most important (US DHHS, 2014; Moy et al., 2011). Under PPACA legislation, insurance plans also cannot charge higher premiums for those with health conditions, such as cancer, drop someone's coverage because they are diagnosed with cancer, or deny access to approved clinical trials but instead are required to help cover costs for participating in a clinical trial (Moy et al., 2011). These reforms are particularly relevant for vulnerable groups of cancer survivors, such as low-income, racial and ethnic minorities, and young adults (Moy et al., 2011). PPACA legislation aims to address other needed reforms, such as increasing access by eliminating co-pays for recommended preventive cancer screening for people on Medicare, placing limits on

out-of-pockets costs for care, and expanding training and residency programs for primary care providers (US DHHS, 2014; Moy et al., 2011).

In addition, new Healthcare Common Procedure Codes were recently released by the Centers for Medicare and Medicaid Services for cancer treatment planning and care coordination (ACS, 2014). These codes do not guarantee payment; however, they are a critical step toward achieving reimbursement for the time and expertise needed to develop a treatment plan and coordinate care for patients (ACS, 2014). With regard to pending legislation, the Comprehensive Cancer Care Improvement Act (CCCIA, H.R., 3705) aims to advance the IOM recommendations for written treatment summaries and SCPs, as well as integrated cancer care by proposing adequate physician reimbursement for these services. (McCabe et al., 2013). Overall, the PPACA, including ACOs, is helping to increase access to equitable, affordability, and efficient quality survivorship care (Moy et al., 2011; US DHHS, 2014). It will be important to assess the effectiveness of the new healthcare procedure codes as well as the impact of bundled payment options like ACOs and PCMHs.

Survivorship care plans (Table 3). As discussed above, a significant component of the current models of survivorship care include the development and implementation of SCPs – comprehensive post-treatment plans aimed at improving patients’ lifestyles and quality of life, in addition to monitoring for recurrent and/or second cancers (ASCO, 2011; Hewitt, Greenfield & Stovall, 2006; Jacobs et al., 2009; NCCN, 2014; NCI, 2010). More specifically, these individualized care plans should include a summary of treatment, discussion of support resources (e.g., mental health referrals, coping and stress-management techniques), and specific guidelines for healthy lifestyle behaviors, screening behaviors (i.e., type and frequency), and routine exams monitoring recovery (Ganz et al., 2008; Hewitt & Ganz, 2006; Jacobs et al., 2009; NCCN, 2014;

NCI, 2010). SCPs are intended to be a vehicle for integrating evidence-based guidelines and improving patient-centered care and care coordination (Ayanian & Jacobsen, 2006; Earle, 2006; Faul et al., 2010; Ganz et al., 2008; Hahn & Ganz, 2011; Hewitt, Greenfield & Stovall, 2006; NCCN, 2014; Snyder et al., 2009).

Behavioral medicine experts and various national cancer organizations have identified the many factors which put survivors at increased risk for cancers and other co-morbid diseases, as well as recommendations for reducing risk and preventing future disease incidence (ACS, 2010; ASCO, 2010; Bultz et al., 2006; Courneya & Friedenreich, 2001; 2007; 2011; Demark-Wahnefeld et al., 2008; Jacobsen et al., 2005; NCCN, 2014; NCI, 2010; Zabora et al., 2001). However, as SCPs are not yet the standard of survivorship care, it is often left up to the patient to search for and locate this type of information (Ganz et al., 2008). While empirical evidence is still needed, the IOM asserts that SCPs have “strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary” (Hewitt, Greenfield & Stovall, 2006, p. 154). Thus, it is believed that comprehensive summaries of the completed course of treatment, recommended tests and treatments, and inclusion of specific health behavior recommendations, among other prescriptions, will enhance the coordination, efficiency and quality of care, thereby improving survivors’ short- and long-term health outcomes (Earle, 2006; Ganz et al., 2008; Hausman et al., 2005; Hewitt, Greenfield & Stovall, 2006).

In addition to the IOM’s report and endorsement of SCPs, ASCO has developed several SCP templates, and so have other survivorship care programs, such as LIVESTRONG, NursingCenter.com, and Journey Forward (Hausman et al., 2011). With the goal of providing “efficient ways to facilitate and simplify communication between doctors, clinicians, and survivors,” Journey Forward, an evidence-based initiative, continues to evolve based on survey

results, focus group findings, and ongoing feedback about the program (Hausman et al., 2011, p. e188). Annual survey data have continued to demonstrate provider satisfaction with the program and increased provider preparedness with regard to delivering comprehensive survivorship care (WellPoint, 2010). In addition, survey, interview, and survivor focus group data have suggested that comprehensive survivorship care planning be of increased focus earlier on in treatment cycles and immediately following completion of treatment to promote and facilitate patient-centered care and communication (Epstein et al., 2005; Hausman et al., 2011).

The differences identified (and discussed above) in adult cancer survivorship models likely warrant implementation of variations of SCPs to ensure goodness of fit within the institution's resources and patient population, among other site-specific factors (Hahn & Ganz, 2011). Hahn and Ganz qualitatively assessed the use of SCPs at four healthcare settings which employed distinct approaches to adult cancer survivorship care (2011). Results supported the flexibility of the IOM-recommended SCP, and the feasibility of successfully implementing modified versions of the SCP in various survivorship care program settings (Hahn & Ganz, 2011). Specifically, Hahn and Ganz found that the IOM-recommended SCP document and ASCO SCP template were both adapted for use in an academic center, community hospital, primary care setting, and county hospital (2011). Other differences with regard to the SCPs were noted with regard to who completed the SCPs at each site. For example, SCPs were developed by a multidisciplinary team at the academic center, while an oncology nurse worked in collaboration with a cancer survivor at the community hospital (Hahn & Ganz, 2011). Thus, similar to the lack of a one-size-fits all model for survivorship care, there is also no one one-size-fits all SCP document. Instead, the over-arching theme is for care models and SCPs to contain

several core elements, and then be adapted based on the distinct characteristics of the institution, its mission, resources and patient population (Hahn & Ganz, 2011).

Overall, SCP documents are generally posited to address survivors' needs, increase their mental and physical functioning, and improve satisfaction and compliance with care (Earle, 2006; Faul et al, 2010; Ganz et al., 2008; Hewitt, Greenfield & Stovall, 2006). Provision of a comprehensive written document is believed to facilitate continuity of care, through easing the transition from on- to off-treatment status, and improve the quality of care, consequently empowering survivors and ultimately enhancing their quality of life (Earle, 2006; Faul et al., 2010; Ganz et al., 2008; Hewitt, Greenfield & Stovall, 2006). SCPs are also predicted to reduce unnecessary testing as a result of improvements in the coordination of care (Earle, 2006; Ganz et al., 2008). Thus, with an increase in understanding of the effectiveness and value of SCPs, challenges include integrating SCPs into electronic medical records, as doing so will likely significantly reduce resource demands (e.g., staff time) and duplicated efforts on the part of staff (Hausman et al., 2011). Despite being strongly endorsed, there is little understanding of the feasibility of SCP development (e.g., time, money, staff required), nor is there much in the way of empirical evidence supporting the beneficial role of SCPs in improving outcomes.

In contrast to the overwhelming support for SCPs, a recent study conducted by Grunfeld and colleagues found no differences in patient-reported outcomes when comparing SCPs with standard discharge/transfer visits (2011). Implementation of SCPs did not appear to improve patient-reported outcomes such as cancer-specific and general psychological distress, health-related quality of life, patient satisfaction, or continuity/coordination of care (Grunfeld et al., 2011). The breast cancer-specific survivor sample, limited follow-up assessment (i.e., 12 months), and possible lack of measurement sensitivity potentially contributed to limited

generalizability of the study's findings; however, study results also raise the question of implementation and adherence to established guidelines (e.g., IOM recommendations). In another study, Tompkins Stricker and colleagues found that across LIVESTRONG survivorship centers, SCPs included less than two thirds of IOM content recommendations (2011). Study results suggest that despite the clinical and policy initiatives to improve survivorship care and care planning, cancer centers and survivorship programs continue to encounter obstacles related to the delivery of quality care (Tompkins Stricker et al., 2011). More research is needed to better understand the posited short- and long-term effects of SCPs on various survivorship outcomes, in addition to the development, implementation, and feasibility of SCPs (Earle, 2006; Ganz et al., 2008; Grunfeld et al., 2011; Hahn & Ganz, 2011).

2.5 The Current Study

The purpose of the current study was to investigate the emerging field of survivorship care, including care planning and follow-up, in survivors of different types of cancer. We quantitatively evaluated the post-treatment care received by a diverse sample of cancer survivors, including the use of SCPs and the impact of these care plans and subsequent follow-up on a variety of behavioral health outcomes. We examined survivors' satisfaction with their care, psychosocial health (e.g., quality of life, self-efficacy, and patient activation), the impact of SCPs on health and quality of life outcomes, and unmet needs to determine the strengths and weaknesses of the current models of care. To gain a different perspective on survivorship care, we also qualitatively assessed issues relevant to comprehensive survivorship care planning and follow-up via interviews with professionals who provide care to survivors of cancer.

Chapter 3. Method

3.1 Quantitative

Participants. Individuals eligible for the quantitative portion of the present study included men and women diagnosed with cancer in the last 5 years. The final sample included 123 eligible individuals who consented to participate. Study participants are 109 women and 14 men (93% Caucasian) between the ages of 23-74 years old ($M = 49$ years, $SD = 10$) who reported a personal history of cancer and their most recent diagnosis with the last 5 years, agreed to participate, and completed the online questionnaire. For complete participants' demographic data, please see Table 4.

Inclusion/exclusion criteria. Inclusion criteria for the quantitative portion of the study is specified as the following: (i) Any individual affected with cancer; (ii) Most recent cancer diagnosis (including recurrences) received within the past 5 years; (iii) Cancer diagnosis at any age; (iv) Males and females; (v) Age 21 and older, and (vi) English speaking. Individuals were excluded based on the following criteria: (i) Currently undergoing treatment; (ii) Inability to provide informed consent.

Recruitment. Participants were recruited from a variety of sources that include: Online advocacy, information, and support organizations (e.g., The Colon Cancer Alliance, Susan G. Komen for the Cure), study flyers in local medical and social establishments, a study Facebook page, and The Roanoke Times. The online organizations contacted included nationally known general and disease-specific groups with a significant number of members. Staff members at these organizations were contacted to request permission to advertise the current study and recruit cancer survivor members through their organization. A recruitment approach was agreed upon by the study investigator and organization staff member, and generally involved a brief

write-up about the study along with a link to the study survey posted on the organization's Facebook page, Twitter account, an approved discussion board, online chat group, or blog website (see Table 5). Following Institutional Review Board (IRB) approval and submission of a HIPAA waiver, the coordinators and moderators affiliated with the online communities were e-mailed an approved letter (prepared by the investigator) briefly describing the study and requesting permission to post recruitment information on their website. Via online postings which were developed collaboratively by the investigator and organization staff, eligible cancer survivors were provided with a brief description of the study and directed to the study survey website, which first reviewed the informed consent protocol (Appendix A) and then provided instructions for completing the questionnaire.

Measures (Appendices B-L). The quantitative portion of this study involved cross-sectional evaluation of survivors' experience with survivorship care planning and follow-up, as well as current psychosocial coping and adjustment. Broadly, the survey measures investigated survivors' experience of survivorship care – including in depth assessment of the use of SCPs, satisfaction with survivorship care, self-efficacy related to managing care during survivorship, and the impact of SCPs on quality of life, psychosocial health, and lifestyle behavior outcomes. Demographic, clinical, psychosocial, and health behavior variables were all measured at one time-point using an online questionnaire. The following measures have been commonly used in prior research conducted with the general population, cancer patients, and cancer survivors.

Assessment Procedures

- ✓ Sociodemographics
 - ✓ Clinical Information
 - ✓ Survivorship Care
 - ✓ Patient Expectations regarding Survivorship Care
 - ✓ Satisfaction
 - Patient Satisfaction with Cancer Care (PSCC)*
 - ✓ Quality of Life
 - Functional Assessment of Cancer Therapy-General (FACT-G)*
 - ✓ Psychological Distress
 - Brief Symptom Inventory (BSI)*
 - Impact of Event Scale (IES)*
 - ✓ Depression Screener
 - Patient Health Questionnaire-2 (Depression Screener; PHQ-2)*
 - ✓ Survivors' Coping Self-Efficacy
 - The Cancer Behavior Inventory-Brief (CBI-B)*
 - ✓ Survivors' Activation
 - Patient Activation Measure (PAM)*
 - ✓ Health Behaviors
 - Block Dietary Fat Screener*
 - Block Dietary Fruit-Vegetable-Fiber Screener*
 - Stanford Free-Time Activity Categorical Item (Free-Cat) 2.1*
 - American College of Sports Medicine (ACSM) Health Guidelines*
-

Sociodemographics (Appendix B). Information was obtained on participants' current age, age at diagnosis, race, marital status, education, and household income.

Clinical information (Appendix C). Self-report data was gathered on participants' personal cancer history, including stage of cancer diagnosis, form of treatment, type of medical setting where they received treatment, and family cancer history.

Survivorship care (Appendix D). No validated survivorship care survey measures were identified. Thus, with a focus on survivorship care planning and follow-up, items were created to assess the type, content, quality, and quantity of survivorship care in this cancer survivor sample.

Levels of survivorship care. Using several items from the survivorship care measure, participant responses were grouped into one of three categories to quantify and qualify the level of survivorship care received (e.g., receipt of a written care plan document, access to a secondary contact for follow-up, perception of the amount of survivorship care follow-up contacts, receipt

of comprehensive survivorship care referrals, and overall satisfaction with survivorship care). These items were carefully selected based on their relevance to and implications for comprehensive survivorship care. Items and scoring for the survivorship care categories are listed in Table 12. The total possible score for survivorship care items is 19.

Patient expectations regarding survivorship care (Appendix E). No validated survey measures related to patient expectations for survivorship care were identified. Thus, with a focus on SCPs and follow-up referrals, items were created to assess expectations related to receiving a SCP, information about monitoring their recovery and surveillance guidelines, specific instructions or referrals for health behaviors (i.e., diet and exercise) and psychosocial concerns, and having a point person or coordinator for their follow-up care.

Patient satisfaction with cancer care (Appendix F). Survivor satisfaction with care was measured as it “reflects a core dimension of health care quality and patient-centered care,” and is considered a high priority for comprehensive cancer survivorship care (Jean-Pierre et al., 2011, p. 855). The Patient Satisfaction with Cancer-Related Care measure (PSCC; Jean-Pierre et al., 2011) is a 35-item self-report instrument assessing cancer survivors’ satisfaction with their cancer-related care. Responses to PSCC items are rated on a 5-point Likert scale (“1 = Strongly Agree” to “5 = Strongly Disagree”). Item responses were summed to create a total score, with *lower scores indicating higher satisfaction* with cancer care (Jean-Pierre et al., 2011). In a sample of 891 English-speaking breast, cervical, colorectal, and prostate cancer survivors, Jean-Pierre and colleagues (2011) report that the PSCC demonstrates high internal consistency (α ranging from 0.95 to 0.96), and good face and convergent validities.

Quality of life (Appendix G). The Functional Assessment of Cancer Therapy - General (FACT-G), version 4.0, is a 27-item self-report measure that assesses quality of life concerns

specific to cancer patients and survivors (Cella et al., 1993). The FACT-G is comprised of four quality of life domains: (i) physical well-being; (ii) social/family well-being; (iii) emotional well-being; and (iv) functional well-being (Cella et al., 1993). Responses were measured on a 5-point Likert scale (0=*not at all*, 2=*somewhat*, 4=*very much*) and were summed to calculate a total quality of life score (Cella et al., 1993). Higher scores on the FACT-G indicate better quality of life (Cella et al., 1993). Cella and colleagues (1993) reported sound psychometric properties, indicating good internal consistency evidenced by a Cronbach's alpha calculation of .89 for the scale total. Test-retest correlation coefficients were also high, ranging from .82-.92 (Cella et al., 1993). Cella et al. (1993) additionally reported good convergent and divergent validity.

Psychological and cancer-related distress (Appendix H). The Brief Symptom Inventory (BSI), an abbreviated version of the 53-item BSI and the SCL-90-R (Derogatis, 1975), and the Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979) were used to measure psychological distress. In order to reduce the overall burden on participants, the BSI-18 was condensed to include 11 items. Furthermore, the item inquiring about suicidality was removed since the questionnaire was administered online and the researcher was unable to follow up with participants appropriately and promptly regarding concerning responses. This approach has been used in prior research with cancer survivors (Peshkin et al., 2008). Responses to items on the BSI scale are rated on a 5-point scale where 0=*not at all*, 1=*a little bit*, 2=*moderately*, and 3=*quite a bit*, and 4=*extremely*. Responses to items on the IES scale were rated on a 4-point scale where 0=*not at all*, 1=*rarely*, 3=*sometimes*, and 5=*often*. The IES has demonstrated strong internal consistency reliability as evidenced by the .92 Cronbach alpha calculation (Horowitz, Wilner, Alvarez, 1979), while the BSI-18 has been found to display good internal consistency, as well as

strong reliability and structural validity when studied in a sample of breast cancer patients (Galdon et al, 2008).

Depression screener (Appendix I). In addition to the BSI and IES, The Patient Health Questionnaire-2 (PHQ-2) was also used to. The PHQ-2 is a two-item measure used to screen for a mood disorder or clinically significant mood symptoms. The PHQ-2 asks participants the following two questions: (i) if there has been a time in the past month when they felt sad, blue, depressed, or down for most of the time for at least two weeks and (ii) if there has been a time in the past month, lasting at least two weeks, when they didn't care about the things that you usually cared about or when they didn't enjoy the things that they usually enjoyed. Participants responded with "yes" and "no," and yes to either question should be evaluated further for the presence of a clinically significant mood disorder and no to both questions results in a negative screen. The PHQ-2 has demonstrated 96% Sensitivity and Specificity of 90% (Kroenke et al., 2003).

Coping self-efficacy (Appendix J). The Cancer Behavior Inventory-Brief version (CBI-B; Heitzmann et al., 2011; Merluzzi et al., 2001; Merluzzi & Martinez Sanchez, 1997) was used to assess participants' overall self-efficacy with regard to their ability to cope with a cancer diagnosis. The CBI-B is a 12-item measure derived from the longer 33-item version. Coping self-efficacy is measured in the following areas: (i) Maintaining independence and a positive attitude; (ii) Actively participating in medical care; (iii) Coping and stress management; and (iv) Managing affect (Heitzmann et al., 2011). Using a 9-point Likert scale, participants rated their confidence in their ability to carry out various coping behaviors (1=*not at all confident*, 5=*moderately confident*, 9=*totally confident*; Heitzmann et al., 2011). Psychometrically, the CBI-B has been found to demonstrate very good internal consistency with Cronbach alpha calculations ranging from 0.84 - 0.88 (Heitzmann et al., 2011). In addition to reliability, the CBI-B is also a valid measure, as evidenced by the positive correlations with measures of quality of

life and optimism, and negative correlations with measures of depression and sickness impact (Heitzmann et al., 2011).

Patient activation (Appendix K) An important aspect of patient-centered care focuses on the patient's ability to actively participate in and effectively manage his or her care. As such, the Patient Activation Measure (PAM; Hibbard et al., 2004; Hibbard et al., 2005) was included in the current study. The PAM is a 13-item self-report measure assessing patient activation, as defined by four primary stages: (i) Believing the patient role is important; (ii) Having the confidence and knowledge necessary to take action; (iii) Actually taking action to maintain and improve one's health; and (iv) Staying the course even under stress. The PAM was developed to assess knowledge, skills, beliefs, and behaviors that a patient needs to manage a chronic illness – all critical elements for patient activation (Hibbard et al., 2004). In an examination of psychometric properties, Hibbard and colleagues (2005) reported that the original 22-item PAM demonstrates good internal consistency, citing a Cronbach's alpha of .91. The shortened 13-item measure demonstrates similarly high alpha calculations (Hibbard et al., 2005).

Health behaviors (Appendix L). Existing dietary measures developed and normed on the general population were used to assess post-diagnosis dietary intake in the current cancer survivor sample. Specifically, Block and colleagues' (2000) brief screeners assessing servings of dietary fats, as well as fruit, vegetable, fiber, and micronutrient intake will be used since these are arguably the dietary factors most relevant to cancer. These screeners can be completed in approximately 5-10 minutes or less (Block et al., 2000). Based on national nutrition data, Block's dietary screeners have been shown to be effective in identifying persons with high-fat and low-fruit/vegetable intake (2000). Correlations of 0.6 - 0.7 ($p < 0.0001$) were found for total fat, saturated fat, cholesterol, and fruit/vegetable intake in these brief food screeners compared to the

Block full-length Food Frequency Questionnaire (Block et al., 1986).

Participants' physical activity practices were measured using the Stanford Leisure-Time Activity Categorical Item (L-Cat; Kiernan et al., 2013). The Stanford L-Cat requires individuals to identify – in the past month – their level of engagement in physical activity during their leisure-time by selecting one of six descriptive categories, ranging from inactive to very active, which best describes them. In a sample of 267 overweight/obese women, The L-Cat demonstrated strong psychometrics, including excellent test–retest reliability ($\kappa=0.64$, $P<0.001$) and adequate concurrent criterion validity (Kiernan et al., 2013). Three additional questions were developed for use in the current study for the purposes of assessing whether participants are meeting the ACSM's (2010) exercise guidelines for cancer survivors. These guidelines and the corresponding questions focus on the overall volume of weekly physical activity, strength training, and stretching/flexibility. Using a simple “yes” and “no” rating, responses indicate whether survivors are meeting a specific ACSM guideline.

