

# Colon Cancer Survivorship Experiences

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## ABSTRACT

The purpose of this project is to explore potential social cognitive and psychosocial predictors of lifestyle changes, including diet and physical activity behaviors, in a sample of colorectal cancer survivors who are at high risk of developing a second colorectal cancer. Participants, recruited from Georgetown University's Lombardi Comprehensive Cancer Center, are colorectal cancer survivors from families at high or confirmed risk of having a hereditary colorectal cancer syndrome. Results indicate that, at the bivariate level, many of the psychosocial and social cognitive variables of interest are significantly associated with one another as well as with various health behaviors and health behavior changes. Correlational data indicate that lower distress is associated with higher psychosocial functioning, self-efficacy, and self-regulatory ability. In addition, the data also suggest that individuals with higher self-efficacy display higher self-regulation and more positive outcome expectations related to health behaviors. Overall, participants were more likely to increase healthy behaviors or remain consistent with moderately healthy lifestyles practiced prior to their colorectal cancer diagnosis and treatment, and decrease unhealthy behaviors. Implications and directions for future research are discussed within the paper.

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## **1. Aims**

The present study aims to extend previous research by exploring potential predictors of lifestyle changes, including diet and physical activity (PA) behaviors, in a sample of colorectal cancer (CRC) survivors who are at high risk of developing a second CRC. Social cognitive and psychosocial variables were quantitatively examined to determine potential predictors of lifestyle changes in this high-risk population. As this is an exploratory study, the primary goal is hypothesis generation. That is, this study aims to generate hypotheses regarding whether and how psychosocial and social cognitive variables are related to health behavior outcomes, specifically diet and PA.

A primary aim of the current study is to enhance the understanding of psychological and behavioral outcomes of high-risk individuals following a cancer diagnosis. Thus, a critical outcome of this exploratory study is to gain additional information for the development of future interventions to improve health and overall quality of life (QoL) outcomes for men and women at high-risk for cancer recurrence through learning about the various psychological factors which may predict health behavior changes in this population. Knowledge gained from this study can contribute to the conceptualization and design of targeted health behavior interventions and may be integrated into physician's post-treatment recommendations. Because high-risk status refers to genetic risk, genetic counseling is a very relevant and beneficial component of a high-risk cancer patient's treatment experience. Genetic counseling is defined by the National Society of Genetic Counselors (NSGC) as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (2005-2009). Therefore, study findings may enhance the psycho-education component of the genetic counseling process for both affected (i.e., individuals who have received a cancer diagnosis) and unaffected (i.e., individuals who have not received a cancer diagnosis) individuals.

## **2. Background**

An estimated 1.5 million individuals will be diagnosed with cancer in the year 2010 (American Cancer Society [ACS], 2010). Currently, there are more than 11 million cancer survivors in the United States (Speck et al., 2010). Colon cancer, affecting men and women alike, accounts for 9-10% of cancer diagnoses in the United States and approximately 9% of cancer deaths (ACS, 2010). It is also the third leading cause of cancer-related death (ACS, 2010). While there is a growing body of literature exploring health behaviors in colon cancer survivors, little is known about the health behaviors of individuals at high-risk due to familial or hereditary cancer syndromes. The most common hereditary cause of colon cancer is Hereditary Non-Polyposis Colon Cancer syndrome (HNPCC), accounting for 5% of all colon cancer diagnoses (Brodersen et al., 2004; Cleveland Clinic, Inherited Colorectal Cancer Registries, 2006). HNPCC is a hereditary cancer syndrome caused by a genetic alteration for which genetic testing is available.

### **2.1 Hereditary Non-Polyposis Colon Cancer (HNPCC)**

Hereditary Non-Polyposis Colon Cancer (HNPCC) is defined by the Johns Hopkins University Hereditary Colorectal Cancer Registry (Axilbund et al., 2005) as:

A condition in which the tendency to develop colon or rectal cancer is inherited.

Nonpolyposis means that colorectal cancer can occur when only a small number of polyps is present (or polyps are not present at all). The characteristics of HNPCC include multiple family members affected with colon cancer, colon cancer in multiple generations, and an earlier age of onset than often seen in the general population (before age 50 years). In HNPCC, colorectal cancer occurs primarily on the right side of the colon. Sometimes other cancers can occur in families with HNPCC. They include cancer of the uterus, ovary, stomach, urinary tract, small bowel, and bile ducts. (p. 2)

For individuals with HNPCC, the lifetime risk of developing CRC is up to 80%. Thus, these individuals are at significantly greater risk than the general population, whose lifetime risk is approximately 5-6% (ACS, 2009; James et al., 2006). In addition, approximately 20% of HNPCC individuals previously affected with colorectal cancer will develop a second colorectal cancer. Courneya and colleagues (2008) have documented the growing interest in health behavior interventions due to the growing number of CRC survivors. As a result of the high risk associated with a cancer diagnosis and more specifically, a hereditary cancer, it is vital that the lifestyle behaviors of these high-risk survivors be examined in order to learn more about how to improve the psychosocial and behavioral health outcomes of this specific survivor subgroup.