Resources (Appendix M). At the end of the online questionnaire, participants were provided with instructions about where to get information and support related to cancer survivorship, depression, and health and wellness. Several websites for nationally known cancer care and research institutions were provided to participants for each of the three topic areas.

Procedure. IRB approval was obtained through Virginia Tech. The researchers submitted a HIPAA waiver in order to ensure confidentiality and protection of participants' privacy. Study data was kept as a password protected file, available only to the researcher. All data was coded with a research identification number.

Following IRB approval, informed consent was obtained online from each participant for their participation in the online questionnaire. Survey Monkey was used to administer both the

informed consent and online questionnaire. Following informed consent, participants completed an online survey that took about 30 minutes to complete. The survey assessed participants' cancer survivorship experience – including survivorship care planning and follow-up related to psychosocial adjustment and health behaviors. As an incentive, at the end of the survey, participants had the option to provide an e-mail address to be sent study results and to be entered into a drawing to receive one of many \$10 Target e-gift cards. A total of 25 \$10 Target gift cards were e-mailed to randomly selected participants. About 1 in 5 participants received a gift card. Furthermore, participants were informed that their contact information (i.e., e-mail address) would be separated from their survey responses and would not be provided to anyone.

3.2 Qualitative

Participants. Individuals eligible for the qualitative portion of the study included healthcare professionals who provide clinical care to survivors of cancer. Medical oncologists, oncology nurses, primary care physicians, psychologists, and psychiatrists were contacted for participation. The final qualitative sample includes 8 healthcare providers – 5 women and 3 men – who agreed to participate and completed the telephone interview.

Inclusion/exclusion criteria. Inclusion criteria for the qualitative portion of the study was specified as the following: (i) Any individual who provides post-treatment healthcare services to survivors of cancer and is (ii) English speaking. Individuals were excluded from the qualitative portion of the study based on the following criteria: (i) Inability to provide informed consent.

Recruitment. Following IRB approval, 10 survivorship care providers were contacted via phone or e-mail. At this time, the investigator briefly described the study and requested permission to schedule a telephone interview appointment. Of the 10 clinical care providers, 8

provided informed consent, agreed to schedule a telephone interview, and completed the telephone interview.

Measures. The qualitative portion of this study assessed healthcare providers' experiences with and perspectives on delivering care to survivors of cancer post-treatment at one time-point using a qualitative telephone interview.

Qualitative interview (Appendix N). Approximately five open-ended questions were developed for use in the current study to assess care providers' perspectives on comprehensive survivorship care and experiences delivering post-treatment services. For example, definitions of survivorship care, use of SCPs and coordination of care, the utility of SCPs, barriers to implementing SCPs, and the next steps in the field of cancer survivorship care were all measured at one time-point using a qualitative interview.

Procedure. IRB approval was obtained through Virginia Tech. Interview data was kept as a password protected file, available only to the researcher. All data is coded with a research identification number. Participants were informed that their contact information (i.e., name, e-mail address) was separated from their survey responses and will not be provided to anyone.

Following IRB approval, informed consent was first obtained via e-mail and then online (using Survey Monkey) from the healthcare providers for the telephone interview. Survivorship clinical care providers then completed a telephone interview, lasting approximately 15-20 minutes, about their experiences with and perspectives on comprehensive survivorship care.

Chapter 4. Results

4.1 Quantitative Analyses

Descriptive statistics of sample.

Sociodemographics. Data are presented in Table 4. The final sample included 123 participants (109 women and 14 men; 93% Caucasian) between ages 23-74 years who consented to and completed the online survey. Overall, the majority of the participants were married, not adopted, had achieved at least a college degree, were employed full-time, and had an annual household income equal to or higher than \$75,001. Participants in this study represent 34 states across the country.

Clinical health information. Clinical health information is presented in Table 6. The average age of cancer diagnosis was 45 (Range = 20-67 years; SD = 10), and 13 participants (11%) reported being diagnosed with more than one type of cancer. Overall, participants in the current study endorsed 10 different types of cancer diagnoses. The most common type of cancer represented is breast (44%; $n = 54$), followed by colon (32%; $n = 39$). The majority of study participants (93%; $n = 115$) reported a family history of cancer.

The majority of participants (69%; $n = 85$) reported *not* receiving a Survivorship Care Plan (SCP) *or* Treatment Summary. A small percentage of participants (31%; $n = 38$) reported receiving some form of written care plan. Within this group, 3% ($n = 4$) received a Survivorship Care Plan, 17% ($n = 21$) received a Treatment Summary, and 11% ($n = 13$) received *both* a SCP and a Treatment Summary. Complete data on survivorship care planning and follow-up are presented in more detail below (*see Survivorship care planning and follow-up data*). The majority of participants (76%; $n = 93$) reported having someone whom they consider to be a caregiver. Of these participants with caregiver support, most (77%; $n = 72$) reported that their

caregiver participated in their survivorship care planning and follow-up appointments. The majority of participants (89%; $n = 110$) reported 0-5 hospital admissions in the past five years. Slightly less than half of participants (46%; $n = 57$) reported currently taking medications with side effects related to appetite, sleep, energy, or mood.

Scale reliability and descriptive statistics. Reliability statistics for each of the psychosocial and health behavior scales are presented in Table 7. Overall, the psychological measures demonstrated high internal consistency with most Cronbach's *alpha* coefficients between .80 - .97, and the lowest being .36 (Survivorship Care Level). Descriptive statistics (e.g., minimum, maximum, mean, standard deviation) for the psychosocial measures are found in Table 8.

Survivorship care planning and follow-up (Aim 1). Summary and frequency data on the type, content, quality, and quantity of survivorship care planning and follow-up is presented in Table 9. Overall, for the total sample, the largest number of participants (43%; $n = 53$) reported receiving their diagnosis at a community hospital. Most participants (59%; $n = 73$) reported receiving their cancer treatment at the same facility they were diagnosed: 29% of participants ($n = 36$) received treatment at a comprehensive cancer center, 28% ($n = 34$) received treatment at a community hospital, 25% ($n = 31$) at a community oncology office, and 18% ($n = 22$) at an academic medical center. Oncologists were most commonly the primary contact for survivorship care follow-up (63%; $n = 77$), and primary care physicians were most commonly endorsed as secondary contacts (37%; $n = 45$). The majority of participants reported an average of 2-3 survivorship care follow-up contacts per year (40%; $n = 49$) and 84% ($n = 103$) indicated having “just enough” visits. Survivorship care follow-up contacts most commonly occurred in person (98%; $n = 120$) lasting 30 minutes or less per contact (74%; $n = 92$).

Expectations for survivorship care and referrals. Results for participants' expectations related to their survivorship care are illustrated in Table 10. Overall, the majority of participants reported expectations for having a point person to contact regarding follow-up care (82%; $n = 101$), and instructions for monitoring recovery (81%; $n = 99$), screening for recurrence (94%; $n = 115$), and screening for other cancers (69%; $n = 85$).

Most participants also reported expectations for receiving (if needed) mental health services or referral information (59%; $n = 73$), and specific instructions or referral information for nutrition (59%; $n = 73$) and exercise (55%; $n = 67$). In contrast, the majority of participants reported that they did *not* expect to receive a written care plan (52%; $n = 64$) or have monthly follow-ups (70%; $n = 86$).

Referrals received. Regarding comprehensive survivorship care referrals and resources (i.e., for mental health, diet, and physical activity), most participants reported *not* receiving any such referrals (71%; $n = 87$). For those who did (28%; $n = 34$), 19% ($n = 23$) received a referral for mental health services (within this group, 10/23 [44%] received some type of written care plan document), 16% ($n = 20$) received a diet/nutrition referral (within this group, 8/20 [40%] received some type of written care plan document), and 15% ($n = 18$) received a referral for physical activity/exercise (within this group, 6/18 [33%] received some type of written care plan document).

Referrals pursued. Many participants (67%; $n = 82$) indicated an interest in receiving follow-up care related to diet and nutrition; however, only 32% ($n = 39$) reported pursuing/receiving this type of follow-up care. For those who did, appointments with a nutritionist/dietician (11%; $n = 13$) and personal research (11%; $n = 13$) were the most common forms of follow-up diet/nutrition follow-up. Similarly, many participants (66%; $n = 81$) indicated

an interest in receiving follow-up care related to physical activity and exercise; however, only 28% ($n = 34$) reported pursuing/receiving this type of follow-up care. For those who did, participants endorsed increasing their general level of physical activity (11%; $n = 13$), joining a group fitness class (6%; $n = 7$), undergoing physical therapy (6%; $n = 7$), and doing personal research on the topic (6%; $n = 7$). A similar trend was identified for the results related to mental health services. Most participants (59%; $n = 73$) indicated an interest in receiving follow-up care related to mental health and wellbeing; however, only 31% ($n = 38$) reported pursuing/receiving this type of follow-up care. For those who did, psychotherapy or counseling sessions with a mental health professional (e.g., psychologist, social worker; 16%; $n = 20$), psychiatric treatment (i.e., medication; 7%; $n = 8$), and support group involvement (7%; $n = 9$) were the most common types of mental health follow-up. Data on participant expectations, interest, receipt, and pursuit of referrals for mental health, diet, and physical activity are illustrated in Figure 1.

Referrals wanted or needed by those who did not receive referrals. For participants who reported *not* receiving any referrals, when asked what type of referrals, if any, they may have *wanted* or *needed*, 45% ($n = 55$) endorsed referrals related to diet/nutrition, 41% ($n = 50$) equally endorsed referrals related to physical activity/exercise and mental health services. A small number of participants (4%; $n = 5$) reported an interest in other referrals, such as for pain management, ostomy management, acupuncture, and clinical trials/research studies.

Satisfaction with survivorship care and perceived impact on health. When asked on a scale from 1 (*extremely dissatisfied*) to 10 (*extremely satisfied*) how satisfied participants were with their survivorship care, 49% ($n = 60$) reported being extremely satisfied (responses ranged from 8-10), 33% ($n = 41$) reported feeling neutral (responses ranged from 4-7), and 6% ($n = 7$) reported being extremely dissatisfied (responses ranged from 1-3). To follow-up on these

responses, all participants were asked what information they needed or wanted that was *not* received. While responses varied significantly across survivorship issues, the largest percentage of participants (15%; $n = 19$) endorsed mental health services (e.g., for managing depression, support group information). Other frequent (or common) responses included resources or referrals for risk reduction/management, namely related to lifestyle behavior change (11%; $n = 14$), information related to expectations and management of side effects (9%; $n = 11$) as well as the post-treatment recovery process (8%; $n = 10$), and resources for general symptom (e.g., pain, fatigue) management (7%; $n = 8$).

Participants were asked more specifically about survivorship care follow-up and the impact of that care on their health. On a scale from 1 (*no improvement*) to 10 (*extreme improvement*), participants mostly reported moderate to extreme improvement in their dietary habits post-treatment, with responses ranging from 4-10 out of 10 (83%; $n = 102$). Of note, 15% ($n = 19$) of participants reported no improvement in their dietary habits since completing treatment for cancer. On a scale from 1 (*no improvement*) to 10 (*extreme improvement*), the majority of participants reported moderate to extreme improvement in their physical activity/exercise habits post-treatment, with responses ranging from 4-10 out of 10 (69%; $n = 85$). Of note, 29% ($n = 36$) of participants reported no improvement in their physical activity/exercise habits since completing cancer treatment. On a scale from 1 (*no improvement*) to 10 (*extreme improvement*), the majority of participants reported moderate to extreme improvement in their mental health post-treatment, with responses ranging from 4-10 (79%; $n = 97$). Of note, 18% ($n = 22$) of participants reported no improvement in their mental health since completing cancer treatment.

Survivorship care plan data (Aim 2). Participants who reported receiving a SCP, Treatment Summary, or both were asked questions pertaining to the development and use of these documents, and how the documents may or may not have impacted their health post-treatment (complete data provided in Table 11). Of those who received some form of written care plan document (31%; $n = 38$), the majority of participants reported that it did *not* include referrals for mental health services (74%; $n = 28$ out of 38), diet/nutrition (79%; $n = 30$ out of 38), or physical activity/exercise (84%; $n = 32$ out of 38).

Of the 38 participants who received a SCP or Treatment Summary, 53% ($n = 20$) reported receiving their treatment at a community hospital or community oncology office, and 47% ($n = 18$) received treatment at a comprehensive cancer center or academic medical center. In addition, 55% ($n = 21$) reported receiving this document *before* the conclusion of treatment. The majority of participants reported that their oncologist was the main person who wrote their care plan document (42%; $n = 16$) and most stated that they did *not* participate in the creation of this document (58%; $n = 22$). Although a few participants indicated that their care plan document had been modified since its creation (11%; $n = 4$), most participants reported it had not (79%; $n = 30$). When asked about the overall helpfulness of their written care plan document, 55% ($n = 21$) of participants indicated it was helpful and a small number (8%; $n = 3$) said it was not. When specifying what was helpful about it, participants reported some combination of the following responses (Figure 2): knowing what to expect (29%; $n = 6$), general guidelines to follow and specific tips for managing my health (24%; $n = 5$), information about my cancer diagnosis and the treatment care I received for it (14%; $n = 3$), and provided a sense of comfort and reassurance (24%; $n = 5$). In addition, participants were asked to rate on a scale of 1 (*no positive impact*) to 10 (*extremely positive impact*) whether their written care document impacted their diet and

physical activity habits, as well as their mental health following treatment. 50% of participants ($n = 19$) indicated the document had a moderate impact (scores ranged from 4-7 out of 10) on their dietary habits, 40% ($n = 15$) reported a moderate impact on physical activity and exercise habits, and 37% ($n = 14$) reported an extremely positive impact on their mental health (scores ranged from 8-10 out of 10).

Levels of survivorship care. Participants' responses to questions about the amount of survivorship care they had received was normally distributed. We created three categories for survivorship care based on participants' scores in relation to the mean. Scores that fell at least one standard deviation *above* the mean represent a "High" level of survivorship care (total scores range from 13-19) and scores that fell at least one standard deviation *below* the mean represent "None/low/minimal" care (total scores range from 0-7). Total scores within one standard deviation of the mean reflect a "Moderate" level of care (total scores range from 8-12). Frequency data on these three levels of survivorship care are reported in Table 13. Overall, 24% of participants ($n = 30$) reported receiving none/low/minimal survivorship care, 54% ($n = 66$) received a moderate level of care, and 22% ($n = 27$) receiving a high level of care.

Differences in psychosocial and health behavior outcomes based on SCP receipt (Aim 3). To explore relationships between psychosocial (e.g., quality of life, distress, coping self-efficacy) and health behavior variables (i.e., diet and physical activity) and receipt of SCPs, multivariate analyses of covariance were conducted, controlling for appropriate clinical variables. Of particular interest, based on study aims and hypotheses, was whether group differences exist between those who received SCPs and those who did not across the study variables. The following analyses were conducted to explore whether and how receipt of SCPs

may have affected an individual's psychosocial health, quality of life, and health behaviors during survivorship.

Preliminary analyses: Correlations and t-tests.

Correlational analyses for survivorship care. Pearson product moment correlations among the psychosocial and health behavior variables of interest, including survivorship care, are presented in Table 14. A higher level of survivorship care was significantly (p values $< .05$) related to higher scores for a number of study variables: QoL ($r = .360$), coping self-efficacy ($r = .338$), and patient activation ($r = .292$). Higher levels of survivorship care were also significantly associated with lower scores for general psychological distress ($r = -.281$), cancer-specific distress ($r = -.189$), and patient dissatisfaction with cancer care ($r = -.348$), indicating that an increase in the level of survivorship care received is associated with a statistically significant decrease in distress and dissatisfaction with care, and a statistically significant increase in quality of life, self-efficacy, and activation.

Correlational analyses for patient satisfaction with care. Dissatisfaction with care was significantly (p values $< .01$) *negatively* associated with several study variables: QoL ($r = -.370$), coping self-efficacy ($r = -.334$), and patient activation ($r = -.451$). Dissatisfaction with care was also significantly *positively* associated with depression ($r = .241$) and measures of general ($r = .312$) and cancer-specific distress ($r = .289$). These results indicate that higher satisfaction with care is associated with lower levels of psychological distress and higher levels of QoL, coping self-efficacy, and activation.

Correlational analyses for psychosocial outcomes. QoL was significantly (p values $< .01$) *negatively* associated with depression ($r = -.568$), general distress ($r = -.713$), cancer-specific distress ($r = -.526$), and dissatisfaction with care ($r = -.370$), and significantly *positively*

associated with survivorship care level ($r = .360$), coping self-efficacy ($r = .665$), patient activation ($r = .500$), and physical activity ($r = .390$). Depression was significantly (p values $< .01$) *negatively* associated with coping self-efficacy ($r = -.515$), patient activation ($r = -.290$), and physical activity ($r = -.295$), and significantly *positively* associated with general psychological distress ($r = .597$), cancer-specific distress ($r = .422$). General psychological distress was significantly (p values $< .01$) *negatively* associated with coping self-efficacy ($r = -.610$), patient activation ($r = -.444$), and physical activity ($r = -.281$), and significantly (p values $< .05$) *positively* associated with cancer-specific distress ($r = .652$). Cancer-specific distress was significantly *negatively* associated with coping self-efficacy ($r = -.599$), patient activation ($r = -.422$), and physical activity ($r = -.184$). Coping self-efficacy was significantly *negatively* associated with (p values $< .01$) with dietary fat intake ($r = -.256$), and *positively* associated with patient activation ($r = .617$) and physical activity ($r = .271$). Patient activation was significantly (p values $< .01$) *negatively* associated with dietary fat intake ($r = -.373$), and *positively* associated with fruit and vegetable consumption ($r = .264$) and physical activity ($r = .302$).

Correlational analyses for health behavior outcomes. Lower scores for dietary fat consumption were significantly (p values $< .05$) associated with higher scores for coping self-efficacy ($r = -.256$) and patient activation ($r = -.373$). Lower dietary fat scores were also significantly associated with lower general distress scores ($r = .200$). Higher scores for fruit and vegetable intake were significantly (p values $< .01$) associated with lower scores for dietary fat consumption ($r = -.244$) and higher scores for patient activation ($r = .264$). Higher levels of physical activity were significantly (p values $< .01$) associated with higher scores for a number of psychosocial variables: QoL ($r = .390$), coping self-efficacy ($r = .271$), patient activation ($r = .302$), and fruit and vegetable intake ($r = .267$). Higher levels of physical activity were also

significantly (p values $< .05$) associated with lower scores for a number of study variables: depression ($r = -.295$), general ($r = -.281$) and cancer-specific ($r = -.184$) distress, and dietary fat consumption ($r = -.230$). Together, these results indicate that dietary and physical activity behaviors are closely associated with one another and healthier lifestyles are associated with greater well-being and higher psychosocial functioning, marked by greater activation and confidence in one's ability to cope with cancer.

T-tests investigating gender differences (Table 15). Independent Student's t -tests were performed to evaluate whether group differences exist between males on females on the psychosocial and health behavior variables. The mean scores for male ($M = 21.38$, $SD = 6.08$) and female ($M = 15.73$, $SD = 7.67$) participants were significantly different for the Block Dietary Fat screener only, $t(117) = 2.56$, $p = .012$. No significant differences were found for males and females across other outcome variables.

Primary analyses: MANCOVA and MANOVA results. Multivariate analysis of variance and covariance were used to explore group differences in outcome variables based on receipt of a written care plan document as well as psychosocial health referrals (i.e., diet, physical activity, mental health). For each multivariate analysis performed, preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multicollinearity, with no serious violations noted.

MANCOVA results investigating group differences in outcome variables based on receipt of a written care plan document. A one-way between-groups multivariate analysis of covariance was performed to investigate group differences in psychosocial and health behavior variables for those who did and did not receive some form of written care plan document. Nine dependent variables were used: Patient satisfaction with cancer care, QoL, general and cancer-specific

distress, coping self-efficacy, patient activation, dietary fat intake, fruit and vegetable consumption, and physical activity. The independent variable was “SCP receipt”, which refers to the group of 38 participants who reported receiving some form of written care plan document including either a SCP or Treatment Summary, or both. Because depression was so highly correlated with many of the psychosocial and health behavior outcomes, it was included as a covariate in the MANCOVA analyses. After adjusting for depression scores ($F [9, 104] = 9.857, p = .000$; Wilks’ Lambda = .540, partial eta squared = .460), there was a significant overall effect of SCP receipt on the dependent variables ($F [9, 104] = 2.260, p = .024$; Wilks’ Lambda = .836, partial eta squared = .164).

When the results for the dependent variables were considered separately, controlling for depression, there were two significant differences for general psychological distress ($F [1, 104] = 8.316, p = .005$, partial eta squared = .069) and coping self-efficacy ($F [1, 104] = 6.627, p = .011$, partial eta squared = .056). An inspection of the depression adjusted mean scores indicated that those who received SCPs reported lower levels of general psychological distress ($M = 14.96$ versus $M = 18.20$) and higher levels of coping self-efficacy ($M = 106.07$ versus $M = 96.49$) compared to those who did not receive a SCP (Table 16, Figure 3).

Two differences trending toward significance were found for patient activation ($F [1, 104] = 3.385, p = .068$, partial eta squared = .029) and dietary fat intake ($F [1, 104] = 3.099, p = .081$, partial eta squared = .027). An inspection of the depression adjusted mean scores indicated that those who received SCPs reported higher levels of patient activation ($M = 45.81$ versus $M = 43.79$) and lower levels of dietary fat intake ($M = 14.54$ versus $M = 17.26$) compared to those who did not receive a SCP (Figure 3).

MANOVA results investigating group differences across dietary outcomes based on receipt of a referral for diet (Table 17). A one-way between-groups MANOVA was conducted to detect group differences in dietary outcomes (i.e., dietary fat, fruit and vegetable) for those who did and did not receive dietary referrals as part of their survivorship care. There were no statistically significant effects for receipt of dietary referrals on the dependent variables ($F [2, 114] = 1.119, p = .330$; Wilks' Lambda = .981, partial eta squared = .019). When the results for the dependent variables were considered separately, no significant differences existed across the dietary outcome variables.

MANOVA results investigating group differences across physical activity outcomes based on receipt of a referral for physical activity (Table 18). A one-way between-groups MANOVA was conducted to detect group differences in physical activity outcomes (i.e., physical activity, meeting ACSM guidelines) for those who did and did not receive physical activity referrals as part of their survivorship care. There were no statistically significant effects for receipt of physical activity referrals on the dependent variables ($F [4, 115] = 1.092, p = .364$; Wilks' Lambda = .963, partial eta squared = .037). When the results for the dependent variables were considered separately, no significant differences existed across the physical activity outcome variables.

MANOVA results investigating group differences across psychosocial outcomes based on receipt of a referral for mental health (Table 19). A one-way between-groups MANOVA was conducted to detect group differences in psychosocial outcomes (i.e., QoL, general and cancer-specific distress, depression, coping self-efficacy, and patient activation) for those who did and did not receive mental health referrals as part of their survivorship care. There were no statistically significant effects for receipt of mental health referrals on the dependent variables, F

(7, 111) = 1.023, $p = .419$; Wilks' Lambda = .939, partial eta squared = .061. When the results for the dependent variables were considered separately, a significant difference existed for the depression screen, $F(1, 117) = 4.734$, $p = .032$, partial eta squared = .039. An inspection of the mean scores indicated that those who received a referral for mental health reported slightly higher scores on the depression screen ($M = .70$, $SD = 0.93$) compared to those who did not receive a referral for mental health ($M = .33$, $SD = 0.66$). This finding likely suggests that those who received a referral for mental health follow-up were those in need of services.

4.2 Summary of Quantitative Results

The results of the quantitative survey represent men and women from various cancer disease groups who received treatment at several types of treatment facilities across the country. The quantitative results suggest that the majority of participants are receiving a moderate level of survivorship care, including minimal receipt of SCPs or Treatment Summaries and some amount of referrals for mental health, diet, and physical activity. Correlational data indicate that a higher level of survivorship care is associated with higher satisfaction with care and higher psychosocial functioning, including lower distress and higher quality of life, self-efficacy, and activation. Correlational results also indicate that higher levels of satisfaction with care are associated with lower levels of psychological distress and higher levels of QoL, coping self-efficacy, and activation. Psychosocial variables were also associated with several health behavior outcomes. Correlational analyses indicate that healthier lifestyles are correlated with greater well-being and higher psychosocial functioning, marked by greater activation and confidence in one's ability to cope with cancer.

In addition, the present data suggest significant differences in general psychological distress and coping self-efficacy for those who received some form of written care plan versus

those who did not. These results indicate that those who received a written care plan reported lower psychological distress and higher coping self-efficacy compared to those who did not receive a written care plan. This finding implies that written care plan documents have the potential to lead to higher psychosocial functioning for survivors of cancer. When investigating group differences across psychosocial and health behavior outcomes for those who received referrals for comprehensive survivorship care versus those who did not, one significant difference was found for depression, indicating that those who received a mental health referral reported slightly higher depression scores compared to those who did not receive a referral. This finding potentially suggests that referrals are provided based on need and aside from whether a referral is provided, patients' follow-up on referrals received and pursuit of recommended treatment is also very important.

4.3 Qualitative Analyses

Qualitative data was collected during a telephone interview in which healthcare providers were asked about five open-ended questions regarding their perspectives on comprehensive survivorship care and experiences delivering post-treatment services (Aim 4). Specifically, definitions of survivorship care, use of SCPs and coordination of care, the utility of SCPs, barriers to implementing SCPs, and the next steps in the field of cancer survivorship care were all measured at one time-point using a qualitative interview.

Participants' responses to open ended questions were grouped based on identified themes, while dichotomous responses were tallied (see Table 20). A total of 8 cancer survivorship healthcare providers (5 women and 3 men), including 2 medical oncologists, 1 oncology nurse, 2 clinical (health) psychologists, and 3 primary care physicians, consented to and completed the qualitative telephone interview.

Question 1. Definition of survivorship care. In response to the first question about the providers' definition of survivorship care, one primary theme emerged with regard to the timeframe defined. Although one provider described survivorship care as starting the minute a patient receives a cancer diagnosis, most providers ($n = 7$) described it as encompassing long-term care for cancer patients who have *completed* cancer treatment. Several providers ($n = 4$) described their view of survivorship care as supporting patients physically, emotionally, and socially, in an ongoing capacity. Similarly, some providers explained their belief that survivorship care means helping patients navigate life after cancer, re-define their lives, adjust to a "new normal," and cope with the ongoing fear of recurrence ($n = 2$). One provider responded:

I think of it [survivorship care] in terms of helping people figure out how they go about living their life the best way they can given the side effects they experience from treatment and medications, various physical limitations, and even ongoing treatments. It means helping patients live life within the limitations they have – functionally, emotionally, socially/interpersonal relationships, and familial roles.

In response to a follow-up question about what survivorship care entails, the healthcare providers interviewed responded in one of two ways: 1) The care received from all healthcare providers throughout the treatment and disease management phases ($n = 5$) and 2) Patient management of chronic and co-morbid diseases (e.g., risk reduction; $n = 4$).

Question 2. A system for creating SCPs or some form of written care plan. Next, healthcare providers were asked about whether their institutions have a system for creating SCPs or some form of post-treatment care plan. Responses to this question were generally unified in that all 8 providers indicated their practice or medical institution does *not* have a system for creating SCPs. One provider exclaimed, "I wish we did, but we don't! And I'm sad about that, I

think it is a very helpful tool.” Another responded, “Absolutely not, there is no formal plan. Diabetics and heart patients get very specialized care plans, but not our cancer patients.” Despite a lack of experience with formal care plans, two providers reported *informally* implementing aspects of a SCP. Specifically, two providers reported giving patients specific written post-treatment guidelines for screening and risk reduction behaviors and one indicated providing patients, upon request, with a document that summarizes diagnostic and treatment information, and lists 5-year follow-up recommendations. In general, providers’ affective response to this line of questions was somewhat discouraged and disheartened. Providers sounded disappointed when admitting they do not implement SCPs or have a formal, standardized system for coordinating care, making referrals, and tracking progress.

Coordination of care. Healthcare providers were then asked about the level of coordination that occurs between providers and across specialties during the survivorship phase of care. While two providers reported that they do *not* coordinate care with other providers, six reported some level of coordination and communication with other providers. More specifically, 5 individuals described engaging in informal communication with other physicians or healthcare providers on behalf of the patient and also reported access to medical record chart notes, which also facilitates coordination of care. One of these providers reported, “Yes, there is brief communication between care providers regarding the reason for referral, but often not much more than that.” One individual reported involvement in a multidisciplinary team that meets regularly for consultation purposes with a focus on patients in active treatment.

Referrals for comprehensive survivorship care and a system for tracking. With regard to referrals for comprehensive care during survivorship (e.g., mental health, diet, exercise), all of those interviewed reported making general recommendations for health and wellness (e.g.,

resources for coping and support, health guidelines) and/or provision of referrals on a case-by-case basis depending on patient reported needs. Seven providers reported making referrals for mental health, diet/nutrition, and physical activity/exercise, and one provider explained, “Yes, we do provide these recommendations and referrals to patients, but this is highly individualized and depends on the oncologist – not all oncologists do it and some do it more than others.” Three providers indicated giving referrals for alternative therapies, including acupuncture, massage, yoga, physical activity, genetic counseling, and smoking cessation. When asked about a system for tracking adherence to recommendations and referrals or health behavior change, the providers interviewed indicated that there is either no system for tracking ($n = 4$) or tracking is done informally via patient self-report and documentation in medical records ($n = 4$).

Question 3. Utility of SCPs. Healthcare providers were asked about their impression of the utility of SCPs. Although all 8 providers reported little or no experience using SCPs, 5 indicated beliefs that SCPs are likely useful and of value to the *patients* and 4 said SCPs could benefit *providers*. One provider summed it up by saying, “Very good for patients. Very hard for practicing physicians to implement.” Although 2 individuals stated they do *not* see a need for a formal written document (Example statement: “I feel like I do many things that are incorporated in the plans across the follow-up period, so I see the utility, but I haven’t yet seen the need for using a formalized plan.”), 3 providers reported that they believe the concept of comprehensive, interdisciplinary, coordinated care is very important.

Perceived helpfulness. In response to a follow-up question regarding the perceived benefits or helpfulness of SCPs, individuals provided 8 total responses, from which 2 themes were identified: (1) Psychological benefit to the patient ($n = 3$) and (2) A resource that can facilitate high quality care during survivorship ($n = 4$). When discussing the perceived

psychological benefit of SCP use, several healthcare providers explained that a written care plan would provide patients with guidance, confidence, and clarity, while reducing uncertainty, confusion, and feelings of abandonment. Specifically, one provider stated, “Those finishing treatment often feel confused and unsure of what to do next. Patients would appreciate a written care plan and would feel less alone, lost, confused.” Another provider commented:

The benefits of survivorship care plans being written and shared shows patients what to focus on once they’ve completed their treatment and how they should proceed during their recovery and remission phase. It helps provide guidance and confidence related to the next phase of their care.

In addition, one oncology provider said:

I believe there is a great deal of utility here. They give patients confidence and clarity. Patients feel less overwhelmed to have something written, because so much information is provided all at once in the beginning, not to mention all of this information comes on the heels of a diagnosis of cancer... patients don’t remember a lot of what I tell them.

Those who described SCPs as a good resource further indicated SCPs would provide patient and provider access to diagnosis and treatment information, as well as follow-up recommendations for survivorship care providers and their care planning. One provider responded:

I think SCPs are a good idea because when patients finish treatment and then go to see other doctors for different types of health issues, they’ll be asked questions about their diagnosis and treatment and will need to know or at least have easy access to this information.

Another provider stated:

From a primary care perspective, I know there are times when I wish I knew more about

the therapies my patients have received, how this impacts their health and risk, and how I should plan their care long-term. It would be very useful for me to have this so that I am aware of the other physicians' recommendations and reasons for recommendations, and then I can make informed decisions regarding their care and my own recommendations.

Falling under the theme of SCPs as an important resource, several providers made additional points regarding the role of SCPs in facilitating provider communication ($n = 2$), and continuity and coordination of care ($n = 2$), as well as assisting patients with re-integration into primary care ($n = 1$). Overall, providers' affective response to this line of questions was quite positive. The providers generally sounded very supportive of SCP use and enthusiastic about the potential benefits.

Should all patients receive a SCP. Due to time constraints and earlier responses, not all healthcare providers were asked the follow-up question about whether they believe all patients should receive a SCP. For those who were asked ($n = 4$), 2 providers reported that all patients should have the option of receiving a SCP. One provider explained, "I think it should be available to everyone; I'm not sure if everyone would want it, but they should at least have the option." In contrast, 2 providers indicated they do not think all patients require a SCP and their belief is that care plans would be more helpful for high-risk patients, survivors of childhood cancer, or young adult survivors.

Question 4. Obstacles or barriers to delivery of comprehensive survivorship care, including implementation of SCPs. The fourth question pertained to obstacles or barriers to delivery of comprehensive survivorship care, including implementation of SCPs, and elicited a variety of responses from healthcare providers. The 8 providers interviewed gave 26 responses comprising 5 themes: (1) Resources, (2) No standard, (3) Levels of translation needed, (4)

Fragmented system, and (5) Lack of empirical data. All 8 providers reported resources to be a significant obstacle, including time ($n = 8$), funding ($n = 3$), and staff and expertise ($n = 5$). Specific to the issue of staffing is a concern about identifying who should be responsible for developing and implementing SCPs ($n = 4$; Example statement: “A significant barrier is figuring out who would or should be implementing SCPs. Doctors say the nurses should do it and nurses say the doctors should do it.”). Providers additionally cited the lack of standard of what should be included, when, and for whom, as another barrier to implementing comprehensive care and SCPs ($n = 2$). One provider reported a need for different levels of translation of information. More specifically, this individual described the opportunity that primary care physicians have to explain and clarify information so that patients are able to understand how best to manage their care, therefore making it ever so important that the disease and treatment-related information passed from oncology to primary care providers be translated to the extent that it is clear for those outside of the oncology to understand.

Providers also expressed concerns about the current medical system as “fragmented” with a lack of adequate interdisciplinary care efforts ($n = 3$). Individuals who endorsed this response theme cited a need for clearer distinctions between providers’ roles throughout survivorship ($n = 1$) and increased communication, collaboration, and coordination between providers ($n = 3$). The final response theme related to a lack of empirical support for comprehensive survivorship care and SCP use ($n = 3$). Providers discussed the critical need for more data on long-term and late effects of cancer treatment ($n = 1$) as well as SCP efficacy ($n = 2$). One provider responded, “We need more data on the efficacy of these plans, more evidence for how they might impact symptom management and long-term outcomes.”

Question 5. Next steps in the field of survivorship care. The fifth and final question inquired about healthcare providers' opinion of the next steps in the field of cancer survivorship care and what we as clinicians and researchers should be working toward. Again, providers gave a range of responses, 28 total, comprising the following 5 themes: (1) Build the evidence base, (2) Standardize delivery of survivorship care, (3) Maximize use of technology and electronic medical records, (4) Increase the focus on healthy lifestyle behaviors and behavior change, and (5) Focus on patient-centered care.

Those who provided responses that fell into theme one ($n = 6$) described a need for data on clinical outcomes and an “end point impact” of SCPs, as well as related to cost outcomes. One provider reported:

We need to gather more evidence of an end point impact that is real and palpable, and that we will regret or feel bad that we're not achieving if we don't do this. Do they make patients more compliant with screening at 3 years? Are patients more likely to change x or y health behaviors? We need to see that these care plans work and really make a difference.

Another provider commented, “I look forward to seeing SCPs implemented in some fashion and beginning to learn what works. I'd like to be a part of an institution piloting SCPs.” The issue of cost outcomes was identified and one provider explained, “We need to work together to contain costs, and show that within this type of healthcare system these care plans really would smooth the transition of care, lead to lower costs, and other long-term clinical benefits.”

Theme two included provider responses related to standardizing cancer survivorship care ($n = 9$). Overall, providers who endorsed theme two described a need to develop a consensus on

what “survivorship care” means and what it entails as well as a system that providers agree on and commit to. Several sub-themes emerged, including the need to designate a survivorship care point person ($n = 2$). One provider discussed the importance of using physician extenders, such as nurse practitioners, as a point person for survivorship care planning and coordination of follow-up. Another provider stated, “A good model might involve someone, a designated survivorship person, to coordinate and lead this type of initiative, including spending time with patients to create plans and then track with patients during follow-up visits over time.” Another common sub-theme references an integrated team approach ($n = 4$) and includes follow-up comments regarding (a) increased collaboration and communication between providers and across specialties ($n = 3$), (b) more standardized integration of psychosocial care ($n = 1$), and greater awareness of the role of primary care physicians in survivorship care planning and follow-up ($n = 1$).

Theme three relates to the use of technology and electronic medical records for survivorship care planning and follow-up ($n = 2$). Two providers cited the need for a system that standardizes, unifies, and tracks follow-up care data. Theme four refers to increasing the focus on healthy lifestyle behaviors and behavior change ($n = 2$). One provider reported, “Beyond prevention, post-diagnosis, we should be making sure that patients are making health behavior changes and are integrating healthy habits into their lifestyle.”

One of the commonly endorsed themes (theme five) refers to increasing focus on patient-centered care ($n = 5$). Providers who gave responses that fall under this theme described patient-centered care in various ways. One provider discussed the importance of tailoring and individualization of SCP documents. Two providers described a need for healthcare providers to do more to smooth the transition to post-treatment care and to incorporate patients in their own

care planning and follow-up. A related sub-theme included the importance of reassuring and empowering patients to manage their health and follow-up care ($n = 2$; Example statement: “We need to be helping to *reassure* and *empower* patients, for example, through long-term periodic follow-up visits to monitor their recovery and screen for recurrent and new primaries.”). Another sub-theme referred to a need to change the mindset of providers and patients to consider survivorship care as an ongoing, longitudinal process. One provider stated:

We need to adjust our mindset away from thinking this is a tumor we have to excise and chemo we need to administer. We need to think of it more as a longitudinal process and helping patients navigate this phase of care. There is no good road map; we need to help people adjust and continually, across time, find ways to cope with things that are bound.

In addition, several providers discussed the need for evaluating patient perspectives, including patient-reported needs ($n = 3$).

4.4 Summary of Qualitative Results

Overall, the survivorship healthcare providers interviewed appeared to be in agreement that survivorship care includes comprehensive, multi-disciplinary care that addresses co-morbid consequences of cancer and its treatment, and is delivered long-term to patients who have completed cancer treatment. Most providers reported a lack of standardized survivorship care, including no formal system for developing/implementing SCPs, providing/tracking referrals, or coordinating care across healthcare specialties. With that said, almost all providers reported some amount of informal coordination and communication with other providers as well as informal tracking through use of chart notes in patients’ medical records. Despite the lack of experience with SCPs, most care providers reported the belief that SCPs hold significant value and benefit for patients and providers, and all patients should at least have the option to receive a SCP. There

was consensus among providers that resources (e.g., time, staff, funding), a fragmented medical system, and a lack of empirical support are the primary barriers to SCP implementation at this time. The providers were also in agreement that patient-centered care, empirical evaluation of SCPs, identification of a designated survivorship care point person, and use of technology and electronic medical records to formalize the care planning and follow-up process are among the most critical next steps in the field of cancer survivorship care.

Chapter 5. Discussion

Global health researchers report that by 2030, chronic diseases such as cancer will account for 70% of deaths worldwide (Samb et al., 2010). This startling trend underscores the importance of the current line of research and the dire need to increase the evidence base and enhance our understanding of the long-term care delivered to survivors of cancer and the factors associated with disease-risk reduction, psychosocial adjustment, health and well-being. As the number of cancer survivors continues to rise, survivorship care has become an increasingly important phase along the continuum of cancer care. The growing cancer survivor population highlights the need for researchers and clinicians to assess the current standard of survivorship care. Equally important is the need to develop and improve evidence-based models for the delivery of high caliber post-treatment care to maximize survivors' short- and long-term outcomes.

The current study investigated cancer survivorship care, including care planning and follow-up, in survivors of different types of cancer. We quantitatively evaluated the post-treatment care received by cancer survivors, including use of SCPs and the impact of these care plans and subsequent follow-up on a variety of psychosocial and health behavior outcomes. We also examined survivors' satisfaction with the care they received and the impact of care on health and quality of life outcomes, as well as unmet needs to determine strengths and weaknesses of the current models of care. The primary goal of this exploratory study was hypothesis generation. Specifically, this study aimed to generate hypotheses regarding whether and how comprehensive survivorship care and receipt of SCP are related to psychosocial and health behavior outcomes in a sample of cancer survivors. Learning more about the current state of cancer survivorship care may help address some of the existing research gaps in this dynamic, understudied area of health

promotion and disease prevention. Learning whether and how the current models of survivorship care meet cancer survivors' needs will provide information to improve delivery of comprehensive survivorship care and consequently lead to improvements in the health and overall quality of life for men and women surviving cancer.

5.1 Quantitative Findings

As predicted, the results of the current study indicate that a higher level of survivorship care is associated with higher satisfaction with care and higher psychosocial functioning (e.g., high QoL, coping self-efficacy, and activation, and low depression and distress). Consistent with research conducted in adult and cancer survivor populations (Bandura, 1997; Anderson et al., 2006; Giese-Davis et al., 1999; Lev et al., 2007; Merluzzi et al., 2001; Weber et al., 2004; Winett et al., 2007), results also indicate that higher coping self-efficacy is associated with other psychosocial outcomes (e.g., high QoL and low levels of depression and distress) and several health behaviors (e.g., low dietary fat intake, high fruit and vegetable consumption, high levels of physical activity) in cancer survivors. Similar to prior research with cancer patients, associations were identified between more positive health behaviors and better QoL and greater distress and poorer QoL post-diagnosis and treatment (Blanchard et al., 2008). Individuals who received more comprehensive survivorship care and demonstrate mastery of coping self-efficacy and activation skills are more likely to experience less distress, exhibit higher psychosocial functioning, and engage in higher levels of healthy behaviors. Unfortunately, the opposite is also true: Individuals who received a lower level of comprehensive survivorship care and had greater difficulty with coping self-efficacy and activation skills may experience higher levels of distress and lower psychosocial functioning, and engage in lower levels of healthy behaviors.

The clinical data collected in the current study, including early age of onset of cancer and high prevalence of family history of disease, suggest that study participants are a fairly high-risk group. In the general population, cancer risk increases with age and the mean age of onset for prevalent cancers such as breast and colorectal is 62 and 75 years, respectively (ASCO, 2013). Notably, the average age of cancer onset in the current sample (age 45) is anywhere from 17-30 years younger than people at average risk for the disease (65 years; ASCO, 2013). In addition, the high rate of participants' family history of cancer (93% of participants reported a family history of cancer) highlights the at-risk nature of the current group. As such, study participants are potentially in need of a higher level of comprehensive survivorship care to manage/reduce their risk of recurrent and new primary tumors and address psychosocial issues related to cancer, such as risk communication with family members.