## **2.2 Health Behaviors in Cancer Survivors**

In the general adult population, health behaviors are linked to cancer deaths, such that “there are more than one half million cancer deaths in the United States each year, and one third of these deaths are attributed to suboptimal diet and PA practices” (Demark-Wahnefeld et al., 2008, p. 1573). Moreover, growing evidence suggests a link between lifestyle and health behaviors and cancer recurrence and death. Specifically, maladaptive health behaviors (e.g., a sedentary lifestyle) have been found to lead to poor health-related outcomes in cancer survivors (Irwin, 2008). Because of this identified connection, examining psychological factors associated with healthy lifestyle changes, including diet and PA, has emerged as an essential avenue of research. Furthermore, because previous research has largely focused on describing the frequency with which cancer survivors engage in health behaviors, little is known about the factors that predict maintenance or adoption of these behaviors. Identifying psychological factors associated with engagement in health behaviors is critical to determine appropriate diet and PA recommendations and effectively tailor interventions for this cancer survivor population.

### **2.3 Diet and Physical Activity Recommendations**

In 2006, ACS released updated weight and dietary recommendations stating the importance of achieving and maintaining a healthy weight by way of a diet focused on nutrient-rich, lower energy density foods, as well as portion control. More specifically, ACS recommends a diet with an emphasis on plant sources, 5+ servings of a variety of fruits and vegetables/day, whole grains rather than refined grains, and limited consumption of processed and red meat (2006). ACS also recommends that adults engage in at least 30 minutes of moderate to vigorous PA on 5 or more days of the week, but that 45-60 minutes of intentional PA is preferable (2006). Building upon these guidelines, Demark-Wahnefried recommends specific diet and exercise regimens as alternative goals for long-term survivorship (2008). In addition, previous research (Demark-Wahnefried, 2005; Schmitz et al., 2005) indicated the safety of PA in cancer survivors and its positive impact on overall physical and psychological functioning (e.g., energy and fitness levels, strength, fatigue, QoL, anxiety, and depression); however, only a minority of survivors (less than 30%; Schmitz et al., 2005) adheres to PA guidelines. Furthermore, only 25%-42% of survivors consume adequate amounts of fruits and vegetables (Demark-Wahnefried, 2005). Thus, these lifestyle modifications appear to be challenging for adults, including cancer survivors post-treatment.

A number of observational and ongoing randomized controlled trials provide support for additional evaluation of health behavior outcomes among CRC survivors. “The Colon Health and Life-Long Exercise Change Trial: A Randomized Trial of the National Cancer Institute of Canada Clinical Trials Group,” conducted by Courneya and colleagues, seeks to build upon observational studies which associate PA and an improvement in disease outcomes for CRC survivors by conducting a randomized trial to determine whether this relationship is causal.

Thus, the purpose of the Canadian study is to investigate the impact of a structured PA intervention for high-risk CRC survivors, classified as such by their stage of CRC (i.e., Stage II or Stage III; Courneya et al., 2008). With a target participant pool of 962, participants are randomly assigned to either the intervention arm, where they receive the PA program and general health education materials, or the control arm, where they receive general health education materials alone. The primary objective of the 3-year intervention is disease-free survival; secondary objectives include patient-reported outcomes (e.g., QoL, fatigue, anxiety and depression), objective assessment of physical functioning (e.g., anthropometric measurements, cardiovascular fitness), and assessment of long-term adherence to PA recommendations. As the study is currently ongoing, results are not yet available.

#### **2.4 Adherence to Diet and Physical Activity Recommendations**

A study conducted by Blanchard and colleagues (2008) assessed the prevalence and associations of various health behaviors (i.e., PA, fruit and vegetable consumption, and smoking) with QoL, in 9,105 cancer survivors from six types of cancer survivor groups (i.e., breast, prostate, colorectal, bladder, uterine, and skin melanoma). Participants completed a national cross-sectional survey which included lifestyle behavioral questions, in addition to the RAND-36 Health Status Inventory.

Results indicated that only a small portion of survivors were meeting the 5-A-Day fruit and vegetable guidelines or the PA recommendations. While most participants were non-smokers, only 5% of survivors met all three of the dietary, PA, and non-smoking health recommendations. Survivors who met the lifestyle behavior recommendations reported higher health-related QoL. Blanchard and colleagues reported a strong positive association between health-related QoL and the number of healthy lifestyle behaviors across all groups of cancer

survivors. In discussion of these results, Blanchard and colleagues (2008) cited the need for interventions aimed at increasing health behaviors, such as PA, and the likelihood that these interventions would produce additive effects on health and QoL in cancer survivors.

## **2.5 Health Behavior Change Comparison Data**

Previous research on health behavior change trends from 2004-2009 was reviewed to provide an estimate of what could be expected as far as changes in the health behaviors of the participants in the current study. ACS's *Cancer Statistics 2009* indicated two primary trends: (1) Between 1994 and 2007, there has been little to no improvement in the rates of adults consuming the five or more recommended vegetable and fruit servings for cancer prevention. Nearly identical to prevalence rates in 1994, in 2007 about one in four adults was eating the recommended servings (ACS, 2009); (2) Similar to the lack of change in dietary prevalence rates noted above, between 1992 and 2007, there has been little improvement in the trends in prevalence of "no leisure-time PA" (ACS, 2009). That is, since the early 1990's, approximately one-fourth of adults do not engage in any leisure-time PA (ACS, 2009). Likewise, as documented by the Centers for Disease Control & Prevention (CDC) in a report detailing health behaviors of adults in the United States between 2005-2007, a small "30.7% engaged in activity sufficient in frequency and duration to be classified as 'regular'" (2010, p. 38). When PA is assessed using pedometers or accelerometers (instead of self-report), however, the percentage of adults meeting recommended activity levels is even lower (Bassett et al., 2010).