Overall, the survivorship care planning and follow-up data indicate that most participants (54%; $n = 66$) are receiving a moderate level of survivorship care that could include one or more of the following: some form of written care plan document, secondary contact person for survivorship care, perceived optimal amount of survivorship contacts, one or more referrals for lifestyle behaviors and mental health, and some level of satisfaction with survivorship care. Collectively, the subjective and objective survivorship care planning data suggest that although the quantity of survivorship care follow-up is adequate, there is room for improvement with regard to the content and quality of those survivorship contacts. This finding supports recent data that suggests our current approach to survivorship care is inadequate when measured by IOM guidelines and standards (Jefford et al., 2013).

Most participants indicated that they did not expect to receive a written care plan and several participants noted in an open-ended response field that they had never heard of SCPs.

Therefore, it is likely that the general cancer survivor population lacks awareness of SCPs / models for comprehensive survivorship care. Overall, participants reported at least a moderate level of satisfaction with their survivorship care, with a few reporting extreme dissatisfaction. These findings support previous research that posits survivorship care planning should be tailored based on individual patients needs. Moreover, the current results suggest a need for patient education to increase awareness of survivorship care recommendations and essential components.

The findings on multidisciplinary survivorship care referrals confirm study hypotheses and previous research indicating that regardless of whether a participant received a SCP, cancer survivors often do not receive adequate referrals for post-treatment care (Burke Beckjord et al., 2008). Most participants reported expectations for and an interest in receiving referrals for mental health, diet, and physical activity; however, only a small portion of participants actually received those referrals and many pursued this type of follow-up care on their own. Although receiving a referral does not guarantee actual receipt of services, such referrals are an essential component of survivorship care and an important first step toward ensuring that patients have the information and resources needed to effectively manage their health during survivorship. Study results indicated that far fewer participants pursued additional services related to mental health, diet, and physical activity than had expressed interest in receiving such follow-up. Although this finding could discount participants' true level of interest or motivation to pursue a particular type of follow-up care, it is also possible that many of those who were interested never received the referral information they needed. The lack of referrals for multidisciplinary survivorship care, especially given the high level of interest, reflects a weakness in the current state of survivorship care and an area in need of improvement.

For those who received referrals for comprehensive survivorship care, less than half had received some form of written care plan. This finding suggests healthcare providers are likely informally giving recommendations and referrals for comprehensive care, outside of the recommended survivorship care plan framework. These results also reflect the lack of standardized or systematic implementation of comprehensive survivorship care planning and follow-up. Many participants who received a SCP or other written care plan document reported that referrals were not included, which suggests that SCPs are likely specific to diagnostic and treatment summary information as well as guidelines for cancer surveillance, but lack specific recommendations for health behaviors such as healthy nutrition and exercise, as well as referrals for mental health services. SCPs are likely not being used to their fullest capacity reflecting another weakness in the current state of survivorship care. In addition, the present results support research by Salz and colleagues (2012) indicating that for those SCPs delivered at NCI-designated cancer centers, none include all components recommended by the IOM. To understand the true efficacy of SCPs, it is important that when developed and implemented, SCPs include the essential components in accordance with national recommendations and standards (ASCO, 2011; Hewitt, Greenfield & Stovall, 2006; Jacobs et al., 2009; NCI, 2010).

Given the findings on inadequate referrals, greater research and clinical attention is needed regarding the delivery of comprehensive evidence-based survivorship care, including multidisciplinary resources and referrals for cancer survivors. The most commonly endorsed post-treatment referrals pursued by study participants include: (i) For diet: Meeting with a nutritionist or dietician and personal research; (ii) For physical activity: Physical therapy, increasing the overall amount of physical activity, joining a group fitness class, and personal research; and (iii) For mental health: Psychotherapy or counseling sessions, psychiatric

treatment, and support group involvement. These results demonstrate the value of integrating multidisciplinary services within cancer care settings. Increasing the presence of psychologists and psychiatrists, nutritionists and dietitians, physical therapists and exercise scientists, and information resource centers would greatly enhance the quality of care accessible to survivors of cancer.

It is critical that SCPs include referrals and recommendations are guided by the most current evidence-based approaches and protocols. For mental health, psychosocial interventions that include cognitive and behavioral components, such as relaxation training and cognitive restructuring, are more efficacious than control conditions in managing psychological distress, as evidenced by improvements in depression, anxiety, quality of life, emotional adjustment, and physical and social functioning (Andersen, 2002; Andrykowski & Manne, 2006; Hart et al., 2012; Meyer et al., 1995; Osborn et al., 2006). For diet and exercise, the latest evidence-based focus for decreased risk of all-cause, cardiovascular disease and cancer mortality is on higher diet quality and healthful nutritional patterns (e.g., the Mediterranean diet) rather than specific macronutrients (e.g., saturated fat; Chowdury et al., 2014; Estruch et al., 2013; Reedy et al., 2014). Recent evidence also suggests body composition (i.e., fat free body mass) is associated with cancer survival, shifting attention away from using body mass index or weight as predictors of health outcomes (e.g., cardiovascular disease) and disease-free survival (Gonzales et al., 2014). Thus, SCPs should likely recommend cognitive behavioral approaches for managing psychological distress, and nutritional patterns (e.g., DASH, Mediterranean) and exercise (e.g., resistance training, moderate intensity endurance training) aimed at reducing fat mass and retaining lean body mass. To understand how SCPs impact survival, QoL, and mental and physical functioning, it is critical that the recommendations and referrals delivered to survivors

via SCPs are based on the most current scientific evidence.

Building on the aforementioned findings, organizations such as the IOM, NIH, ASCO, and ACS are charged with the task of increasing advocacy and educational efforts on national, state, and local levels for the purposes of calling for more standardized survivorship care delivery, including mandatory implementation of SCPs that meet quality care recommendations and evidence-based guidelines. Movement in this direction comes from the American College of Surgeons Commission on Cancer (CoC) and their latest (2012) accreditation standards related to ensuring that key elements of quality cancer care are provided to every patient with cancer who receives treatment at a CoC-accredited facility, where about 70% of all cancer patients are treated. The focus of these standards is on patient-centered care and includes, among other things, distress screening and a SCP that documents the care each patient received and seeks to improve cancer survivors' overall health and QoL (American College of Surgeons Commission on Cancer, 2014).

For study participants who received a written care plan document, a treatment summary was the most common form (17%; $n = 21$). As defined in the questionnaire, a treatment summary typically includes: A brief summary of a patient's cancer treatment. It is commonly used to organize information about a patient's cancer, cancer treatment, follow-up care, and basic information related to his or her medical history and future doctors. A treatment summary usually does *not* offer anything in the way of comprehensive follow-up care, such as referrals and resources for a variety of healthcare services (e.g., mental health and lifestyle interventions), whereas a SCP usually does. As previously mentioned, the results of the current study support this finding since only a minority of the participants who received a written care plan received multidisciplinary survivorship care referrals along with it.

The survivorship care plan data support prior research suggesting a continued lack of implementation and testing (Faul et al., 2010). For those who did receive a care plan document, data suggest fairly even distribution across cancer care settings, with a little over half of study participants receiving their written care document from a community hospital or oncology office and just less than half receiving it from a comprehensive cancer center or academic medical center. This finding is somewhat surprising given that most survivorship programs exist within comprehensive cancer and academic medical center settings. However, Salz and colleagues recently reported that only 23 of the total 53 NCI-designated cancer centers that treat adult cancer patients are using SCPs for their breast cancer survivors, colorectal cancer survivors, or both (Salz et al., 2013). While this estimate is low, the researchers indicated that those institutions not currently implementing SCPs reported planning survivorship programs or developing SCPs for future use (2013). Collectively, these findings are disappointing in that they reflect a lack of widespread use of SCPs, even for more prevalent cancers like breast and colorectal, but hold promise as SCP adoption is likely underway at many institutions (Faul et al., 2010; Salz et al., 2013).

For the participants in this study, written care plan documents were most commonly delivered before the conclusion of treatment. This finding contradicts IOM guidelines, which recommend delivering SCPs at the end of treatment, largely because of the abundance of information patients are inundated with at the time of diagnosis and beginning active treatment. More research is needed to investigate the optimal timing of care plan delivery. Research that documents survivors' perspectives on this topic suggests varying opinions, with some preferring to receive the SCP at the last visit and others well afterward (Marbach et al., 2011; Smith et al., 2011). A 2013 NIH funding opportunity announcement calls for examination of survivorship

care planning efficacy and impact, with one suggested research question pertaining to what is the optimal timing for delivery of survivorship care planning. Thus, it is likely researchers will have an improved understanding of this issue in coming years.

In addition, study results suggest that the oncologist is the most common healthcare provider developing care plans, although this does not mean they are the best providers for the job. In fact, based on the survivorship care model data, written care plan documents are least frequently created by oncologists. In the survivorship care model literature, it is more commonly believed to be a task completed by nurses and/or multidisciplinary teams and sometimes in collaboration with the patient. The finding that most care plan documents had not been modified since their creation does not necessarily suggest there is no need for revision or updating. It is possible that in some cases, time and staff resource barriers prevented the modification of documents.

For the current sample of participants, a written care plan document was reportedly helpful for a variety of reasons, including informing patients about what to expect during survivorship, providing general guidelines to follow and specific tips for managing health, documenting diagnostic and treatment information, and providing comfort and reassurance. Most participants also reported that their written care plan had an extremely positive impact on mental health and at least a moderate impact on their dietary and physical activity habits. Collectively, these results provide empirical support for theoretical findings that posit written care plans address survivors' needs, increase their mental and physical functioning, and improve satisfaction and compliance with care (Earle, 2006; Faul et al., 2010; Ganz et al., 2008; Hewitt, Greenfield & Stovall, 2006). More research is needed to better understand if and how care plans impact other important facets of high quality care, such as continuity and coordination of care,

and ultimately, enhance quality and longevity of life for survivors (Earle, 2006; Faul et al., 2010; Ganz et al., 2008; Hewitt, Greenfield & Stovall, 2006; Snyder et al., 2009).

In contrast to results of a study conducted by Grunfeld and colleagues (2011), which found no differences in patient-reported outcomes (e.g., general psychological distress) when comparing SCPs with standard discharge/transfer visits, results of the current study reveal significantly lower general distress and higher coping self-efficacy for those who received a written care plan. The difference in distress scores for those who received a written care plan versus those who did not is more than half of a standard deviation and could be considered clinically significant meaningful change, keeping in mind the cross-sectional nature of the data. Furthermore, non-statistically significant trends suggest that receipt of a written care plan might also be associated with higher patient activation and lower dietary fat intake. These findings provide initial empirical support for the use of written care plans and illustrate the potential of these documents to impact psychosocial outcomes, which are believed to play a role in disease management and risk reduction. For example, research has shown that psychological distress in cancer survivors is associated with non-adherence to treatment recommendations, poorer satisfaction with care, and poorer QoL across many domains (Jacobsen et al., 2005).

Furthermore, distress and coping self-efficacy have been shown to have implications for communication with providers, psychosocial adjustment, as well as seeking and understanding medical information (Mosher et al., 2010; Philip et al., 2013; Shields et al., 2010). Therefore, the current findings are significant as they indicate written care plans might be one vehicle for targeting psychosocial health, which can have a number of impacts on compliance with care and disease management, QoL, and risk reduction during survivorship. While the current study is an important step in gathering empirical evidence, longitudinal research is needed to better

understand how delivery of written care plans and improvements in patient-reported outcomes impact long-term clinical endpoints and disease-free survival.

5.2 Qualitative Findings

Several important themes emerged from the qualitative results reflecting consensus among survivorship care providers spanning a variety of disciplines. Results suggest that although a patient may be considered a “survivor” as early as post-diagnosis, most healthcare providers define survivorship care as the long-term care delivered to patients following completion of active treatment. Thus, by definition and provider report, survivorship care encompasses multidisciplinary care that addresses a wide range of patient needs. Learning how survivorship care is defined, especially by those responsible for delivering the care, is an important step in the process of evaluating the current state of survivorship care, understanding strengths and weaknesses, and ultimately identifying areas in need of improvement.

Providers not only agreed on the definition of survivorship care, but also the need for multidisciplinary care during survivorship, including SCPs. Supporting study hypotheses and research assessing provider perspectives, nearly all providers interviewed said comprehensive post-treatment care and SCPs hold significant value and utility (Hewitt et al., 2007; Watson et al., 2010). As predicted, SCPs were hypothesized to be helpful to patients for the purposes of making diagnostic and treatment information accessible, and providing psychological benefit. Somewhat unexpected was the indication that SCPs are also helpful to providers – as a resource to guide survivorship care planning and follow-up, and for the purposes of increasing provider communication and facilitating continuity and coordination of care. This finding supports research documenting the helpfulness, namely for primary care providers, for increasing

knowledge of patients' cancer history thereby influencing patient care, and as an important communication tool (Mayer et al., 2012; Shalom et al., 2011).

Despite the abovementioned findings, there does not appear to be a formal system or coordinated effort for delivering this care, nor is there widespread use of written care plans. The issue of a fragmented system was also identified as a barrier to delivering comprehensive care, and combined with a lack of coordinated effort and minimal use of written care plans reflects a significant weakness in the current state of survivorship care. These results support findings by Jefford and colleagues (2013) who described our healthcare system as fragmented and further reported that the current approach to survivorship care does not adequately meet the goals set forth by the IOM. With that said, providers are regularly engaging in informal communication and coordination of care, as well as referral delivery, all of which is very encouraging. This finding potentially reflects the culture of the providers' healthcare institution, but also individual clinical practice. Despite the promising nature of this finding among providers interviewed for the current study, there exists the implication that survivorship care varies across providers and institutions, therefore lacking standardization or consistency. As a result, many survivors are likely receiving inadequate care. For the current group of providers, though, reported informal coordination of care and referral delivery suggests there exists a need for comprehensive, high quality care. If several aspects of comprehensive survivorship care are currently implemented informally in many institutions / clinical settings, provision of more systematic cancer survivorship care may be more attainable without drastic changes in approaches to care.

Consistent with prior research, survivorship care providers currently perceive and/or experience several barriers to delivering comprehensive care and implementing SCPs, with lack of resources as one of the most significant (Campbell et al., 2011; Salz et al., 2013). Time was

also a prevalent concern in this group of providers, which raised the critical issue of staffing/expertise and who should be in charge of developing and implementing SCPs. Despite some variability in responses, data provide support for an oncology nurse provider as a possible lead contact person within the context of cross-provider collaboration. A nurse-led approach could potentially minimize financial burden and allow for the most thorough and efficient process, including patient tailoring. This finding contrasts the present study's quantitative data citing the oncologist as most commonly responsible for creating SCPs, but supports previous research on comprehensive survivorship care and survivorship care models, which point to nurses as ideal candidates for this role (Hahn & Ganz, 2011; Hewitt, Greenfield & Stovall, 2006; Jefford et al., 2011; Knowles et al., 2007; Koinberg et al., 2004; Lewis & Hendry, 2009; Lewis et al., 2009; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006).

Several important themes were identified and agreed upon with regard to future directions in the field of survivorship care. Researchers and clinicians are calling for empirical evaluation of multidisciplinary survivorship care and SCPs, and results from the current study further support this call to action. Unsurprisingly, lack of empirical evidence was commonly cited as both a barrier and a next step in the field. While an increasing evidence base exists documenting short-term symptoms and patient-reported outcomes (e.g., pain, fatigue, distress, patient satisfaction, QoL), research is needed to evaluate long-term outcomes and clinical endpoints (e.g., treatment compliance, disease-free survival; Davies & Batehup, 2011; Grunfeld et al., 2011; Richardson et al., 2011). Other ideas for next steps point to increasing the focus on patient-centered care and formalizing a system for care planning and follow-up. Both of these themes are commonly cited in the literature and support the IOM's agenda as well as the American College of Surgeons CoC accreditation standards for 2015 (American College of

Surgeons Commission on Cancer, 2014; Davies & Batehup, 2011; Hewitt, Greenfield & Stovall, 2006; Jefford et al., 2013). The current findings, in conjunction with previous research, suggest that important next steps involve working toward coordinated multidisciplinary efforts and patient tailoring, all within the context of educating and empowering patients to effectively manage their health during survivorship.

5.3 Synthesis of Quantitative and Qualitative Findings

Both quantitative and qualitative results indicate a critical need to formalize a system for survivorship care delivery. Implementing a more systematic, evidence-based model has the potential to reduce fragmentation and the lack of coordinated care, standardize the use of SCPs, reduce access to care inequities, and increase the effectiveness and efficiency of survivorship care. Recent healthcare reform (e.g., PPACA, CCIA) holds promise in this regard, and as previously discussed, ACOs and the PCMH framework are two potential models for systematically integrating comprehensive care for cancer survivors (Hudson et al., 2011; Jefford et al., 2013).

In addition, results of this mixed-methods study support previous research reporting that patient and providers' opinion of SCPs, regardless of experience using or receiving one, is highly favorable (Baravelli et al., 2009; Hewitt et al., 2007; Marbach et al., 2011; Salz et al., 2012). Furthermore, both stakeholder groups agree on the key ways in which SCPs are beneficial. Unfortunately, the combined results also support previous findings indicating that most SCPs do not include all essential components and thus do not adhere to IOM guidelines (Salz et al., 2012). To increase the evidence base for SCPs and understand their long-term impact – which researchers and clinicians alike have called for – it is critical that medical institutions pilot SCPs

designed to include all essential components in accordance with IOM guidelines (American College of Surgeons Commission on Cancer, 2014).

Study findings highlight the importance of several dimensions of patient-centered care, including education and tailoring. Improving patient education and increasing provider awareness of survivorship care guidelines has the potential to impact survivor outcomes in a number of ways. Raising awareness of guidelines among survivorship care providers could improve the quality of care, standardize care delivery, and decrease disparities in access to quality care. Education can empower patients to take responsibility for managing their health potentially impacting treatment adherence, and ultimately QoL and survival outcomes. Health education and counseling interventions comprise one tier of Frieden's Health Impact Pyramid, which asserts increasing individual efforts related to managing care and risk reduction can have "considerable impact" (Frieden, 2010). One example of this type of education intervention comes from the World Cancer Research Fund, United Kingdom (WCRF UK), and their campaign, "Move More for Life" (2014). This evidence-based program specifically targets individuals at risk for cancer as well as cancer survivors, and its mission is to teach patients to take responsibility for their care and reducing their risk during survivorship (WCRF UK, 2014).

Along these lines, an increasing amount of educational information has become available to cancer survivors on the Internet. For example, MD Anderson provides comprehensive survivorship care guidelines on their website for patients and providers to access. In addition, ASCO's patient education website has a comprehensive survivorship section that includes multimedia educational platforms (e.g., videos, patient booklets, downloadable forms) and other informational content on a variety of topics (McCabe et al., 2013). Furthermore, evidence-based cancer self-management programs, such as *Cancer: Thriving and Surviving*, are available cost-

free via the Internet for the purposes of increasing survivors' confidence in their ability to manage their health and lead active and fulfilling lives (National Council on Aging, 2014).

Patient and provider data also underscore the need for a survivorship care system that addresses the unique needs of survivors. Although survivorship care, including SCPs, should adhere to evidence-based guidelines for quality care, the specific content (e.g., multidisciplinary referrals, surveillance recommendations) should be tailored to meet patient needs. This finding supports research documenting survivors' preferences for individualized SCP content based on physical and psychosocial effects (Smith et al., 2011). Patient tailoring has the potential to impact not only patient-reported outcomes (e.g., satisfaction with care), but also improve the quality of care delivered and increase the effectiveness of care planning and follow-up procedures.

Taken together, the quantitative and qualitative results suggest more research is needed for the purposes of building the evidence base and resolving inconsistent findings. For example, a discrepancy was revealed between patient and provider report with regard to survivorship care referrals. Many participants reported that they wanted referrals (e.g., for mental health services) but did not receive them, while most providers reported that they regularly discuss referrals with their patients. This finding potentially reflects a disconnect in survivorship care referrals, suggesting some patients may be falling through the cracks. Further research is needed to evaluate potential breakdowns in the delivery of survivorship care referrals as well as patient-provider communication. Results could provide valuable information for targeting this particular aspect of survivorship care. Formalizing a system for survivorship care delivery, as discussed above, could improve patient access and therefore reduce inequity.

The combined results also indicate more research is needed to evaluate not only the efficacy of SCPs, but also the impact of comprehensive survivorship care on long-term outcomes that are both patient-reported and clinical in nature. Emerging evidence, including the current data, suggest that aspects of comprehensive survivorship care such as SCPs can improve patient-reported outcomes (e.g., distress, coping self-efficacy). In sum, the current study is an important step toward increasing knowledge of cancer survivorship experiences – from both the patient and providers’ perspective. Collectively, the current findings facilitate an improved understanding of the current state of survivorship care and highlight areas of strength while also identifying weaknesses to target.

Chapter 6. Strengths and Limitations

The current study has several strengths. These strengths include: (i) The mixed-methods approach; (ii) use of a clinical population; (iii) in depth assessment of an important phase of cancer care in need of empirical evaluation; (iv) data are representative of various cancer survivor disease groups, age ranges, and geographical location; (v) assessment of the perspective of both patients and healthcare providers; (vi) use of social media to recruit a clinical population; and (vii) use of an online survey. Although the qualitative interview data may not be generalizable to the wider healthcare provider population, qualitative measurement is a commonly used exploratory method and therefore matches the purpose of the current study. Furthermore, this mixed-methods approach allows a more complete understanding of the survivorship phase of cancer care, including strengths, limitations, challenges, and future directions.