Alfano & Rowland (2009) indicated that over half (i.e., 58%) of their breast cancer survivor sample reported making positive health behavior changes (i.e., diet, PA) since their cancer diagnosis. Specifically, trends revealed an overall increase in fruit and vegetable consumption (43%), fiber intake (42%), and exercise (32%), and a decrease in fat intake (44%)

and fatigue (Alfano, 2009). In addition, 26.5% of participants reported making some positive change in both their exercise and diet behaviors, while 18.5% reported making positive changes in their exercise behavior and all three dietary behaviors (Alfano & Rowland, 2009).

Furthermore, Harper and colleagues (2007) reported a generally high rate of positive behavior change in a sample of cancer survivors post diagnosis and treatment. Specific to diet and exercise behaviors, 49% of participants reported a positive change in diet, while a smaller 26% indicated a positive change in exercise behavior post cancer diagnosis and treatment (Harper et al., 2006).

Research conducted by Mullens and colleagues (2004) examined the prevalence of health behavior changes in a sample of CRC survivors. Specifically, participants reported on health behavior changes made following completion of their treatment as well as intentions to make health behavior changes in the future. Results revealed that 45.7% of participants reported making post-treatment changes in PA engagement, while 51.9% reported changes in dietary practice post-treatment. Furthermore, 45.7% of CRC survivors reported intentions to make changes in PA practices, while 30.9% reported intentions to make changes in dietary practices (Mullens et al., 2004).

## **2.6 Psychological Outcomes for Survivors**

Prior research conducted with cancer survivor populations has identified an overall decrease in psychological health and well-being following a cancer diagnosis (Costanzo et al., 2009), and a number of factors have been identified that may relate to psychological health and well being. For example, psychological factors such as resilience, perception of risk of future cancer, self-efficacy, self-regulation, and outcome expectations, are all thought to play a role in the social and emotional adjustment to a cancer diagnosis. Furthermore, these identified factors have been found to be significantly associated with lifestyle and health behavior changes

(Anderson et al., 2006, 2007; Bandura, 2004; James et al., 2006; Winett et al., 2007). While very little is known about what predicts the adoption and maintenance of healthy lifestyle behaviors in cancer survivors, even less is known about these behaviors and predictors in high-risk groups.

## **2.7 Distress and Quality of Life**

For about one-third to one-quarter of cancer patients, higher psychological distress occurs at the time of diagnosis, throughout treatment, and in the short-term following completion of treatment, with long-term disease-free survival being associated with lower levels of psychological distress (Cella & Tros, 1987; Epping-Jordan et al., 1994; Zabora et al., 2001). Specifically, Mullens and colleagues (2004) identified a correlation between age, survival status and distress levels; higher distress levels (e.g., worry and anxiety) were correlated with younger age among patients who had completed treatment within an average of two years. For longer term survivors, defined as individuals who had completed treatment an average of five years prior, distress rates were lower. Similarly, Costanzo and colleagues (2009) found that compared to younger survivors, older survivors exhibited more resiliency, and were more likely to exhibit psychosocial functioning comparable to their same-age unaffected peers.

In a sample of CRC survivors within five years of their diagnosis and treatment, Phipps and colleagues (2008) found that a significant percentage of participants attributed their difficulties with low energy, sexual functioning, bowel problems, poor body image, and emotional problems to their personal history of CRC. Younger survivors appear more likely to experience greater levels of distress because a cancer diagnosis is less expected and thus more disruptive to work and family related responsibilities (Phipps et al., 2008). Evidence to date suggests that among most cancer survivors, including CRC survivors, psychological factors impact adjustment following a cancer diagnosis and treatment (Phipps et al., 2008).

## **2.8 Resilience**

A cancer diagnosis can have a variety of effects on an individual's emotional health as well as lifestyle and health behaviors. More specifically, the effect of a cancer diagnosis (e.g., side effects of surgery and treatment) can interrupt and interfere with an individual's established health behaviors and may also exacerbate maladaptive health behaviors (Pinto & Trunzo, 2005). As a result, resilience, or a return to normal functioning following an adverse experience (Carver, 1998; Costanzo et al., 2009), has been found to be an influential factor in an individual's adjustment to a cancer diagnosis. Resilience, also described as the ability to bounce back from a stressor or traumatic event, is believed to be a key component of the recovery process, likely affecting emotional well-being and lifestyle behaviors following a cancer diagnosis. Costanzo and colleagues (2009) found that many cancer survivors exhibit resilience in various psychological domains of their life (e.g., social well-being, spirituality, personal growth). However, little is known about potential health-related outcomes for cancer survivors based on their resilience. Thus, in order to extend previous research, associations between resilience and health behavior change will be examined to determine the impact of resilience on lifestyle and health behavior changes.

## **2.9 Risk Perception**

Although a cancer survivor's perception of risk is not necessarily an accurate reflection of their actual risk level, it is nevertheless important to examine as it is believed to impact his or her psychological and emotional adjustment as well as health and lifestyle behaviors. Previous research has examined both short- and long-term cancer survivors and found that CRC survivors did not report exaggerated risk perceptions (Mullens et al., 2004). More specifically, Mullens and colleagues (2004) found that long-term survivors reported lower risk perceptions of their risk

of recurrence on both personal and comparative risk items, while short-term survivors saw their risk of recurrence, compared to other CRC survivors, as comparable. Overall, long-term survivors viewed their risk as lower compared to short-term survivors. Of note, Mullens and colleagues (2004) refer to Leventhal's Parallel Processing Model (Leventhal et al., 2001) to support their findings, as Leventhal's Model indicates that survivors' perceived risk of recurrence typically decreases as time since diagnosis and treatment increases, due to a decrease in threat reminders coupled with an increase in feelings of safety.