Despite the various strengths of the present study, several limitations should be noted. First, based on sample size and sample characteristics, the results may not be generalizable to male cancer survivors or those from a lower socioeconomic status. The sample is fairly small ($N = 123$) and homogenous, as participants are primarily Caucasian, female, highly educated, and report a high socioeconomic status. The low number of male participants ($n = 14$) is a significant limitation, although not surprising given that many study participants are breast cancer survivors. Also, to find a moderate size effect (i.e., $d = 0.5$) at 80% power with 95% confidence, approximately 64 participants in each group were needed (Cohen, 1988). The disproportionate number of participants who did not receive SCPs versus those who did is a limiting factor and reveals a gap in need of research attention. Furthermore, given the many disease groups represented, results may not be specific to any one disease group and study findings may not be

applicable to more culturally or economically diverse populations of cancer survivors. It is also important to note that participants in the current study may be more highly motivated given their potentially higher risk status based on young age at diagnosis and family history.

Second, the findings of the current study are based on self-report data, which potentially reflect impression management biases (e.g., self-presentation, social desirability), in addition to likely being influenced by emotion and memory. Third, the cross-sectional study design prohibits causal inference; assessment of psychosocial and health behavior constructs over time (i.e., pre-diagnosis, during treatment, post-treatment) could allow for examination of changes in patterns of psychosocial functioning and health behavior across the continuum of the cancer experience.

A fourth and final limitation can be considered the inclusion of two measures that were created by the investigator and one measure that was adapted from its original version. Although the scales generally demonstrated very good internal consistency, more research is needed to examine the reliability and validity of these scales within larger samples.

Chapter 7. Future Directions

Attention to survivorship care is a critical issue with implications for survivors' short- and long-term health and well-being (Earle, 2006; Ganz et al., 2008; Hewitt & Ganz, 2006). Further research is needed to examine the efficacy and effectiveness of survivorship care models and SCPs so that researchers and clinicians can better understand the effects of survivorship care strategies and tools on actual survivor outcomes. Advancements in our knowledge and understanding of the needs of cancer survivors, survivorship care approaches, and SCPs will allow healthcare professionals to provide high-quality care based on empirical evidence (Earle, 2006). The current study provides important contributions to the field of comprehensive cancer survivorship care, as it identifies positive impacts of SCPs on patient-reported outcomes, while also revealing deficits in our current system of care delivery.

A vital next step in this line of research is to increase the evidence-base examining the efficacy of SCPs, including short- and long-term impacts of comprehensive survivorship care on both patient-reported and clinical outcomes. Empirical evidence is needed to guide and improve the development and implementation of effective comprehensive care models. For research purposes, there is a critical need for more people to be getting SCPs to better understand how they work. The current data show SCPs have a positive effect on distress and coping self-efficacy, and based on marginal significance SCPs might also positively impact additional psychosocial and health behavior outcomes (i.e., patient activation, dietary fat intake). The lack of statistically significant findings may be attributable to the relatively small sample size of the study. This limitation, which is also a finding, illustrates the low frequency with which SCPs are provided to patients and highlights the need for increased frequency of SCP implementation to

allow researchers to measure the effects. As previously noted, it is critical that the SCPs being implemented include all essential components.

Although further research examining the short- and long-term impact of comprehensive survivorship care, including SCP delivery, on psychosocial and clinical outcomes is warranted, we must first work toward developing a standardized system for delivering survivorship care and SCPs, including identification of a designated survivorship care provider/contact for patients. These first steps will facilitate equity of medical care delivery and furthermore lead to more precise and informative findings. After formalizing a system for delivery of survivorship care and SCPs, more research is needed to 1) examine the impact of SCPs on short- and long-term patient-reported and clinical outcomes, 2) determine how patient-reported outcomes might influence clinical outcomes, 3) increase the focus on patient-centered care to address the unique needs of survivors through tailoring of care delivery and improve patient education and advocacy efforts, and 4) explore if, when, and how SCPs are of benefit to vulnerable groups of survivors such as those with less education, language barriers or those with historically higher rates of cancer morbidity and mortality (e.g., racial / ethnic minority groups).

Enhanced understanding of survivors' post-treatment needs could aid behavioral health researchers in the design of interventions aimed at enhancing comprehensive survivorship care. Thus, results of the current study and future research can contribute to the conceptualization and design of survivorship care interventions that address the multidisciplinary needs of survivors post-treatment. Patient-centered care, including improvements in patient education and tailoring and physician-patient communication, is believed to positively impact the quality of care delivered as well as patient satisfaction with care. More broadly, high-quality comprehensive care is likely to lead to better overall health outcomes, such as higher quality of life, increases in

healthy behaviors, lower incidence of disease, and fewer physical and psychosocial comorbidities. Furthermore, increased empirical evidence documenting the multitude of benefits of comprehensive survivorship care, including SCP delivery and psychosocial and health behavior follow-up, is believed to increase the likelihood of policy support and insurance coverage for comprehensive survivorship care programs for people surviving cancer (similar to those covered by insurance for cardiac rehabilitation).

Overall, an increase in the quality of survivorship care provides patients with the tools necessary to make informed decisions related to their ongoing survivorship. High-quality, comprehensive, patient-centered survivorship care is likely to empower and enable survivors of cancer to make necessary lifestyle changes, seek out support resources, and better understand issues related to professional and social re-integration, all the while reducing stress and confusion related to ongoing treatment and follow-up care. Survivors are also less likely to feel overwhelmed and lost in the system as a result of receiving quality survivorship care. Therefore, improvements in the quality of survivorship care are likely to translate to improvements in survivors' quality of life (e.g., decreased rates of depression and anxiety, increased adoption/maintenance of healthy behaviors). Improved quality of care is likely to empower cancer survivors and consequently maximize health and quality and longevity of life. This line of innovative patient-centered research promises to change the face of survivorship care through increasing disease-free survival and improving survivors' physical and psychological functioning (Ganz et al., 2008). The ultimate goal of this line of research is to reduce the overall burden of a cancer diagnosis and treatment.

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Table 1. *Components of Survivorship Care Common Across Models and Settings*

Models of Care Essential Components
✓ Surveillance for recurrence
✓ Screening for new cancers
✓ Identification and interventions for consequences of cancer and its treatment
✓ Health promotion strategies
✓ Development of a written care plan to facilitate coordination between oncology specialists and primary care providers

Source: *From Survivorship Care Models and Programs*; page 203, Table 2 (McCabe & Jacobs, 2008).

Table 2. *Characteristics and Components of Cancer Survivorship Care Models*

Survivorship Care Model					
	Shared-Care Model	Nurse-Led Model of Care	Survivorship Follow-Up Clinic Model: <i>Comprehensive and Disease-Site Specific (DSS) Clinics</i>	Pediatric Oncology: Nurse-Led Comprehensive Care	
Site	<ul style="list-style-type: none"> • Community oncology offices 	<ul style="list-style-type: none"> • Community hospitals 	<ul style="list-style-type: none"> • Academic institutions 	<ul style="list-style-type: none"> • Academic institutions 	
	<ul style="list-style-type: none"> • Community hospitals 	<ul style="list-style-type: none"> • Hospital outpatient departments 	<ul style="list-style-type: none"> • Comprehensive cancer centers • Community hospitals 	<ul style="list-style-type: none"> • Comprehensive cancer centers • Community hospitals 	
Coordinator of Care	<ul style="list-style-type: none"> • Ongoing communication between providers • Primary care physician and staff 	<ul style="list-style-type: none"> • Oncology nurse with expertise in survivorship • Nurse practitioner with expertise in survivorship 	<ul style="list-style-type: none"> • Oncology nurse practitioner with expertise in survivorship • Nurse practitioner in collaboration with multidisciplinary team 	<ul style="list-style-type: none"> • Pediatric oncology nurse practitioner, in collaboration with pediatric oncologist(s) 	
Medical and Psychosocial Recovery; Health Promotion	<ul style="list-style-type: none"> • Ongoing assessment and follow-up, including primary and specialty care needs met by respective physicians 	<ul style="list-style-type: none"> • In-person evaluation by a nurse specialist, sometimes including a multidisciplinary team; One-time and ongoing (e.g., annual) consult(s) 	<ul style="list-style-type: none"> • In-person evaluation by multidisciplinary team member(s); One-time consult or ongoing (e.g., annual) risk-based care 	<ul style="list-style-type: none"> • Annual in-person evaluation by multidisciplinary team member(s); Ongoing risk-based care 	
		<ul style="list-style-type: none"> • Telephone follow-up and informational mailings 	<ul style="list-style-type: none"> • Availability of psychosocial and health behavior interventions 	<ul style="list-style-type: none"> • Availability of psychosocial and health behavior interventions 	
		<ul style="list-style-type: none"> • Health education classes and support groups 	<ul style="list-style-type: none"> • Health education classes, support groups, and educational materials 	<ul style="list-style-type: none"> • Health education classes, support groups, and educational materials 	<ul style="list-style-type: none"> • Health education classes, support groups, and educational materials
		<ul style="list-style-type: none"> • Community/network referrals 	<ul style="list-style-type: none"> • In-house and community referrals 	<ul style="list-style-type: none"> • In-house referrals 	<ul style="list-style-type: none"> • In-house referrals

Table 2. *Characteristics and Components of Cancer Survivorship Care Models, continued*

Survivorship Care Model				
	Shared-Care Model	Nurse-Led Model of Care	Survivorship Follow-Up Clinic Model: <i>Comprehensive (C)</i> and <i>Disease-Site Specific (DSS)</i> Clinics	Pediatric Oncology: Nurse-Led Comprehensive Care
Care planning	<ul style="list-style-type: none"> • Treatment summary/SCP created by one or more of the following: patient, nurse specialist, oncologist, primary care physician 	<ul style="list-style-type: none"> • Treatment summary/SCP created by nurse in charge of care, sometimes in collaboration with survivor 	<ul style="list-style-type: none"> • Treatment summary/SCP created by multidisciplinary survivorship team, sometimes in collaboration with survivor (C; DSS) 	<ul style="list-style-type: none"> • SCP created by multidisciplinary survivorship team
Potential benefits of model	<ul style="list-style-type: none"> • Treatment/management of co-morbidities 	<ul style="list-style-type: none"> • Care accessible by low-income individuals and those in rural settings 	<ul style="list-style-type: none"> • Holistic and coordinated approach (C) 	<ul style="list-style-type: none"> • Holistic and coordinated approach
	<ul style="list-style-type: none"> • Collaborative approach to multidisciplinary care 	<ul style="list-style-type: none"> • Continuity of care 	<ul style="list-style-type: none"> • Specialized, cancer-specific approach (DSS) 	<ul style="list-style-type: none"> • Continuity of care during childhood and adolescence
Potential disadvantages of model	<ul style="list-style-type: none"> • Miscommunication between care providers 	<ul style="list-style-type: none"> • Shortage of trained oncology nurses 	<ul style="list-style-type: none"> • Resource intensive; Complex in nature (C) 	<ul style="list-style-type: none"> • Resource intensive
	<ul style="list-style-type: none"> • Confusion among patients about who the primary contact is 	<ul style="list-style-type: none"> • Concentration of nurses in hospitals, not in outpatient and community-based settings 	<ul style="list-style-type: none"> • Separation of survivorship care from other routine care and separation of survivors of different cancers (DSS) 	<ul style="list-style-type: none"> • Complex in nature; Difficulty effectively transitioning survivors to adult care
	<ul style="list-style-type: none"> • Primary care physicians' lack of specialized oncology training and familiarity with long-term cancer-related sequelae 	<ul style="list-style-type: none"> • Preference among some cancer patients to receive care from physicians 	<ul style="list-style-type: none"> • Division of labor and role responsibilities not well established, leading to: (1) miscommunication or difficulty coordinating care; and (2) difficulty obtaining financial reimbursement (C; DSS) 	<ul style="list-style-type: none"> • Difficulty obtaining financial reimbursement

Table 2. *Characteristics and Components of Cancer Survivorship Care Models, continued*

Survivorship Care Model				
	Shared-Care Model	Nurse-Led Model of Care	Survivorship Follow-Up Clinic Model: <i>Comprehensive (C)</i> and <i>Disease-Site Specific (DSS)</i> Clinics	Pediatric Oncology: Nurse-Led Comprehensive Care
Empirical Evidence	<ul style="list-style-type: none"> • Earle et al., 2003 • Earle & Neville, 2004 • Grunfeld et al., 1996 • Grunfeld et al., 1999a,b 	<ul style="list-style-type: none"> • Beaver et al., 2009 • Jefford et al., 2011 • Knowles et al., 2007 • Lewis et al., 2009 • Verschuur et al., 2009 	<ul style="list-style-type: none"> • Berry et al., 1998 • Gabel et al., 1997 • MacBride & White, 1998 • Campbell et al., 2011 • Hausman et al., 2011 • Horvath et al., 2011 • Walker et al., 2003 	<ul style="list-style-type: none"> • Carlson et al., 2008 • Eshelmen-Kent et al, 2011 • Henderson et al., 2010 • Hewitt, Greenfield & Stovall, 2006

Table 3. *Components of a Survivorship Care Plan*

Survivorship Care Plan Essential Components
✓ Cancer type, treatments received, and their potential consequences
✓ Specific information about the timing and content of recommended follow-up
✓ Recommendations regarding preventive practices and how to maintain health and well-being
✓ Information on legal protections regarding employment and access to health insurance
✓ The availability of psychosocial services in the community

Source: *From Cancer Patient to Cancer Survivor*; page 4, (Hewitt, Greenfield, & Stovall, 2006).

Table 4. *Sociodemographic Data (N = 123)*

Demographic Variable	Number of Participants	%
Age (<i>M</i> = 49, <i>SD</i> = 10)		
20-29	1	0.8%
30-39	18	15%
40-49	44	36%
50-59	45	37%
60-69	12	10%
70-79	1	0.8%
Gender		
Male	14	11%
Female	109	89%
Adopted		
No	117	95%
Ethnicity		
Not Hispanic or Latino	120	98%
Racial Background		
White	114	93%
Marital Status		
Married	89	72%
Divorced or separated	21	17%
Education		
High school graduate, or GED	10	8%
Some college	31	25%
College graduate or beyond	81	66%
Religion		
Catholic	33	27%
Protestant	38	31%
Jewish	3	2%
Atheist/Agnostic/None	22	18%
Employment		
Not employed	21	17%
Full-time employed	60	49%
Part-time employed	18	15%
Retired	14	11%
Disability	7	6%
Household Income		
Under \$25,000	11	9%
\$25,001-\$50,000	17	14%
\$50,001-75,000	21	17%
\$75,001-100,000	13	11%
\$100,001-\$150,000	27	22%
Over \$150,000	21	17%
Prefer not to answer	13	11%
Number of Different States Represented	34	N/A

Table 5. *Recruitment Information*

	Recruitment Data	Number of Participants	%
Source			
	Online support and information group advertisement	19	15%
	Blog advertisement	1	0.8%
	Facebook	76	62%
	Flyer	7	6%
	Word of mouth (e.g., family, friend)	3	2%
	Other	17	14%
Name of Organizations (Online support / information groups, Facebook)			
	Colon Cancer Alliance	19	15%
	Dr. Susan Love Research Foundation	14	11%
	Susan G. Komen for the Cure	1	0.8%
	American Sexual Health Association National Cervical Cancer Coalition	1	0.8%
	Young Cancer Survivors	1	0.8%
Other			
	Carilion	1	0.8%
	Blue Ridge Cancer Care	1	0.8%
	Georgetown University, LCCC (new and previous participants)	12	10%
	Roanoke Times	1	0.8%
	About.com	1	0.8%
	Twitter	1	0.8%

Table 6. *Clinical Health Information*

Variable	Number of Participants	%
Type of Cancer		
Breast	54	44%
Cervical	2	2%
Colon	39	32%
Colorectal/rectal	17	14%
Leukemia	1	0.8%
Lung	1	0.8%
Lymphoma	1	0.8%
Skin	5	4%
Testicular	2	2%
Thyroid	1	0.8%
Age at Diagnosis (M = 45)		
20-29	9	7%
30-39	29	24%
40-49	40	33%
50-59	37	30%
60-69	4	3%
More Than One Cancer Diagnosis		
Yes	13	11%
No	110	89%
Family History of Cancer		
Yes	115	93%
No	8	7%
Number of Hospital Admissions in Past 5 Years		
0-5	110	89%
6-10	6	5%
11-15	6	5%
21 or more	1	0.8%
Currently taking Medication with Side Effects Related to Appetite, Sleep, Energy, or Mood		
Yes	57	46%
No	66	54%
Caregiver Support		
Yes	93	76%
No	30	24%
Caregiver: Participated/included in survivorship care planning and follow-up appointments		
Yes	72	77%
No	21	23%

Table 7. *Reliability Statistics for Psychosocial Measures*

Scale	Cronbach's <i>alpha</i>
Survivorship Care Level	.358
PSCC (Patient Satisfaction)	.965
FACT-G (Quality of Life)	.927
PHQ-2 (Depression Screener)	.778
BSI (General Distress)	.935
IES (Cancer-Related Distress)	.919
CBI-B (Self-Efficacy & Activation)	.929
PAM (Patient-Activation)	.859
Block Dietary Fat Screener	.800
Block Fruits and Vegetables Screener	.584
American College of Sports Medicine (Guidelines for Physical Activity, Strength Training, and Stretching/Flexibility)	.700

Table 8. *Descriptive Statistics for Psychosocial Measures*

	N	Minimum	Maximum	Mean	Std. Deviation
Survivorship Care Level (<i>out of 19</i>); higher scores = higher level of care)	123	2	17	10	3.14
PSCC (Patient Satisfaction, <i>out of 90</i> ; higher scores = dissatisfaction)	123	17	89	36.90	17.10
FACT-G (Quality of Life, <i>out of 108</i>)	123	6	106	78.61	18.97
PHQ-2 (Depression Screener, <i>out of 2</i>)	121	0	2	.40	.724
BSI (General Distress, <i>out of 44</i>)	122	11	44	17.05	6.90
IES (Cancer Distress, <i>out of 75</i>)	121	0	75	19.74	16.58
CBI-B (Self-Efficacy & Activation, <i>out of 126</i>)	121	30	126	99.83	21.27
PAM (Patient-Activation, <i>out of 52</i>)	121	26	52	44.38	5.68
Block Dietary Fat Screener (<i>out of 68</i>)	119	0	38	16.34	7.70
Block Fruits and Vegetables Screener (<i>out of 35</i>)	118	3	31	14.14	5.26
L-Cat (Physical Activity, <i>out of 6</i>)	120	1	6	3.02	1.38

Table 9. *Descriptive Statistics for Survivorship Care Planning and Follow-Up for All Participants (N = 123)*

Variable	Number of Participants	%
Location for receipt of cancer diagnosis		
Community hospital	53	43%
Community oncology offices	24	20%
Academic institution/medical center	25	20%
Comprehensive cancer center	21	17%
Received treatment at same facility		
Yes	73	59%
No	50	41%
Location for receipt of cancer treatment		
Community hospital	34	28%
Community oncology offices	31	25%
Academic institution/medical center	22	18%
Comprehensive cancer center	36	29%
Receipt of Survivorship Care Plan or Treatment Summary		
Survivorship Care Plan	4	3%
Treatment Summary	21	17%
Survivorship Care Plan AND Treatment Summary	13	11%
None	85	69%
Primary contact for survivorship care follow-up		
Oncologist	77	63%
Oncology nurse	1	1%
Nurse practitioner	4	3%
Primary care physician	8	7%
A combination of 2 or more providers	14	11%
None of the above	16	13%
Secondary contact for survivorship care follow-up		
Oncologist	10	8%
Oncology nurse	14	11%
Nurse practitioner	3	2%
Primary care physician	45	37%
A combination of 2 or more providers	11	9%
None of the above	35	29%
Average number of survivorship care follow-up contacts (per year)		
0-1 contacts per year	13	10%
2-3 contacts per year	49	40%
4-5 contacts per year	32	26%
6 or more contacts per year	29	24%
Perception of the amount of survivorship care follow-up contacts		
Too few visits	13	11%
Just enough visits	103	84%
Too many visits	6	5%

Table 9. *Descriptive Statistics for Survivorship Care Planning and Follow-Up for All Participants (N = 123), continued*

Variable	Number of Participants	%
Average duration (in minutes) of survivorship care follow-up contacts		
15 minutes or less per contact	30	24%
16-30 minutes per contact	62	50%
31-45 minutes per contact	19	15%
46-60 minutes per contact	5	4%
61 minutes or more per contact	5	4%
Primary mode of contact for survivorship care follow-up contacts		
In-person visits	120	98%
Telephone check-ups	0	0%
Skype or FaceTime	0	0%
Other (<i>e-mail</i>)	2	2%
Receipt of referrals related to comprehensive survivorship care		
Yes	34	28%
No	87	71%
If yes, type of referrals received (<i>check all that apply</i>)		
Referrals related to diet and nutrition	20	16%
Referrals related to physical activity and exercise	18	15%
Referrals related to mental health and well-being	23	19%
Other (<i>physical therapy, neurosurgeon, acupuncture, Genetic counseling, pulmonary rehabilitation</i>)	4	3%
If no, type of referrals needed or wanted		
Referrals related to diet and nutrition	55	45%
Referrals related to physical activity and exercise	50	41%
Referrals related to mental health and well-being	50	41%
Other (<i>ostomy management, pain management, acupuncture, Clinical trials/research studies</i>)	5	4%
Satisfaction with survivorship care (1-10 scale)		
Extremely Dissatisfied (1-3)	7	6%
Neutral (4-7)	41	33%
Extremely Satisfied (8-10)	60	49%
Information needed or wanted that was <i>not</i> received		
Symptom management (e.g., pain, fatigue/energy)	8	7%
Mental health services (e.g., managing depression, support groups)	19	15%
Risk reduction and management: resources and referrals (e.g., diet/nutrition, physical activity/exercise)	14	11%
Side effects (expectations and management)	11	9%
Post-treatment and recovery (expectations and management)	10	8%
Clinical trials and research studies	2	2%
Insurance issues	1	1%
Fertility issues	1	1%
Continuity and coordination of care	3	2%
Survivorship Care Plan	7	3%

Table 9. *Descriptive Statistics for Survivorship Care Planning and Follow-Up for All Participants (N = 123), continued*

Variable	Number of Participants	%
Interested in receiving follow-up care related to diet and nutrition		
Yes	82	67%
No	38	31%
Pursued/received follow-up care related to diet and nutrition		
Yes	39	32%
No	81	66%
If yes, descriptions of diet and nutrition follow-up pursued/received		
Nutritionist/dietician	13	11%
Consulted a nurse (e.g., holistic nurse, home health nurse)	2	2%
Talked with my doctor (e.g., oncologist)	8	7%
Cancer survivor seminar	2	2%
Joined a weight management program (e.g., Weight Watchers)	2	2%
Personal research (e.g., books, internet)	13	11%
Medication (e.g., diet pills)	1	1%
Dietary habits improved since completion of cancer treatment (1-10 scale)		
No Improvement (1-3)	19	15%
Moderate Improvement (4-7)	55	45%
Extreme Improvement (8-10)	47	38%
Interested in receiving follow-up care related to physical activity/exercise		
Yes	81	66%
No	41	33%
Pursued/received follow-up care related to physical activity and exercise		
Yes	34	28%
No	87	71%
If yes, descriptions of physical activity/exercise follow-up pursued/received		
Personal trainer	3	2%
Physical therapy	7	6%
Occupational therapy	3	2%
Pulmonary rehabilitation	2	2%
Group fitness (e.g., yoga, dance, running club, Livestrong at YMCA)	7	6%
Increased weekly physical activity (e.g., walking, swimming, biking)	13	11%
Talked with my doctor (e.g., oncologist)	5	4%
Personal research (e.g., books, internet)	7	6%
Physical activity/exercise habits improved since completion of cancer treatment (1-10 scale)		
No Improvement (1-3)	36	29%
Moderate Improvement (4-7)	43	35%
Extreme Improvement (8-10)	42	34%
Interested in receiving follow-up care related to mental health		
Yes	73	59%
No	47	38%
Pursued/received follow-up care related to mental health		
Yes	38	31%
No	81	66%

Table 9. *Descriptive Statistics for Survivorship Care Planning and Follow-Up for All Participants (N = 123), continued*

Variable	Number of Participants	%
If yes, descriptions of mental health follow-up pursued/received		
Psychotherapy/support services (e.g., psychologist, social worker)	20	16%
Joined a support group (e.g., coping skills, mindfulness meditation)	9	7%
Sought support from a friend	1	1%
Psychiatrist and medication (e.g., anti- anxiety/depressant)	8	7%
Primary care physician prescribed psychiatric medication	3	2%
Medical oncologist prescribed psychiatric medication	3	2%
Nurse practitioner prescribed psychiatric medication	1	1%
Neuropsychologist (for “chemobrain”)	1	1%
Researched information on my own (e.g., books, internet)	1	1%
Mental health improved since completion of cancer treatment (1-10 scale)		
No Improvement (1-3)	22	18%
Moderate Improvement (4-7)	57	46%
Extreme Improvement (8-10)	40	33%

Table 10. *Descriptive Statistics for Patient Expectations for Survivorship Care (N = 122)*

Variable		Number of Participants	%
Expectations for receiving a written care plan	Yes	58	47%
	No	64	52%
Expectations for having a “point person” to contact regarding follow-up care	Yes	101	82%
	No	21	17%
Expectations for receiving monthly follow-ups	Yes	35	29%
	No	86	70%
Expectations for receiving specific instructions for monitoring your recovery	Yes	99	81%
	No	23	19%
Expectations for receiving specific instructions for screening for a recurrence	Yes	115	94%
	No	7	6%
Expectations for receiving specific instructions for screening for other cancers	Yes	85	69%
	No	37	30%
Expectations for receiving mental health counseling (if needed)	Yes	73	59%
	No	48	39%
Expectations for receiving specific instructions (or referral information) for nutrition	Yes	73	59%
	No	48	39%
Expectations for receiving specific instructions (or referral information) for exercise	Yes	67	55%
	No	53	43%

Table 11. *Descriptive Statistics for Survivorship Care Planning and Follow-Up Data Specific to Participants who Received a Survivorship Care Plan or Treatment Summary (n = 38)*

Variable	Number of Participants	%
Receipt of Survivorship Care Plan or Treatment Summary		
Survivorship Care Plan	4	11%
Treatment Summary	21	55%
Survivorship Care Plan AND Treatment Summary	13	34%
Timing for receipt of Survivorship Care Plan/Treatment Summary		
Before the conclusion of treatment	21	55%
At the end of treatment	6	16%
After the conclusion of treatment	7	18%
Main person who wrote Survivorship Care Plan/Treatment Summary		
Oncologist	16	42%
Oncology nurse	3	8%
Nurse practitioner	1	3%
Primary care physician	0	0%
Combination of 2 of more providers	11	29%
Other	3	8%
Patient participation in creation of Survivorship Care Plan or Treatment Summary		
Yes	12	32%
No	22	58%
Modification of Survivorship Care Plan or Treatment Summary since its creation		
Yes	4	11%
No	30	79%
Survivorship Care Plan was helpful		
Yes	21	55%
No	3	8%
If yes (helpful), what was helpful about it		
“Knowing what to expect”	6	29%
“General guidelines and specific tips for managing my health”	5	24%
“Information about my care”	3	14%
“Provided comfort and reassurance”	5	24%
Survivorship Care Plan’s impact on <u>dietary</u> habits (1-10 scale)		
No positive impact (1-3)	8	21%
Moderate impact (4-7)	19	50%
Extremely positive impact (8-10)	11	29%
Survivorship Care Plan’s impact on <u>physical activity and exercise</u> habits		
No positive impact (1-3)	13	34%
Moderate impact (4-7)	15	40%
Extremely positive impact (8-10)	10	26%
Survivorship Care Plan’s impact on <u>mental health</u>		
No positive impact (1-3)	12	31.5%
Moderate impact (4-7)	12	31.5%
Extremely positive impact (8-10)	14	37%

Table 12. *Items and Scoring for Survivorship Care Categories*

Survivorship Care Measure Items	Points
26. Did you receive a Survivorship Care Plan or Treatment Summary?	
Yes, a Survivorship Care Plan	2
Yes, a Treatment Summary	1
Yes, a Survivorship Care Plan <i>and</i> a Treatment Summary	2
No, none of the above	0
32. Who is your secondary contact for survivorship care follow-up?	
Oncologist	1
Oncology nurse	1
Nurse practitioner	1
Primary care physician	1
A combination of 2 or more of these healthcare providers	1
None of the above; please specify	1 = other
	0 = no secondary contact
34. How would you rate the amount of your survivorship care follow-up contacts?	
Too few visits	0
Just enough visits	1
Too many visits	0
37. Have you received referrals related to comprehensive survivorship care?	
Yes	1
No	0
38. If yes, what type of referrals did you receive?	
Referrals related to diet and nutrition	1
Referrals related to physical activity and exercise	1
Referrals related to mental health and wellbeing	1
Other; please specify	1
40. On a scale of 1-10, being <i>Completely Dissatisfied</i> and 10 being <i>Completely Satisfied</i>, how satisfied are you with your survivorship care?	
Scores ranging from 1-3 (completely dissatisfied)	1-3
Scores ranging from 4-7 (neutral)	4-7
Scores ranging from 8-10 (completely satisfied)	8-10
<i>Total possible (denominator)</i>	19

Table 13. *Categorization of Survivorship Care (N = 123)*

Survivorship Care Level		Number of Participants	%
None/Low/Minimal	Scores ranging from 0-7	30	24%
Moderate	Scores ranging from 8-12	66	54%
High	Scores ranging from 13-19	27	22%

Table 14. *Pearson Product Moment Correlations Between Psychosocial Variables (N = 118-123)*

	Survivorship Care Level	Patient Satisfaction	Quality Of Life	Depression Screen	General Distress	Cancer Distress	Coping Self- Efficacy	Patient Activation	Dietary Fat	Fruits and Vegetables	Physical Activity
Survivorship Care Level	-										
Patient Satisfaction	-.348**	-									
Quality of Life	.360**	-.370**	-								
Depression Screen	-.125	.241**	-.568**	-							
General Distress	-.281**	.312**	-.713**	.597**	-						
Cancer Distress	-.189*	.289**	-.526**	.422**	.652**	-					
Coping Self- Efficacy	.338**	-.334**	.665**	-.515**	-.610**	-.599**	-				
Patient Activation	.292**	-.451**	.500**	-.290**	-.444**	-.422**	.617**	-			
Dietary Fat	.023	.135	-.146	.149	.200*	.070	-.256**	-.373**	-		
Fruits and Vegetables	-.069	-.072	-.032	.003	.021	.035	.178	.264**	-.244**	-	
Physical Activity	.102	-.075	.390**	-.295**	-.281**	-.184*	.271**	.302**	-.230*	.267**	-

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 15. Means and Standard Deviations for Males ($n = 14$) and Females ($n = 109$), and Independent T-Test Significance Values Assessing Group Differences Across Psychosocial and Health Behavior Variables

	Males ($n = 14$)	Females ($n = 109$)	<i>p</i>
Survivorship Care Level Mean (SD)	11.21 (2.97)	9.89 (3.14)	.138
Patient Satisfaction Mean (SD)	36.00 (19.53)	37.02 (16.85)	.835
Quality of Life Mean (SD)	84.79 (14.71)	77.82 (19.36)	.197
General Distress Mean (SD)	15.07 (4.29)	17.31 (7.14)	.256
Depression Screen Mean (SD)	0.29 (0.73)	0.41 (0.73)	.544
Cancer Distress Mean (SD)	21.86 (18.36)	19.47 (16.41)	.614
Coping Self Efficacy Mean (SD)	100.50 (21.53)	99.74 (21.34)	.900
Patient Activation Mean (SD)	44.07 (6.67)	44.42 (5.58)	.830
Dietary Fat Mean (SD)	21.38 (6.08)	15.73 (7.67)	.012
Fruits and Vegetables Mean (SD)	14.46 (7.42)	14.10 (4.98)	.819
Physical Activity Mean (SD)	3.29 (1.54)	2.98 (1.37)	.441

Table 16. Means and Standard Deviations of Groups for Receipt of SCP, and Multivariate Analysis of Covariance Values Assessing Group Differences Across Psychosocial and Health Behavior Variables

	Received SCP (n = 35)	Did Not Receive SCP (n = 81)	P
Patient Satisfaction Mean (SD)	35.28 (17.15)	38.26 (17.12)	.398
Quality of Life Mean (SD)	81.14 (16.03)	77.19 (16.00)	.231
General Distress Mean (SD)	14.96 (5.49)	18.20 (5.48)	.005
Cancer Distress Mean (SD)	17.92 (14.98)	20.27 (14.95)	.446
Coping Self Efficacy Mean (SD)	106.07 (18.20)	96.49 (18.16)	.011
Patient Activation Mean (SD)	45.81 (5.37)	43.79 (5.36)	.068
Dietary Fat Mean (SD)	14.54 (7.54)	17.26 (7.52)	.081
Fruits and Vegetables Mean (SD)	13.29 (5.35)	14.49 (5.35)	.275
Physical Activity Mean (SD)	2.94 (1.34)	3.01 (1.34)	.809

Table 17. Means and Standard Deviations of Groups for Receipt of Dietary Referrals, and Multivariate Analysis of Variance Values Assessing Group Differences Across Dietary Outcomes

	Received Dietary Referral (<i>n</i> = 17)	Did Not Receive Dietary Referral (<i>n</i> = 100)	<i>P</i>
Dietary Fat Mean (SD)	17.76 (9.11)	16.04 (7.5)	.397
Fruits and Vegetables Mean (SD)	12.47 (5.5)	14.41 (5.22)	.163

Table 18. Means and Standard Deviations of Groups for Receipt of Physical Activity Referrals, and Multivariate Analysis of Variance Values Assessing Group Differences Across Physical Activity Outcomes

	Received Physical Activity Referral (<i>n</i> = 17)	Did Not Receive a Physical Activity Referral (<i>n</i> = 103)	<i>P</i>
Physical Activity Mean (SD)	2.65 (1.27)	3.08 (1.4)	.236
ACSM – Total (for Aerobic, Strength Training, and Flexibility) Mean (SD)	.94 (1.03)	1.12 (1.15)	.556

Table 19. Means and Standard Deviations of Groups for Receipt of Mental Health Referrals, and Multivariate Analysis of Variance Values Assessing Group Differences Across Psychosocial Variables

	Received Mental Health Referral (<i>n</i> = 23)	Did Not Receive Mental Health Referral (<i>n</i> = 96)	<i>P</i>
Quality of Life Mean (SD)	74.00 (24.22)	79.72 (17.63)	.198
Depression Screen Mean (SD)	.70 (0.93)	.33 (0.66)	.032
General Distress Mean (SD)	19.26 (7.82)	16.56 (6.67)	.095
Cancer Distress Mean (SD)	24.52 (19.67)	18.71 (15.68)	.132
Coping Self Efficacy Mean (SD)	95.61 (23.31)	100.68 (20.79)	.307
Patient Activation Mean (SD)	44.22 (6.00)	44.45 (5.54)	.860

Table 20. *Qualitative Results (N = 8)*

Survey Item	Participant Responses / Identified themes
1 (a)	<p>Definition of survivorship care</p> <ul style="list-style-type: none"> ● Care delivered to a patient starting the minute they have received their diagnosis (<i>n</i> = 1) ● Long-term care delivered to a patient who has <i>completed</i> treatment (<i>n</i> = 7) <ul style="list-style-type: none"> ■ Care designed to help patients navigate life after cancer/re-define their lives/adjust to a new normal/cope with a fear of recurrence (<i>n</i> = 2) ■ Care designed to support patients physically, emotionally, socially, in an ongoing capacity (<i>n</i> = 4)
1 (b)	<p>What does survivorship care entail?</p> <ul style="list-style-type: none"> ● Includes the care received from all healthcare providers throughout the treatment and disease management phases (<i>n</i> = 5) ● Patient management of chronic and co-morbid diseases (e.g., risk reduction; <i>n</i> = 4)
2 (a)	<p>Does your institution have a system for creating SCPs or some form of post-treatment plan?</p> <ul style="list-style-type: none"> ● Yes (<i>n</i> = 0) ● No (<i>n</i> = 8) ● Informally (<i>n</i> = 2) <ul style="list-style-type: none"> ■ Document summarizing diagnostic and treatment information, and 5-year follow-up recommendations (<i>n</i> = 1) ■ Guidelines for screening recommendations and risk reduction (<i>n</i> = 2)
2 (b)	<p>Coordination of care?</p> <ul style="list-style-type: none"> ● Yes (<i>n</i> = 6) <ul style="list-style-type: none"> ■ Informal communication between providers, access to medical record chart notes (<i>n</i> = 5) ■ Formal team consult meetings, but focused on patients in active treatment (<i>n</i> = 1) ● No (<i>n</i> = 2)
2 (c)	<p>Do you personally make referrals for mental health, diet, and exercise?</p> <ul style="list-style-type: none"> ● Mental health (<i>n</i> = 7) ● Diet (<i>n</i> = 7) ● Exercise (<i>n</i> = 7) ● Alternative therapies (acupuncture, massage, yoga, physical therapy, genetic counseling, smoking cessation; <i>n</i> = 3)
2 (d)	<p>Any system for systematically tracking health behaviors?</p> <ul style="list-style-type: none"> ● Yes (<i>n</i> = 0) ● No (<i>n</i> = 4) ● Informally via self-report and documentation in medical records (<i>n</i> = 4)
3 (a)	<p>What is your impression of the utility of survivorship care plans?</p> <ul style="list-style-type: none"> ● Never used (<i>n</i> = 8) ● Useful for <i>patients</i> (<i>n</i> = 5) ● Useful for <i>providers</i> (<i>n</i> = 4) ● Concept of comprehensive, coordinated, interdisciplinary care is useful/important (<i>n</i> = 3) ● Do not see need for a formal written document (<i>n</i> = 2)
3 (b)	<p>How are they helpful?</p> <ul style="list-style-type: none"> ● Psychological benefit: Reduce uncertainty, confusion, feelings of abandonment (<i>n</i> = 3) <ul style="list-style-type: none"> ■ Provide patients with guidance, confidence, and clarity (<i>n</i> = 2) ■ Reduce uncertainty, confusion, feelings of abandonment (<i>n</i> = 1) ● A good resource providing patient/provider access to diagnosis/treatment information and follow-up recommendations for survivorship care providers and their care planning (<i>n</i> = 4) <ul style="list-style-type: none"> ■ Facilitate provider communication (<i>n</i> = 2) ■ Important for continuity and coordination of care (<i>n</i> = 2) <ul style="list-style-type: none"> ◆ Assist patients with re-integration into primary care (<i>n</i> = 1)

Table 20. *Qualitative Results (N = 8), continued*

Survey Item	Participant Responses / Identified themes
3 (c)	<p>Should all patients receive a survivorship care plan?</p> <ul style="list-style-type: none"> ● Yes (<i>n</i> = 2) <ul style="list-style-type: none"> ■ Should be made available to all, cannot pick and choose who needs one (<i>n</i> = 2) ● No (<i>n</i> = 2) <ul style="list-style-type: none"> ■ More helpful for high-risk patients, survivors of childhood cancer, or young adult survivors (<i>n</i> = 2)
4	<p>Primary obstacles/barriers to delivery of comprehensive care and implementation of SCPs?</p> <ul style="list-style-type: none"> ● Resources (<i>n</i> = 8) <ul style="list-style-type: none"> ■ Time (<i>n</i> = 8) ■ Funding (<i>n</i> = 3) ■ Staff and expertise (<i>n</i> = 5) <ul style="list-style-type: none"> ◆ Need to identify <i>who</i> should be developing/implementing SCPs (<i>n</i> = 4) ● No standard of what should be included, when, and for whom (<i>n</i> = 2) <ul style="list-style-type: none"> ■ Issue of tailoring (<i>n</i> = 1) ● Need for translation of information for non-oncological providers (<i>n</i> = 1) ● Fragmented system and lack of interdisciplinary care efforts (<i>n</i> = 3) <ul style="list-style-type: none"> ■ Need clearer distinctions between care providers' role in survivorship care (<i>n</i> = 1) ■ Need increased communication, collaboration, coordination between providers (<i>n</i> = 3) ● Lack of empirical data (<i>n</i> = 3) <ul style="list-style-type: none"> ■ Need more data on long-term / late effects of cancer treatment (<i>n</i> = 1) ■ Need more data on SCP efficacy (<i>n</i> = 2)
5	<p>What do you think are the next steps in the field of survivorship care? What should we be working toward as clinicians and researchers?</p> <ul style="list-style-type: none"> ● Build evidence base (<i>n</i> = 6) <ul style="list-style-type: none"> ■ Clinical outcomes and “end point impact” of SCPs (<i>n</i> = 5) ■ Cost outcomes (<i>n</i> = 1) ● Standardization of survivorship care delivery (<i>n</i> = 9) <ul style="list-style-type: none"> ■ Consensus on what “survivorship care” means and what it entails (<i>n</i> = 1) ■ Develop a system that providers agree and commit to (<i>n</i> = 2) ■ Designated survivorship care “point person” (<i>n</i> = 2) <ul style="list-style-type: none"> ◆ Use of physician extenders (e.g., nurse practitioners; <i>n</i> = 1) ■ Integrated team approach (<i>n</i> = 4) <ul style="list-style-type: none"> ◆ Collaboration and communication between providers and across specialties (<i>n</i> = 3) ◆ More standardized integration of psychosocial care (<i>n</i> = 1) ◆ Greater awareness of role of primary care physicians (<i>n</i> = 1) ● Use of technology and electronic medical records (<i>n</i> = 2) <ul style="list-style-type: none"> ■ System to standardize, unify, and track follow-up care data (<i>n</i> = 2) ● Increasing focus on healthy lifestyle behavior/behavior change (<i>n</i> = 2) ● Patient-centered care (<i>n</i> = 5) <ul style="list-style-type: none"> ■ Individualization of SCP documents (<i>n</i> = 1) ■ Doing more to smooth the transition to post-treatment care (<i>n</i> = 1) ■ Doing more to incorporate patients in their own care planning and follow-up (<i>n</i> = 1) ■ Evaluation of patient perspective, including needs assessment (<i>n</i> = 3) ■ Reassuring and empowering patients to manage their health and care (<i>n</i> = 2) ■ Adjust mindset to consider survivorship an ongoing, longitudinal process (<i>n</i> = 1)