### **2.10 Self-Efficacy, Self-Regulation, and Outcome Expectations**

Although little is known about the role that social cognitive variables, such as self-efficacy and self-regulation, play in the adoption and maintenance of health behaviors in a high-risk cancer population, there is a large body of literature documenting the salience of these variables to health behaviors in the general population. Social Cognitive theorist, Albert Bandura, defines *perceived self-efficacy* as "people's beliefs about their capabilities to produce effects," and *self-regulation* as the "exercise of influence over one's own motivation, thought processes, emotional states and patterns of behavior" (Bandura, 1994, p. 72). In a study looking at exercise behaviors of breast cancer patients during treatment, Rogers and colleagues (2005) found that a higher daily energy expenditure was associated with higher self-efficacy. In addition, Lev (1997) has found that increased self-efficacy is associated with increased self-care behaviors.

As Graves & Carter state, "expectancies about the outcome of one's behavior directly influences that behavior, such that when an individual expects a negative outcome from a behavior, he or she is less likely to engage in that behavior, regardless of belief in ability to perform it" (2005, p. 210). Thus, in order to learn more about an individual's adjustment to

illness, one's expectations for the outcome of his or her behaviors must be examined. That is, because there is a cyclic nature with regard to an individual's expectations and behaviors, learning more about what types of expectations an individual has for engaging in PA and consuming a healthful diet is believed to shed light on the likelihood of that individual carrying out those health behaviors. A large body of research continues to examine the role of these social cognitive variables in health behaviors (e.g., Graves & Carter, 2005; Lev et al., 2001; Merluzzi et al., 2001). Although little is known about the connection between social cognitive variables and health behaviors in a high-risk CRC population, there is an established association in cancer populations more broadly. Even though it is believed that this association will undoubtedly translate to a high-risk cancer population, research is needed to empirically address this assumption.

### **2.11 Standard of Medical Care for Colorectal Cancer Patients**

Important to this study is an understanding of the "gold standard" of care that CRC patients receive when undergoing treatment. The American Society of Clinical Oncology (ASCO; 2010), a non-profit organization made up of more than 27,000 oncology practitioners of various specialties, has outlined the best treatments currently available for CRC. Treatment is individualized, typically based on the size, location, and stage of the tumor, as well as the patient's general health (ASCO, 2010). This tailored course of treatment should be decided upon by a transdisciplinary team of doctors (e.g., gastroenterologist, surgical oncologist, medical oncologist, radiation oncologist), in collaboration with the patient.

Removal of the tumor is typically the first step in the treatment of patients with stage 0 through stage III CRCs. These removal procedures can range from a simple polypectomy during a colonoscopy for stage 0 CRC to surgical removal of the tumor and its nearby lymph nodes. For

patients with stage 0 and I diagnoses, removal of the tumor is oftentimes the only treatment necessary. Depending on the location of the tumor and the segment of the colon that is removed, patients may need to have a colostomy (i.e., surgical opening, or stoma, providing an exit pathway for bodily waste) and a temporary or permanent ostomy appliance (i.e., a bag worn by the patient that collects the waste). Stage II CRC diagnoses may or may not require chemotherapy following surgical removal. Oncologists report that cure rates following surgery alone are generally good for patients with Stage II CRC (ASCO, 2010), and further report uncertainty regarding the benefits of chemotherapy following surgery in Stage II patients. Thus, the decision to pursue chemotherapy following surgical treatment should be a collaborative decision reached by the team of doctors and the patient. Stage III CRC diagnoses typically require that surgery be followed by adjuvant chemotherapy due to the spread of the cancer. The usual care for patients with a Stage IV diagnosis typically begins with chemotherapy in addition to treatment targeting damaged genes or proteins that contribute to the growth and development of cancer and/or radiation therapy to shrink the tumor. Surgical treatment may follow depending on the need to remove metastases (i.e., areas where the cancer has spread). Overall, surgical removal of the tumor is the most common treatment for CRC. Clinical trials testing new treatments are also available and may be an option for patients with later stages of CRC (ASCO, 2010; National Comprehensive Cancer Network [NCCN], 2010; National Cancer Institute [NCI], 2010).

Although researchers and doctors have made significant progress in recent years to reduce physical side effects such as pain, fatigue, nausea, and vomiting, CRC patients still commonly experience physical and psychosocial side effects from both surgery and adjuvant therapy. ASCO's guidelines (2010) convey the importance of preventing and controlling side

effects as a significant focus of a patient's healthcare team. Although methods to provide relief for treatment-related physical symptoms are improving, patients are still at risk for experiencing psychological side effects (ASCO, 2010; NCI, 2010), including subsets of patients who report anxiety and depression (Bultz et al., 2006; Jacobsen et al., 2005; Zabora et al., 2001). Clinical Practice Guidelines set by the NCCN (2010) recommend routine screening for distress in cancer patients (2010), and although healthcare professionals are more aware of the acute emotional distress that is frequently co-morbid with a cancer diagnosis, the detection, monitoring, and treatment of psychological health issues must become a more essential component of patient care (Bultz et al., 2006; Jacobsen et al., 2005).