Figure 1. *Participant Reports Regarding Survivorship Care Referrals*

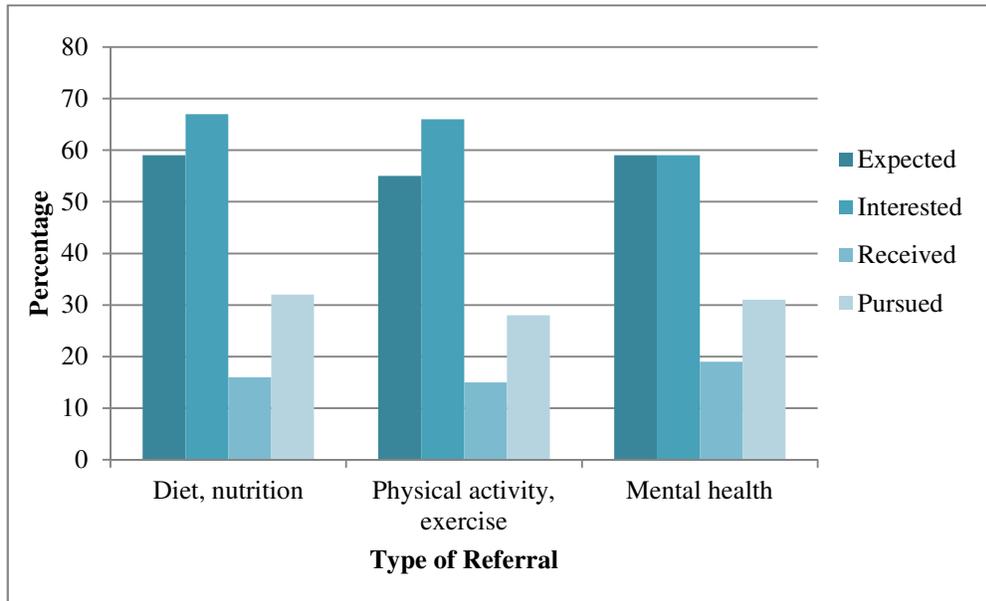


Figure 2. *Participants' Perceptions of the Helpfulness of Their Written Care Plan*

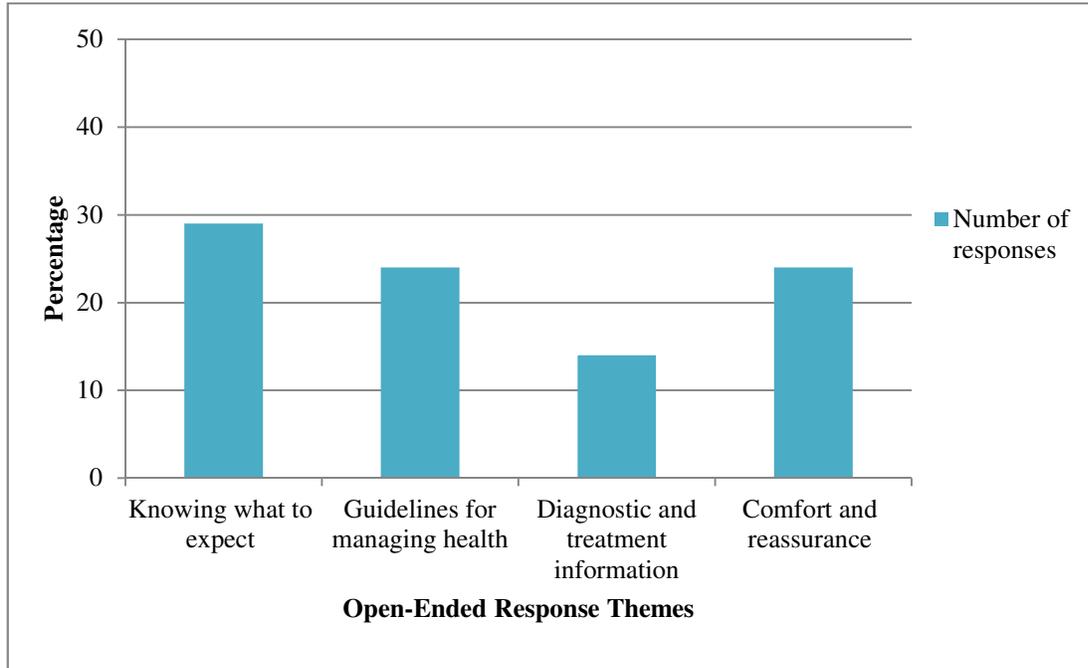
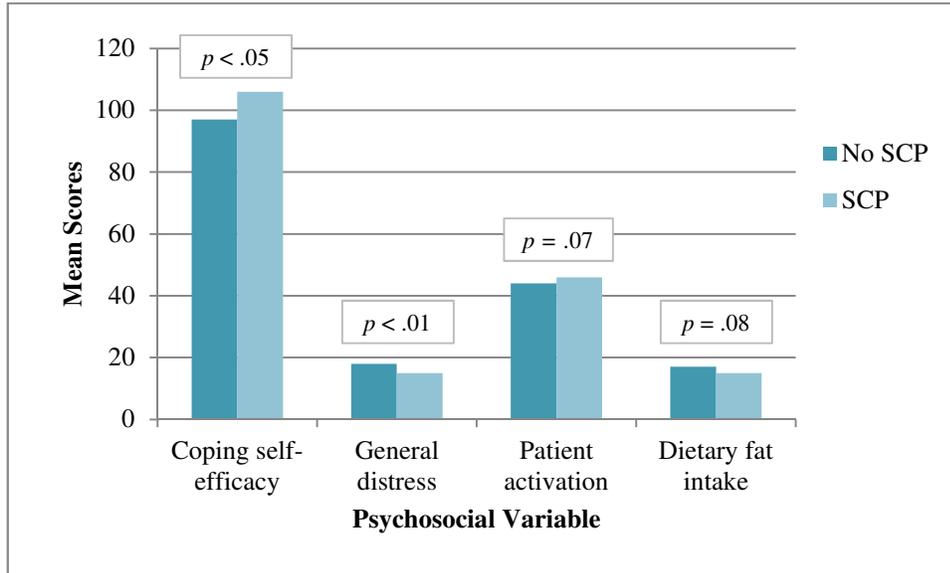


Figure 3. Significant MANCOVA Results for SCP Receipt on Psychosocial Outcomes



Appendix A

INFORMED CONSENT

Welcome to the *Cancer Survivorship Care Planning and Follow-Up* research study!

All of us at the *Center for Research in Health Behavior*
at Virginia Tech are glad you found us!

Please click "Next" to view our Informed Consent document, which explains all you need to know about the study and your participation. After viewing the Informed Consent, if you decide to participate and click "Agree," you will be immediately directed to the start of the survey. *Should you have questions at any time, please contact the study investigator, Sarah Kelleher, M.S., at skelleher@vt.edu. All participants will be entered into a drawing to receive one of many \$10 gift cards!*

Thank you for your interest in our research!

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants
In Research Projects Involving Human Subjects

Adult Cancer Survivorship: An Evaluation of Survivorship Care Planning and Follow-Up

Sarah Kelleher, Richard S. Winett, Ph.D., Kristi D. Graves, Ph.D.

INTRODUCTION

You are invited to consider participating in this study. The study is called “*Adult Cancer Survivorship: An Evaluation of Survivorship Care Planning and Follow-Up.*” Please take your time to make your decision. It is important that you read and understand several general principles that apply to all who take part in our studies:

- (a) Taking part in the study is entirely voluntary;
- (b) Personal benefit to you may or may not result from taking part in the study, but knowledge may be gained from your participation that will benefit others;
- (c) You may withdraw from the study at any time without any of the benefits you would have received normally being limited or taken away.

The purpose and nature of the study, possible benefits, risks, and discomforts, other options, your rights as a participant, and other information about the study are discussed below. Any new information discovered, at any time during the research, which might affect your decision to participate or remain in the study will be provided to you. You are urged to ask any questions you have about this study with the staff members who explain it to you. If you decide to participate, please sign and date where indicated at the end of this form. The investigators (persons in charge of this research study) are Sarah A. Kelleher, M.S., Richard S. Winett, Ph.D., and Kristi, D. Graves, Ph.D.

WHY IS THE STUDY BEING DONE?

Cancer is currently one of the leading causes of death in the United States. Over 1 million Americans are diagnosed with cancer in a given year and currently there are approximately 12 million cancer survivors in the United States. With improved detection strategies and continued medical advances, the number of cancer survivors continues to rise, making survivorship care an increasingly important phase along the continuum of cancer care. This research is being done because currently there is little research on the post-treatment care and follow-up of survivors of cancer. **In this study we are trying to learn about the medical care you received after you finished your cancer treatment. We want to know how your diagnosis and your treatment made you feel, both mentally and physically. Furthermore, we are interested in learning whether you have been satisfied with your survivorship care, whether and how your post-treatment care has met your expectations and needs, and finally how it has impacted you personally. Learning about your survivorship care experiences will allow us to understand**

how to most effectively help people throughout the survivorship phase of their cancer care in order to improve their quality of life and therefore lead healthier lives.

You are being asked to participate in this study because you are aged 18 or over and a cancer survivor who has had a diagnosis of cancer (new or recurrent) in the past 5 years. All adults who have had a diagnosis of cancer in the past 5 years are eligible.

You may not participate in this study if any of the following apply to you:

You are under age 18;

You are currently undergoing treatment for your cancer diagnosis;

You are unable to provide informed consent.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 75-100 people will take part in this study. Participants are men and women, aged 18 or over, able to read and understand English, and not cognitively impaired.

WHAT IS INVOLVED IN THE STUDY?

If you participate in this study, we will ask you to complete a one time online survey asking questions about your post-treatment follow-up care experience, thoughts and attitudes about managing your follow-up care, psychological adjustment, and present health behaviors (specifically diet and exercise).

HOW LONG WILL I BE IN THE STUDY?

Participation involves a one time online survey that takes about 45 minutes to complete.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the researcher first. There are no consequences related to withdrawal from this study.

WHAT ARE THE RISKS OF THE STUDY?

Risks related to participating in the survey are minimal. You may feel slightly uncomfortable answering certain questions about your cancer diagnosis, survivorship care experiences, psychological adjustment, or your health behaviors. You may, of course, choose to not answer any question you do not want to answer. We will make every effort to protect your confidentiality.

ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?

If you agree to take part in this study, there will be no direct benefit to you. We cannot promise that you will experience benefits from participating in this study. We hope the information learned from this study will benefit others in the future.

WHAT OTHER OPTIONS ARE THERE?

Whether you participate in this study or not, you will continue to receive the usual medical care provided to you by your doctor. There are no alternatives except not participating in this study.

WHAT ABOUT CONFIDENTIALITY?

This one time online survey is *confidential*. We do not ask participants for identifying information such as name or phone number. You will be asked to provide your e-mail address only. Every effort will be made to protect all of the information you share with us to the extent allowed by law. However, we cannot guarantee absolute confidentiality. This study does not involve your medical records in any way. Your answers to our questions will be kept completely confidential. Only project staff will see your information. Your answers will be identified by a secret project number. Information provided by research study participants is stored and kept according to legal requirements. We will use what we learn from this study to publish or present reports in books, articles, or at meetings, and in other ways Virginia Tech's Department of Psychology decides is in the interest of education, knowledge, or research. Personal information will not be used in any reports of the study. It is possible that the Institutional Review Board (IRB) at Virginia Tech may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

If information about your participation in this study is stored in a computer, we will take the following precautions to protect it from unauthorized disclosure, tampering, or damage:

All information kept on a computer will be accessed only through secure servers available only by password. All study computers are kept in individual offices accessible only to members of the study team.

WHAT ARE THE COSTS?

There are no costs associated with participating in this study. All participants will be entered into a drawing for a \$10 gift card to a nationally known vendor. Specifically, about 1 out of every 5 participants will be randomly selected for the \$10 gift card. Gift cards will be sent electronically via e-mail.

PAYMENT FOR PARTICIPATION

Not all who participate will be provided with a gift card. However, about one in five participants will receive a \$10 gift card in appreciation of their time. You should not expect anyone to pay you for pain, worry, lost income, or non-medical care costs that occur from taking part in this research study.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this study is voluntary. You may choose not to take part in or leave the study at any time. If you choose to not take part in or to leave the study, your regular care will not be affected nor will your relations with your physicians, other personnel and the hospital or university. In addition, you will not lose any of the benefits to which you are entitled.

WITHDRAWAL BY INVESTIGATOR, PHYSICIAN, OR SPONSOR

The investigators, physicians or sponsors may stop the study or take you out of the study at any time should they judge that it is in your best interest to do so, if you experience a study-related injury, if you need additional or different medication, or if you do not comply with the study plan. They may remove you from the study for various other administrative and medical reasons. They can do this without your consent.

Should you have any pertinent questions about this research or its conduct, research subjects' rights, and whom to contact in the event of a research-related injury to the subject, you may contact:

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Investigator

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Co-Investigator

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Board for the Protection of Human Subjects
Office of Research Compliance
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, VA 24060

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After reading the entire consent statement, if you agree to provide your consent and continue on to the survey, please click the "agree" button. By clicking "agree" you are pledging that you have read the consent statement, printed a copy for your files, and agree to participate in the study and accept that only your e-mail address will be electronically supplied to the researcher to document your participation. Your e-mail address will only be used to document your participation and also to enter you in a drawing to receive one of many \$10 gift cards. Your email address will not be part of the research record and will not be permanently stored or distributed in any way.

If you do not consent to participate, please exit out of this page and close your web browser. We thank you for your time.

1. I pledge that I have read the consent statement, printed a copy for my files, and agree to participate in the study.

Agree

2. **E-mail address:** _____

Welcome to *Adult Cancer Survivorship: An Evaluation of Survivorship Care Planning and Follow-Up*, a study evaluating cancer survivors' experience with post-treatment care and follow-up.

Please read the following directions carefully before beginning the survey.

We want to remind you that the following survey requires approximately 45 minutes. It is lengthy and time-consuming, and some items may appear to be asking similar questions. However, we also want to remind you that you are providing valuable information which is greatly appreciated and will benefit this area of cancer research as well as individuals at future risk for a cancer diagnosis or recurrence.

Due to the time-sensitive nature of the questions, we ask that you please complete this questionnaire in one sitting. However, should you be unable to complete participation at one time-point, you may exit and return later at your convenience. *Here's how to do it!...*

- **To save the information you've already entered**, before exiting the survey, click "Next" at the bottom of the last fully completed page.
- Then, select "Exit this survey" located at the top right corner of the next page.
- **Note:** If you select "Exit this survey" before clicking "Next", then the information you entered on that last page will **not** be saved. If you select "Next" and then "Exit this survey" the information you've already entered and the questions you've answered will be saved for you up to 30 days.
- **To re-enter the survey**, simply re-open the survey website from the *same computer* and you will be directed back to where you left off.
- Upon re-entering, you may also go back to change any previously entered information by clicking the "Previous" button at the bottom of each page.
- **You have the option to skip any item that you wish.** However, because of this, the survey will not require you to complete an item before moving forward, making it possible to *accidentally skip items*. We ask that you please be mindful of this as you complete each item to the best of your ability.
- **Once you have finished the survey in its entirety, please click the "Done" button on the very last page in order to save and submit your completed survey.** Please do not click the "Exit this survey" button when you are done, doing so will *not record* your completed survey.

Should you have any questions while completing this questionnaire, please contact the study researcher, Sarah Kelleher, by e-mail (skelleher@vt.edu) or phone (703-946-9130).

We thank you in advance for your time and interest in our study.

- Virginia Tech Center for Research in Health Behavior

3. For the results of this research to be most effective, it is very important that only survivors of cancer participate.

- By clicking here I am confirming that I am a person surviving cancer

Appendix B

SOCIODEMOGRAPHIC INFORMATION

The following questions ask about your background. Your name will not be included and all information will remain confidential. Please check or write in your answers. You can skip any questions you do not wish to answer.

4. What is your age? _____ years	
5. What is your gender?	
<input type="checkbox"/>	(1) Male
<input type="checkbox"/>	(2) Female
6. What is your current state of residence? _____	
7. What is your height and weight?	
	Height: _____ (feet) & _____ (inches)
	Weight: _____ (pounds)
8. Since this time last year, is your weight...	
(1) A lot lower (i.e., More than 12 lbs) (2) Lower (i.e., 8-12 lbs) (3) About the same (i.e., Gained or lost about 3 lbs) (4) Higher (i.e., 8-12 lbs) (5) A lot higher (i.e. More than 12 lbs)	
9. Are you adopted?	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
10. What is your ethnicity?	
<input type="checkbox"/>	(1) Hispanic or Latino
<input type="checkbox"/>	(2) Not Hispanic or Latino
11. What is your racial background?	
<input type="checkbox"/>	(1) Black or African American
<input type="checkbox"/>	(2) White
<input type="checkbox"/>	(3) Asian
<input type="checkbox"/>	(4) American Indian of Alaska Native
<input type="checkbox"/>	(5) Native Hawaiian or Other Pacific Islander
12. If Other: Please specify here.	

13. Which of the following describes your current marital status?	
<input type="checkbox"/>	(1) Single or never married
<input type="checkbox"/>	(2) Married
<input type="checkbox"/>	(3) Divorced or Separated
<input type="checkbox"/>	(4) Widowed
14. How many years of school have you completed?	
<input type="checkbox"/>	(1) 8 years or less
<input type="checkbox"/>	(2) Some high school
<input type="checkbox"/>	(3) High school graduate, or GED
<input type="checkbox"/>	(4) Some college
<input type="checkbox"/>	(5) College graduate or beyond
15. What is your religious background?	
<input type="checkbox"/>	(1) Catholic
<input type="checkbox"/>	(2) Protestant
<input type="checkbox"/>	(3) Jewish
<input type="checkbox"/>	(4) Atheist/Agnostic/None
16. If other: Please specify here.	
<input type="checkbox"/>	
17. Are you currently employed for salary or wages?	
<input type="checkbox"/>	(1) Not Employed
<input type="checkbox"/>	(2) Full-time employed
<input type="checkbox"/>	(3) Part-time employed
<input type="checkbox"/>	(4) Retired
<input type="checkbox"/>	(5) Receiving Disability
<input type="checkbox"/>	(6) Student
18. What was your annual household income before taxes last year?	
<input type="checkbox"/>	(1) under \$25,000
<input type="checkbox"/>	(2) \$25,001-\$50,000
<input type="checkbox"/>	(3) \$50,001-\$75,000
<input type="checkbox"/>	(4) \$75,001-\$100,000
<input type="checkbox"/>	(5) \$100,001-\$150,000
<input type="checkbox"/>	(6) Over \$150,000

<input type="checkbox"/>	(7) Prefer not to answer
19. Do you have health insurance?	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
20. How did you learn about this research study?	
<input type="checkbox"/>	(1) Online support and information group advertisement Please specify organization: _____
<input type="checkbox"/>	(2) Blog advertisement
<input type="checkbox"/>	(3) Facebook
<input type="checkbox"/>	(4) Flyer posted in store or doctor's office
<input type="checkbox"/>	(5) Word of mouth (e.g., family, friend)
21. If organization or other: Please specify in the appropriate box: _____	
Name of Organization:	
Other:	
22. If there are other studies for which you may be eligible, may we contact you to tell you about them? <i>You would be free to participate or decline at that time.</i>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No

Appendix C

CLINICAL HEALTH INFORMATION

Now, we'd like to find out about your personal and family history of cancer. If skin cancer, please indicate if it was melanoma or non-melanoma (for example, basal cell carcinoma).

23. Please indicate the <u>type(s) of cancer(s)</u> you've been diagnosed with and your <u>age(s)</u> at diagnosis:	
<i>Type of cancer:</i>	
<i>Age at diagnosis:</i>	
<i>Type of cancer:</i>	
<i>Age at diagnosis:</i>	
<i>Type of cancer:</i>	
<i>Age at diagnosis:</i>	
<i>Type of cancer:</i>	
<i>Age at diagnosis:</i>	
<i>Type of cancer:</i>	
<i>Age at diagnosis:</i>	
24. Have any of your family members been diagnosed with <u>cancer</u>? (check all that apply)	
<input type="checkbox"/>	Mother
<input type="checkbox"/>	Father
<input type="checkbox"/>	Sister(s)
<input type="checkbox"/>	Brother(s)
<input type="checkbox"/>	Daughter(s)
<input type="checkbox"/>	Son(s)
<input type="checkbox"/>	Maternal Aunt(s)
<input type="checkbox"/>	Paternal Aunt(s)
<input type="checkbox"/>	Maternal Uncle(s)

<input type="checkbox"/>	Paternal Uncle(s)
<input type="checkbox"/>	Maternal Grandmother
<input type="checkbox"/>	Paternal Grandmother
<input type="checkbox"/>	Maternal Grandfather
<input type="checkbox"/>	Paternal Grandfather

25. <u>If you indicated a family history of cancer above:</u> Please specify the age(s) at diagnosis and type(s) of cancer for your family members.	
<i>Mother, Type of cancer:</i>	
Age at diagnosis:	
<i>Father, Type of cancer:</i>	
Age at diagnosis:	
<i>Sister(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Brother(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Daughter(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Son(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Maternal Aunt(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Paternal Aunt(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Maternal Uncle(s), Type of cancer:</i>	
Age at diagnosis:	
<i>Paternal Uncle(s), Type of cancer:</i>	

Age at diagnosis:	
<i>Maternal Grandmother, Type of cancer:</i>	
Age at diagnosis:	
<i>Paternal Grandmother, Type of cancer:</i>	
Age at diagnosis:	
<i>Maternal Grandfather, Type of cancer:</i>	
Age at diagnosis:	
<i>Paternal Grandfather, Type of cancer:</i>	
Age at diagnosis:	

- 26. How many hospital admissions have you had in the past five years?**
- 0-5
 - 6-10
 - 11-15
 - 16-20
 - 21 or more
- 27. Are you currently taking any medications that have side effects related to appetite, sleep, energy, or mood?**
- Yes
 - No
- 28. Do you have someone whom you consider to be a caregiver?**
- Yes
 - No
- 29. If yes, has your caregiver been included/participated in your survivorship care planning and follow-up appointments?**
- Yes
 - No

Appendix D

SURVIVORSHIP CARE

- *Survivorship Care* refers to the *post-treatment* care delivered to survivors of cancer. Survivorship Care includes the ongoing management of a patient's disease, including the treatment of co-morbid conditions and the prevention of disease recurrence. Survivorship care can include assistance from one or many of the following healthcare disciplines: Oncology, primary care, mental health, physical therapy, nutrition and dietetics, and occupational therapy.