Although a wealth of information exists regarding specific guidelines and recommendations for the usual care treatment of CRC, specific health behavior recommendations, or prescriptions, are notably absent from standard cancer treatment protocols. These types of lifestyle prescriptions also appear to be lacking in the current model of post-treatment care. After completion of treatment for CRC, patients are encouraged to talk with their doctor about developing a follow-up care plan. These post-treatment care plans generally include scheduling of routine physical exams and medical tests to monitor recovery (ASCO, 2010). According to ASCO (2010), CRC patients are also encouraged to follow established health guidelines, which include maintaining a healthy weight, not smoking and eating a balanced diet. 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). Therefore, there is a need for healthcare teams to expand their follow-up care to include more specific and individually tailored prescriptions that ensure CRC survivors are feasibly and

successfully able to make the necessary health behavior changes (Hewitt & Ganz, 2006; Jacobs et al., 2009; Rowland et al., 2006).

## **2.12 Considerations for After-Care**

As stated above, post-treatment plans to medically monitor recovery are quite common. In building upon the current follow-up model, The Institute of Medicine (IOM), among other national organizations (e.g., NCI), has highlighted the need for development of “survivorship care plans,” or “wellness plans,” comprehensive post-treatment plans aimed at improving patients’ lifestyles and QoL, in addition to monitoring for recurrent and/or second cancers. Recommendations for these survivorship care plans, from IOM (Hewitt & Ganz, 2006), NCI (2010), and ACS (Jacobs et al., 2009), include the active engagement of patients in collaboration with their team of physicians to develop appropriate and individualized plans that 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. Websites of several national cancer organizations (ACS, 2010; ASCO, 2010; NCI, 2010) include general information about the maladaptive health behaviors that put individuals at risk for cancer and other diseases, recommendations for adopting healthy lifestyles, and the benefits of making those healthy lifestyle changes. However, as specific prescriptions for adoption and maintenance of healthy lifestyle behaviors are not yet integral components of post-treatment care plans, it is left up to the patient to search for and locate this information. Thus, although it remains to be seen whether and how healthcare providers are developing survivorship care plans with their patients, it is clear there is considerable need for more systematic implementation of post-treatment plans that encompass health promotion and behavior change, in addition to prevention and surveillance.

### **2.13 Standard of Medical Care for HNPCC Colorectal Cancer Patients**

Compared to follow-up care for patients with sporadic CRC cases, post-treatment care for individuals with HNPCC-related CRC involves a greater frequency of thorough medical exams as well as additional types of screening due to their increased risk for other cancers (e.g., cancer of the endometrium, ovary, stomach, and urinary tract; Axilbund et al., 2005). Recommended screening guidelines include: (i) sigmoidoscopy every year; (ii) annual hemoccult test; (iii) annual physical exam; and (iv) for women, annual gynecological exam including endometrial screening (Axilbund et al., 2005). Below is a description of the typical standard of care genetic counseling sessions where individuals receive education regarding their hereditary cancer risk status.

### **2.14 Usual Care for HNPCC Genetic Counseling**

Also important to the current study is an understanding of standard care for patients pursuing HNPCC genetic counseling. Genetic counseling for HNPCC is a complex process which typically includes two visits, with the second visit contingent upon the patient's pursuit of genetic testing (DeMarco et al., 2007; Roche et al., 2001). Although it can vary, these genetic counseling sessions tend to last between one and two hours. Prior to the patient's first visit, the genetic counselor (GC) prepares by reviewing the patient's medical records and calculating hereditary cancer risk using established statistical models (e.g., *CancerGene*). The purpose of the first visit is to educate the patient about familial risk and medical management options. The GC begins by constructing a pedigree (i.e., a family tree) following a thorough review of the patient's personal and family medical history. Then, the GC provides a risk assessment, detailing probabilities related to the risk of carrying a HNPCC mutation as well as related lifetime risk estimates for colon cancer (or a subsequent diagnosis). Following this risk assessment, the GC

presents various screening and prevention options (e.g., prophylactic surgery). Furthermore, the GC will discuss the pros and cons of genetic testing, as well as family communication and logistical issues. Depending on the patient's decision to pursue testing, blood or buccal (i.e., saliva) samples may be taken and sent for testing. If the patient opts to test and receive his or her results, then a second genetic counseling visit will be scheduled (DeMarco et al., 2007; NSGC, 2010).

The second genetic counseling visit will entail discussion and review of genetic testing results, cancer risks, surveillance and prevention options, disclosure to relatives, testing of at-risk family members, and appropriate referrals (e.g., physicians, psychologists). Although the two-visit model is most commonly used (Alvarado et al., 2001), GCs may indicate their availability to schedule additional follow-up visits as needed to further discuss medical management decisions, family communication issues, and support resources (DeMarco et al., 2007; NSGC, 2010).

### **2.15 Considerations for HNPCC Genetic Counseling**

Standard genetic counseling visits do not typically include discussion of specific recommendations regarding how to adopt and maintain health and lifestyle behaviors. Genetic counseling sessions are already multifaceted and information intensive due to the variety and content of material covered. As such, visits would likely have to be extended in order to include a focused discussion of health guidelines and personalized recommendations. If it were to become standard care, this health behavior component could be incorporated into discussion of screening and other risk reduction options. However, to include this as part of usual care, GCs would likely need to complete additional training in order to provide competent and appropriately tailored health behavior recommendations. Although this is not currently the

standard of care, the addition of this type of health component could likely serve to enhance the overall genetic counseling experience and provide patients with more complete information regarding health and risk management options.

Of note, pathways other than through the genetic counseling process might be more amenable to the communication of specific health behavior information. For example, various cancer centers (e.g., Dana Farber Cancer Institute) include Quality of Life Clinics within their institution to offer specialized services such as nutrition and exercise counseling as well as psychosocial/support programs (Dana Farber Cancer Institute, 2010). Likewise, Survivorship Clinics, described in detail below, are another similar pathway conducive to the provision of specific health behavior recommendations. Other options include CRC treatment programs involving oncology nurses trained to deliver this information as well as integration of health behavior prescriptions into existing post-treatment models of care (e.g., survivorship care plans) as previously discussed. Finally, it should be noted that even though adoption and maintenance of healthy lifestyle behaviors are known to be of significant benefit to general health and well being (e.g., reduction of risk for various cancers and diseases), more research is needed to develop an evidence base exploring the impact of health behaviors in genetically high-risk populations such as HNPCC survivors.

## **2.16 Previous Research Findings and Implications**

Careful review of the literature highlights the importance of healthy lifestyle behaviors, specifically diet and PA, in the cancer survivor population. That is, previous research has demonstrated the importance of adopting and maintaining healthy lifestyle behavior changes on cancer-related outcomes. Cancer survivors are at increased risk of poorer health outcomes due to their fairly prevalent obese and sedentary lifestyles (Blanchard et al., 2008; Demark-Wahnefeld

et al., 2008; Irwin, 2008; Schmitz et al., 2005). Because previous research has also revealed low adherence rates for diet and PA recommendations, it is believed that HNPCC individuals are at increased risk not only due to the hereditary nature of their CRC, but also due to the prevalence of obesity and sedentary lifestyles in the general cancer survivor population.

At the time of a diagnosis and immediately following, cancer patients are inundated with a tremendous amount of information regarding their diagnosis, prognosis, and various treatment options. What remains to be seen is whether patients receive recommendations regarding personal lifestyle choices, including diet and PA behaviors. While there is follow-up regarding the individual's diagnosis and treatment decisions, there is little follow-up, short- or long-term, regarding the psychological impact of this life-changing event as well as subsequent lifestyle changes. Thus, research is needed to explore the lifestyles of these high-risk survivors in order to learn more about their adoption and maintenance of healthy behaviors. As previous research has indicated that adopting such lifestyle behaviors would significantly benefit cancer survivors in terms of increasing disease-free survival, it is also thought that this finding translates to an improvement in psychological health and QoL as well. Thus, a critical next step in this line of research is to determine the impact of lifestyle changes on non-cancer related outcomes. More specifically, it is important to examine how these lifestyle changes affect CRC survivors' psychological health and QoL. In addition, another important next step is to determine what psychological factors predict who makes these lifestyle changes. Learning more about the factors that predict lifestyle changes in this survivor population will provide us with valuable information that can be integrated into physician's post-treatment recommendations, and can additionally help target the psycho-educational component of the genetic counseling process for both affected and unaffected individuals who may have a hereditary cancer syndrome.

Psychosocial factors frequently associated with a cancer diagnosis, including resilience and risk perception, as well as social cognitive factors including self-efficacy, and self-regulation, all influence an individual's ability to cope as well as their ability to create and maintain adaptive lifestyle changes. Due to the influence of these variables, it is important to determine which have the most prognostic influence, in terms of predicting an individual's ability to make lifestyle changes, in order to learn more about the psychological processes underlying an individual's survivorship experience as it specifically relates to health behaviors. Although there is a growing body of literature exploring these health behaviors in cancer survivors, there is little to no research on these behaviors and their predictors in the high-risk HNPCC group.

High-risk individuals have the potential to be particularly motivated to engage in healthy lifestyle behaviors due to their elevated risk; however, there are a variety of potentially inhibiting factors as well. That is, individuals who have survived a cancer diagnosis and treatment may experience any number of the following: diminished QoL, poor self-efficacy and/or self-regulation, pessimism, a lack of resilience, extreme fatigue, and pain. Moreover, the stage of a person's diagnosis and their treatment experience may also serve to discourage him/her and interfere with plans to adopt and maintain a healthy lifestyle. It is also possible that due to the hereditary basis of their CRC, high-risk CRC survivors may be resigned to the role of genetics and may consequently be less likely to engage in healthy behaviors due to a belief that such behaviors may do little in the way of risk reduction.

### **2.17 The Current Study**

Prior work has documented the positive impact of diet and PA on the improvement of health-related outcomes in cancer survivors. The present study aims to build upon this prior

research by examining the non-medical related outcomes for CRC survivors at high risk for a recurrent diagnosis. Although previous research has investigated health behaviors of various cancer survivor populations, it has largely failed to examine predictors of health behavior change among cancer survivors who are at increased risk due to their personal and family cancer history. Therefore, the purpose of the present study is to fill this gap in the research by exploring potential predictors of lifestyle changes, including diet and PA behaviors, in a population of CRC survivors who are at high risk of developing a second CRC. The current study is part of a larger study examining predictors of lifestyle behavior changes in both average and high-risk individuals to provide a comparison for responses between these survivor groups and evaluate differences in psychological and behavioral outcomes in these distinct survivor subgroups; however, the proposed study will focus only on the high-risk group.