- A *Survivorship Care Plan* is often considered a "wellness plan" and is described as a *comprehensive* document that is used after treatment has been completed. Survivorship Care Plans include recommendations and referrals that are designed to improve a patient's health and well-being, both physically and mentally. These care plans also provide guidelines to monitor a patient's recovery as well as screen for recurrent and/or second cancers.

- A *Treatment Summary* is typically a brief summary of a patient's cancer treatment. It is commonly used to organize information about a patient's cancer, cancer treatment, follow-up care, and basic information related to his or her medical history and future doctors.

Note: Although *Survivorship Care Plans* and *Treatment Summaries* share many similarities, a difference is that a *Survivorship Care Plan* usually offers more in the way of *comprehensive* follow-up care (e.g., referrals and resources for a variety of healthcare services, such as mental health and lifestyle interventions) whereas a *Treatment Summary* usually does not.

30. Where did you receive your cancer diagnosis?

- a. Community hospital
- b. Community oncology offices
- c. Academic institution/medical center
- d. Comprehensive cancer center

31. Did you receive your cancer treatment at the same facility?

- a. Yes
- b. No

32. If no, where did you receive treatment for your cancer diagnosis?

- a. Community hospital
- b. Community oncology offices
- c. Academic institution/medical center
- d. Comprehensive cancer center

33. Did you receive a Survivorship Care Plan or Treatment Summary?

- a. Yes, a Survivorship Care Plan (continue)
- b. Yes, a Treatment Summary (continue)
- c. Yes, a Survivorship Care Plan *and* a Treatment Summary
- d. No, none of the above (skip to #40)

- 34. When did you receive this document?**
- a. Before the conclusion of treatment (e.g., during chemotherapy or radiation)
 - b. At the end of treatment (e.g., during your last chemotherapy visit or immediately following conclusion of your treatment)
 - c. After the conclusion of your treatment?
- 35. Who was the main person who wrote this document?**
- a. Oncologist
 - b. Oncology nurse
 - c. Nurse practitioner
 - d. Primary care physician
 - e. A combination of the 2 or more of these healthcare providers
 - f. Other; Please specify below
- 36. If other: Please specify in the box below**
- _____
- 37. Did you participate in the creation of this document?**
- a. Yes
 - b. No
- 38. Has this document been *modified* since its creation?**
- a. Yes; Please specify below
 - b. No
- 39. If Yes: Please specify in the box below**
- _____
- 40. Who is your primary contact for follow-up with regard to your survivorship care?**
- a. Oncologist
 - b. Oncology nurse
 - c. Nurse practitioner
 - d. Primary care physician
 - e. A combination of the 2 or more of these healthcare providers
 - f. None of the above; Please specify below
- 41. If none of the above: Please specify in the box below**
- _____
- 42. Who is your secondary contact for follow-up with regard to your survivorship care?**
- a. Oncologist
 - b. Oncology nurse
 - c. Nurse practitioner
 - d. Primary care physician
 - e. A combination of the 2 or more of these healthcare providers
 - f. None of the above; Please specify below

43. **If none of the above: Please specify in the box below**

44. ***On average, approximately how many survivorship care follow-up contacts have you had (i.e., contacts occurring following completion of your cancer treatment)?***

- a. 0-1 contact per year
- b. 2-3 contacts per year
- c. 4-5 contacts per year
- d. 6 or more contacts per year

45. **How would you rate the amount of your survivorship care follow-up contacts?**

- a. Too few visits
- b. Just enough visits
- c. Too many visits

46. ***On average, what is the approximate duration (in minutes) of your follow-up contacts?***

- a. 15 minutes or less per contact
- b. 16-30 minutes per contact
- c. 31-45 minutes per contact
- d. 46-60 minutes per contact
- e. 61 minutes or more per contact

47. **Were your survivorship care follow-up appointments mostly...**

- a. In-person visits
- b. Telephone check-ups
- c. Skype or FaceTime
- d. Other; Please specify below

48. **If other: Please specify in the box below**

49. **Have you received referrals related to comprehensive survivorship care (here we're referring to health and wellness referrals such as diet, exercise, or mental health)?**

- a. Yes
- b. No

50. **If yes, what type of referrals did you receive? Please check *all* that apply.**

- a. Referrals related to diet and nutrition
- b. Referrals related to physical activity and exercise
- c. Referrals related to mental health and well-being
- d. Other; Please specify below

51. **If other: Please specify in the box below**

52. **If no, what type of referrals *did or do* you want/need? Please check *all* that apply.**
- Referrals related to diet and nutrition
 - Referrals related to physical activity and exercise
 - Referrals related to mental health and well-being
 - Other; Please specify below
53. **If other: Please specify in the box below**
- _____
54. **On a scale of 1-10, 1 being *Completely Dissatisfied* and 10 being *Completely Satisfied*, how satisfied are you with your survivorship care?**
- 1 2 3 4 5 6 7 8 9 10
55. **If you received one, was the survivorship care plan document helpful?**
- Yes
 - No
56. **If yes, what did you find helpful about it?**
57. **What did you *want/need* information about (related to your survivorship care) that you did *not* receive?**
58. **Were you interested in receiving follow-up care related to diet?**
- Yes
 - No
59. **Did you pursue/receive follow-up related to diet?**
- Yes
 - No
60. **If yes, please *describe* the follow-up you pursued/received:**
61. **On a scale of 1-10, 1 being *No Improvement* and 10 being *Extreme Improvement*, have your dietary habits improved since completion of your cancer treatment?**
- 1 2 3 4 5 6 7 8 9 10
62. **If you received a survivorship care plan: On a scale of 1-10, 1 being *No Positive Impact* and 10 being *Extremely Positive Impact*, has your survivorship care plan positively impacted your dietary habits?**
- 1 2 3 4 5 6 7 8 9 10

63. Were you interested in receiving follow-up care related to physical activity and exercise?
- Yes
 - No
64. Did you pursue/receive follow-up related to physical activity and exercise?
- Yes
 - No
65. If yes, please *describe* the follow-up you pursued/received:
66. On a scale of 1-10, 1 being *No Improvement* and 10 being *Extreme Improvement*, have your physical activity/exercise habits improved since completion of your cancer treatment?
- 1 2 3 4 5 6 7 8 9 10
67. If you received a survivorship care plan: On a scale of 1-10, 1 being *No Positive Impact* and 10 being *Extremely Positive Impact*, has your survivorship care plan positively impacted your physical activity/exercise habits?
- 1 2 3 4 5 6 7 8 9 10
68. Were you interested in receiving follow-up care related to psychological/emotional health?
- Yes
 - No
69. Did you pursue/receive follow-up related to psychological/emotional health?
- Yes
 - No
70. If yes, please *describe* the follow-up you pursued/received:
71. On a scale of 1-10, 1 being *No Improvement* and 10 being *Extreme Improvement*, has your psychological/emotional health improved since completion of your cancer treatment?
- 1 2 3 4 5 6 7 8 9 10
72. If you received a survivorship care plan: On a scale of 1-10, 1 being *No Positive Impact* and 10 being *Extremely Positive Impact*, has your survivorship care plan positively impacted your psychological/emotional health?
- 1 2 3 4 5 6 7 8 9 10

Appendix E

PATIENT EXPECTATIONS REGARDING SURVIVORSHIP CARE

73. Please click yes or no for the following questions related to your expectations for your survivorship care.

	Yes	No
Did you expect to receive a <u>written care plan?</u>		
Did you expect to have a <u>“point person”</u> to contact regarding your follow-up care?		
Did you expect to receive <u>monthly follow-ups?</u>		
Did you expect <u>specific instructions</u> for <u>monitoring your recovery?</u>		
Did you expect <u>specific instructions</u> for <u>screening for a recurrence?</u>		
Did you expect <u>specific instructions</u> for <u>screening for other cancers?</u>		
Did you expect <u>mental health counseling</u> (if needed)?		
Did you expect <u>specific instructions</u> (or referral information) for <u>nutrition?</u>		
Did you expect <u>specific instructions</u> (or referral information) for <u>exercise?</u>		

Additional thoughts:

Appendix F

PATIENT SATISFACTION WITH CANCER CARE

Patient Satisfaction with Cancer-Related Care (PSCC):

74. On a scale from 1 to 5, 1 being *Strongly Agree* and 5 being *Strongly Disagree*, please indicate how much you agree with the following statements related to your cancer-related care.

	Strongly Agree (1)	Agree (2)	Neutral (3)	Disagree (4)	Strongly Disagree (5)
I felt that my health concerns were understood.					
I felt that I was treated with courtesy and respect.					
I felt included in decisions about my health.					
I was told how to take care of myself.					
I felt encouraged to talk about my personal health concerns.					
I felt I had enough time with my doctor.					
My questions were answered to my satisfaction.					
Making an appointment was easy.					
I knew what the next step in my care would be.					
I feel confident in how I deal with the health care system.					
I was able to get the advice I needed about my health issues.					
I knew who to contact when I had a question.					
I received all the services I needed.					
I am satisfied with the care I received.					
The doctors seemed to communicate well about my care.					
I received high-quality care from my regular doctor.					
I received high-quality care from my specialists.					
My regular doctor was informed about the results of the tests I got.					

Appendix G

QUALITY OF LIFE

75. FACT-G, version 4: 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 past 7 days.

<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	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box</i>					

GS7	I am satisfied with my sex life.....	0	1	2	3	4
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76. Continued. Below is a list of statements other people with your illness have said are *important*. Please click one circle per line to indicate your response as it applies to the past 7 days.

<u>EMOTIONAL WELL-BEING</u>		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

<u>FUNCTIONAL WELL-BEING</u>		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	0	1	2	3	4

Appendix H

PSYCHOLOGICAL AND CANCER-RELATED DISTRESS

77. BSI: Below are a list of problems and complaints that people sometimes have (i.e., general life stress). Please indicate how much *discomfort* that problem has caused you in the last 2 WEEKS.

	Not at All	Slightly	Moderately	Extremely
a. Nervousness or shakiness inside.....	1	2	3	4
b. Suddenly scared for no reason.....	1	2	3	4
c. Feeling lonely	1	2	3	4
d. Feeling fearful	1	2	3	4
e. Feeling blue	1	2	3	4
f. Feeling not interested in things	1	2	3	4
g. Feeling tense or keyed up	1	2	3	4
h. Spells of terror or panic	1	2	3	4
i. Feeling hopeless about the future	1	2	3	4
j. Feeling so restless you couldn't sit still	1	2	3	4
k. Feeling of worthlessness.....	1	2	3	4

NOTE: Item “b” on suicidal ideation is not asked.

CANCER-RELATED DISTRESS

78. Impact of Event Scale: Below is a list of comments made by people after stressful life events, such as a cancer diagnosis. Using the following scale, please indicate *how frequently* each of these comments were *true for you* during the past 7 DAYS, as related to your cancer diagnosis, treatment and follow-up care.

	Not at all	Rarely	Sometimes	Often
I thought about it when I didn't mean to.				
I avoided letting myself get upset when I thought about it or was reminded of it.				
I tried to remove it from memory.				
I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind.				
I had waves of strong feelings about it.				
I had dreams about it.				
I stayed away from reminders of it.				
I felt as if it hadn't happened or wasn't real.				
I tried not to talk about it.				
Pictures about it popped into my mind.				
Other things kept making me think about it.				
I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
I tried not to think about it.				
Any reminder brought back feelings about it.				
My feelings about it were kind of numb.				

Appendix I

DEPRESSION SCREENER

Two-item version of the *Patient Health Questionnaire* (PHQ-2):

79. *In the past month*, have you had a time when you felt *sad, blue, depressed, or down* for most of the time for at least two weeks?

- a. No
- b. Yes

80. *In the past month*, have you had a time, lasting at least two weeks, when you *didn't care* about the things that you usually cared about or when you *didn't enjoy* the things that you usually enjoyed?

- a. No
- b. Yes

Appendix J

COPING SELF-EFFICACY

81. Cancer Behavior Inventory-Brief: The next set of questions contains many things that a person might do when receiving treatment for cancer. We are interested in your judgment of *how confident you are that you can accomplish those things*. Make sure your ratings accurately reflect *your confidence*, regardless of whether or not you have done it in the past. So, your ratings reflect *your confidence that you can do these things* now (or in the near future).

Please rate each item on *how confident* you are that you can accomplish that behavior. If you click a "1," you would be stating that you are *not at all confident* that you can accomplish that behavior. If you click a "9," you would be stating that you are *totally confident* that you can accomplish that behavior. Numbers in the middle of the scale indicate that you are *moderately confident* that you can accomplish that behavior.

Please rate all items. If you are not sure about an item please rate it as best you can.

Not all confident				Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9

Maintaining independence.	1	2	3	4	5	6	7	8	9
Maintaining a positive attitude.	1	2	3	4	5	6	7	8	9
Maintaining a sense of humor	1	2	3	4	5	6	7	8	9
Expressing feelings about cancer	1	2	3	4	5	6	7	8	9
Putting things out of my mind at times	1	2	3	4	5	6	7	8	9
Maintaining activities (work, home, hobbies, social)	1	2	3	4	5	6	7	8	9
Trying to be calm throughout treatments and not allowing scary thoughts to upset me	1	2	3	4	5	6	7	8	9
Actively participating in treatment decisions	1	2	3	4	5	6	7	8	9
Asking physicians questions	1	2	3	4	5	6	7	8	9
Seeking social support	1	2	3	4	5	6	7	8	9
Sharing my worries or concerns with others	1	2	3	4	5	6	7	8	9
Managing nausea and vomiting (whether or not I have had these problems in the past)	1	2	3	4	5	6	7	8	9
Coping with physical challenges	1	2	3	4	5	6	7	8	9
Trying to be calm while waiting at least one hour for my appointment	1	2	3	4	5	6	7	8	9

Appendix K

PATIENT ACTIVATION

82. Patient Activation Measure (PAM): Below are some statements that people sometimes make when they talk about their health. Please indicate how much you Agree or Disagree with each statement as it applies to you personally.

Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, click N/A.

	Strongly Disagree	Disagree	Agree	Strongly Agree
When all is said and done, I am the person who is responsible for managing my health condition.				
Taking an active role in my own health care is the most important factor in determining my health and ability to function.				
I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.				
I know what each of my prescribed medications do.				
I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.				
I am confident I can tell my health care provider concerns I have even when he or she does not ask.				
I am confident that I can follow through on medical treatments I need to do at home.				
I understand the nature and causes of my health condition(s).				
I know the different medical treatment options available for my health condition.				
I have been able to maintain the lifestyle changes for my health that I have made.				
I know how to prevent further problems with my health condition.				
I am confident I can figure out solutions when new situations or problems arise with my health condition.				
I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.				

Appendix L

HEALTH BEHAVIORS

83. NUTRITION: Block Dietary Fat Screener: Think about your eating habits over the *past year or so*. About *how often* do you eat *each of the following foods*? Remember breakfast, lunch, dinner, snacks and eating out. Mark *one* option for *each food*.

Meats and Snacks	(0)	(1)	(2)	(3)	(4)	Score
	1/ MONTH or less	2-3 times a MONTH	1-2 times a WEEK	3-4 times a WEEK	5+ times a WEEK	
Hamburgers, ground beef, meat burritos, tacos						
Beef or pork, such as steaks, roasts, ribs, or in sandwiches						
Fried chicken						
Hot dogs, or Polish or Italian sausage						
Cold cuts, lunch meats, ham (not low-fat)						
Bacon or breakfast sausage						
Salad dressings (not low-fat)						
Margarine, butter or mayo on bread or potatoes						
Margarine, butter or oil in cooking						
Eggs (not Egg Beaters or just egg whites)						
Pizza						
Cheese, cheese spread (not low-fat)						
Whole milk						
French fries, fried potatoes						
Corn chips, potato chips, popcorn, crackers						
Doughnuts, pastries, cake, cookies (not lowfat)						
Ice cream (not sherbet or non- fat)						
Fat Score = _____						

84. Block Fruit-Vegetable Screener: Think about your eating habits over the *past year or so*. About *how often* do you eat *each of the following foods*? Remember breakfast, lunch, dinner, snacks and eating out. Mark *one* option for *each food*.

Fruits and Vegetables	(0)	(1)	(2)	(3)	(4)	(5)	Score
	Less than 1/WEEK	Once a WEEK	2-3 times a WEEK	4-6 times a WEEK	Once a DAY	2+ a DAY	
Fruit juice, like orange, apple, grape, fresh, frozen or canned. (Not sodas or other drinks)							
How often do you eat any fruit, fresh or canned (not counting juice?)							
Vegetable juice, like tomato juice, V-8, carrot							
Green salad							
Potatoes, any kind, including baked, mashed or french fried							
Vegetable soup, or stew with vegetables							
Any other vegetables, including string beans, peas, corn, broccoli or any other kind							
Fruit Vegetable Score = _____							

**85. PHYSICAL ACTIVITY: STANFORD Leisure-TIME ACTIVITY
CATEGORICAL ITEM (L-Cat) 2.1**

During the past month, which statement best describes the kinds of physical activity you usually did during your LEISURE TIME (i.e., time spent other than working at a job)? Please read all six statements before selecting one.

- a. I did not do much physical activity. I mostly did things like watching television, reading, playing cards, or playing computer games. Only occasionally, no more than once or twice a month, did I do anything more active such as going for a walk or playing tennis.

- b. Once or twice a week, I did light activities such as getting outdoors on the weekends for an easy walk or stroll. Or once or twice a week, I did chores around the house such as sweeping floors or vacuuming.

- c. About three times a week, I did moderate activities such as brisk walking, swimming, or riding a bike for about 15-20 minutes each time. Or about once a week, I did moderately difficult chores such as raking or mowing the lawn for about 45-60 minutes. Or about once a week, I played sports such as softball, basketball, or soccer for about 45-60 minutes.

- d. Almost daily, that is five or more times a week, I did moderate activities such as brisk walking, swimming, or riding a bike for 30 minutes or more each time. Or about once a week, I did moderately difficult chores or played sports for 2 hours or more.

- e. About three times a week, I did vigorous activities such as running or riding hard on a bike for 30 minutes or more each time.

- f. Almost daily, that is five or more times a week, I did vigorous activities such as running or riding hard on a bike for 30 minutes or more each time.

The American College of Sports Medicine (ACSM) guidelines for cancer survivors:

86. Aerobic Activity

Do you engage in weekly aerobic activity of 150 minutes of moderate-intensity exercise or 75 minutes of vigorous-intensity exercise, or an equivalent combination?

- a. Yes
- b. No

87. Strength training

Do you perform two to three weekly strength training sessions that include exercises for major muscle groups?

- a. Yes
- b. No

88. Flexibility

Do you stretch major muscle groups and tendons on days that other exercises are performed?

- a. Yes
- b. No

89. For participants who may be interested in learning about the results of this study, a brief general report will be available *via e-mail* within the *next 6-12 months*. In order to receive this summary report, please indicate below whether you are interested. Would you like to receive a brief report summarizing the results of this study?

- a. Yes
- b. No

Appendix M

RESOURCES

To get information and support related to cancer survivorship, depression, or health and wellness, please visit the following sites:

a. Cancer survivorship:

1. <http://www.cancer.gov/cancertopics/coping/survivorship>
2. <http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/NationalCancerSurvivorshipResourceCenter/index>
3. <http://www.cancer.net/patient/Survivorship/Survivorship+Resources>

b. Depression:

1. <http://www.nimh.nih.gov/health/topics/depression/index.shtml>
2. <http://www.nimh.nih.gov/health/publications/depression/complete-index.shtml>
3. <http://www.nimh.nih.gov/health/topics/getting-help-locate-services/index.shtml>

c. Health and wellness:

1. <http://health.nih.gov/category/WellnessLifestyle>
2. <http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/index?ssSourceSiteId=null>
3. <http://www.cancer.org/Healthy/index>
4. <http://www.cancer.org/Cancer/News/ExpertVoices/post/2012/04/26/New-healthy-living-guidelines-for-cancer-survivors.aspx>

Appendix N

QUALITATIVE INTERVIEW

Hi, <participant name>, this is Sarah Kelleher, calling from Virginia Tech's *Center for Research in Health Behavior*. Is now still a good time for you for the telephone interview?

Yes: Continue.

No: I understand, when would be a good time to reschedule with you?

Great. Thank you again for your willingness to be contacted for this telephone interview. The purpose of this interview is to learn more about your professional perspective on comprehensive cancer survivorship care planning and your experiences providing post-treatment care to survivors of cancer. The questions I will ask you are open-ended. We are simply interested in learning more about what you do when you meet with patients post-treatment as well as your opinions related to the issues and challenges facing the survivorship care field. If at any time you do not wish to answer, please do not hesitate to tell me. We can skip questions or end the interview at any time. Do you have any questions at this point?

Yes: Answer factually.

No: Great, let's begin...

1. How do you think of and define survivorship care? What does it entail?

2. Does your hospital/medical center/practice have a system for creating SCPs or some form of treatment plan for survivors once they've completed treatment?

- If so, what is the system? How does it work/what does it involve?
- What is its purpose?
- Who does it involve? Coordination between care providers?
- Written document that the patient receives?
- Do all patients get this?
- When you meet with patients, do you personally make referrals for mental health, diet, and/or exercise?
- If so, is there a way to track whether patients follow through on recommendations and/or whether they make health behavior changes?

3. What is your impression of the utility of comprehensive SCPs? Are they necessary/helpful? How so? Should all patients receive a SCP?

4. What are the primary obstacles, or barriers, to delivery of comprehensive (interdisciplinary) care for survivors (including implementation of SCPs)?

5. What do you think are the next steps in the field of survivorship care? What should we be working toward as clinicians and researchers?

END:

Those are all the questions that I have for you. Your input is very valuable to us and we thank you again for your time and participation. Are there any final remarks you would like us to include?