### **3. Method**

#### **3.1 Participants**

Participants eligible for the present study included men and women who have been diagnosed with CRC and are from families at high or confirmed risk of having a hereditary CRC syndrome. CRC survivors enrolled in the Familial Cancer Registry (FCR) or seen through the Clinical Genetics Program at Georgetown University's (GU) Lombardi Comprehensive Cancer Center were potentially eligible to participate in the present study. 22 eligible men and women were recruited and all 22 consented to participate. As 2 participants had not yet completed the online survey at the time the data analyses were conducted, the final sample includes 18 women and 2 men (95% Caucasian, 5% Asian) between the ages of 33-69 years old ( $M = 48.83$  years,  $SD = 11.70$ ) who reported a previous diagnosis of CRC, received genetic counseling for

HNPCC, agreed to participate, and completed the online questionnaire. Of these 20 participants, 17 agreed to and completed the follow-up telephone survey.

### **3.2 Inclusion/Exclusion Criteria**

Inclusion criteria was as follows: (i) any individual affected with CRC; (ii) CRC diagnosis at any age; (iii) received HNPCC genetic counseling; (iv) males and females; and (v) English speaking. Individuals were excluded based on the following criteria: (i) currently undergoing treatment or (ii) inability to provide informed consent.

### **3.3 Recruitment**

It was originally estimated that there would be approximately 40 to 50 potentially eligible individuals constituting the ‘high-risk’ group, per having received HNPCC genetic counseling. As noted, a smaller sample of 22 individuals was identified as being eligible. This high-risk survivor group was recruited from the FCR and the Cancer Genetics Clinical program at GU’s Lombardi Comprehensive Cancer Center. Separate recruitment procedures were followed for both recruitment sources.

#### **Familial cancer registry.**

Following IRB approval and submission of a HIPAA waiver, eligible FCR patients were mailed an approved letter (prepared by the investigator and sent from the FCR staff) briefly describing the study and informing them that they would soon be contacted via telephone by FCR staff with more information. Next, the FCR staff member obtained consent for the FCR to share the patients’ contact information with the researchers. The investigator then contacted the eligible participants to further describe the study and obtain informed consent.

### **Clinical genetics program.**

Although the eligible pool of participants identified by the FCR was expected to include individuals who have been seen through the GU Clinical Program, it was anticipated that a few additional eligible participants would be ascertained through the Clinical program who were not enrolled in the FCR. As such, following IRB approval and submission of a HIPAA waiver, the Clinical Program Genetic Counselor, Tiffani DeMarco, sent a letter directly to the eligible clinical patients informing them of the study and asking for permission to share their contact information with the collaborating investigator. In addition to a brief description of the study, the letter also included a toll-free telephone number so that participants could decline further contact.

At this point, one of Dr. Graves' research team members with the Cancer Control Program (who has worked as part of the clinical genetics research team through which many patients are referred to the Clinical Genetics Program) then contacted eligible individuals who had not yet declined further contact. This individual briefly described the collaboration with the Virginia Tech (VT) research team and the current study for which they were eligible. For interested individuals, the Georgetown research team member then obtained verbal consent to share their contact information. For those who agreed to further contact by the collaborating investigators, their contact information was then provided to the collaborating researchers at VT. The investigator then followed-up with these individuals who had indicated their interest and who had consented to be contacted to further explain the purpose of the study, provide the option to decline participation, and for interested individuals, obtain informed consent. This recruitment and consent procedure detailing initial contact made by an internal GU research team member to obtain verbal consent for further contact by a collaborating investigator has been used by Dr. Graves's research team before and therefore was accepted by the GU IRB in the past.

### 3.4 Measures

Social cognitive, psychosocial (including perceived risk), clinical, and health behavior variables were all measured at one time-point using an online questionnaire. The following measures have all been used extensively in prior research conducted with cancer populations.

#### **Predictor variables.**

***Sociodemographics (Appendix A).*** Information was obtained on participants' age, race, marital status, education, household income, and religion.

***Clinical and risk management information (Appendices B & C).*** Self-report data were gathered on participants' personal cancer history (e.g., form of treatment) and family cancer history. Self-report data assessing participants' past and present risk management behaviors (e.g., screening behaviors) were also collected.

***Psychological distress (Appendix D).*** The Brief Symptom Inventory (BSI), an abbreviated version of the 53-item BSI (Derogatis, 1975) and the SCL-90-R (Derogatis, 1975), and the Impact of Events 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 measuring general distress with the anxiety and depression subscales. Furthermore, the item inquiring about suicidality was removed since the questionnaire was administered online and the researcher would have been unable to follow up with participants appropriately and promptly regarding concerning responses. This approach has been used in prior research with individuals at risk for carrying a genetic mutation indicative of a hereditary cancer syndrome (Peshkin et al., 2008). Examples of statements from the BSI-18 include: Feeling not interested in things; Feeling fearful; and Feeling hopeless about the future. Responses to items on the BSI scale are rated on a 5-point scale where 1=*not at all*, 2=*slightly*,

3=*moderately*, and 4=*extremely*. Examples of statements from the IES, keyed to thoughts about cancer, include: Any reminder brought back feelings about it; I was aware that I still had a lot of feelings about it, but I didn't deal with them; and I had waves of strong feelings about it.

Responses to items on the IES scale are rated on a 4-point scale where 0=*not at all*, 1=*rarely*, 3=*sometimes*, and 5=*often*. The IES demonstrates 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).

***Quality of life (Appendix E).*** The FACT-C (Colorectal), version 4.0, is a 36-item self-report measure that assesses QoL concerns specific to CRC patients as well as concerns common to all cancer patients (Ward et al., 1999). The FACT-C is comprised of four primary subscales: (i) physical well-being; (ii) social/family well-being; (iii) emotional well-being; and (iv) functional well-being, in addition to a subscale measuring CRC specific concerns. Responses are measured on a 5-point Likert scale (0=*not at all*, 1=*a little bit*, 2=*somewhat*, 3=*quite a bit*, 4=*very much*) and are summed to calculate a total QoL score. Higher scores on the FACT-C indicate better QoL (Ward et al., 1999). In an English-speaking sample, Ward and colleagues (1999) reported sound psychometric properties, indicating good internal consistency as evidenced by the Cronbach's alpha calculation of .87. Ward et al. (1999) also reported adequate convergent and divergent validity.

***Resilience (Appendix F).*** The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) is a 25-item measure which was included to assess participants' resilience. Resilience has been categorized by Connor & Davidson as a measure of "stress coping ability" (2003, p. 76). Responses were measured on a 5-point Likert scale ranging from

*not true at all to true nearly all the time.* Therefore, the range of total scores is from 0 to 100, with higher scores reflecting greater resilience. In an examination of the psychometric properties of the scales, Connor & Davidson (2003) reported that the CD-RISC demonstrates good internal consistency, citing a Cronbach's alpha of .89. Connor & Davidson (2003) additionally reported strong test-retest reliability, with an intraclass correlation coefficient of .87.

***Perceived risk (Appendix G).*** Based on instruments used in previous research conducted with cancer survivor groups, three items were used to assess participants' absolute, numerical, and comparative perceived likelihood of CRC recurrence (Graves et al., 2008; Lipkus et al., 2000; Mullens et al., 2004; Weinstein, 1998). In order to measure absolute risk, participants used a 5-point Likert scale, with responses ranging from 1=*not at all likely* through 3=*somewhat likely* to 5=*definitely likely*, to answer the question, "In your opinion, how likely is it that you will develop colon cancer again?" The numerical risk item asked participants to use a scale from 0 (*no chance*) to 100 (*guaranteed to happen*) to rate their responses to the question, "How likely is it that you will develop colon cancer again sometime in your life?" Comparative risk was assessed by asking participants to use a 5-point Likert scale (1=*much less*, 3=*about the same*, 5=*much greater*) when responding to the question, "Compared to other people who have had colon cancer, how would you rate your chances of having a recurrence?"

***Self-efficacy (Appendix H).*** The Cancer Behavior Inventory, version 2.0 (CBI; Merluzzi et al., 2001; Merluzzi & Martinez Sanchez, 1997), is a 33-item measure assessing an individual's overall self-efficacy with regard to their ability to cope with a cancer diagnosis. Coping self-efficacy is measured in the following areas: maintenance of activity and independence, seeking and understanding medical information, stress management, coping with treatment-related side-effects, accepting cancer/maintaining a positive attitude, affective

regulation, and seeking support. Using a 9-point 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*; Merluzzi & Martinez Sanchez, 1997). Psychometrically, the CBI has been found to demonstrate very good internal consistency with an alpha calculation of 0.94 for the entire measure. The CBI has also demonstrated good test-retest reliability as evidenced by the alpha coefficient 0.74 (Merluzzi et al., 2001).

In addition to the CBI, another self-efficacy measure assessing participants' confidence in their diet and exercise behaviors, as well as their confidence in behaviors related to their medical care, was adapted from the validated colon-cancer specific self-efficacy section of the *Adherence Determination Scale* (DiMatteo, 1993). Items were added to more specifically assess participants' self-efficacy with regard to their diet and PA behaviors. Questions generally ask about participants' confidence in their ability to reduce consumption of unhealthy food and drink, increase intake of healthier food and drink, and engage in more frequent PA marked by increased duration and intensity.

***Self-regulation (Appendix I).*** Self-regulation was assessed using modified versions of two previously developed scales. First, a 22-item self-regulation measure developed by Graves and colleagues (2003; Graves & Carter, 2005) was used to assess participants' ability to problem solve and make plans in the context of their cancer treatment. In a fairly diverse sample of cancer patients, this scale has demonstrated high internal consistency with a strong alpha coefficient of .92 (Graves & Carter, 2005).

Second, sections of the *Health Beliefs Survey* (Winett et al., 2007) were modified for use to measure self-regulatory abilities as related to diet and exercise behaviors. The *Health Beliefs Survey* measures social support, outcome expectations, and self-regulation for nutrition and PA

among other social cognitive variables, however, only the self-regulation sections were used here (the outcome expectations section were also used, but will be described later). Generally, the questions included asked participants how likely they are to engage in self-regulatory skills believed essential to PA behavior change (Winett et al., 2007). With regard to the psychometric properties, the *Health Beliefs Survey* scales have demonstrated good internal consistency as evidenced by a Cronbach's alpha calculations between 0.68 and 0.9 (Winett et al., 2007).

***Outcome expectations (Appendix J).*** In order to measure participant's outcome expectations with regard to their cancer diagnosis and treatment experience, as well as diet and PA behaviors, measures were adapted based on validated assessments examined in Graves' "Outcome expectations and self-regulation in cancer patients: Reliability, initial factor structure, and relationships with benefit finding" (2005) and Winett's "Guide to Health" study (2007). Specifically, Graves' outcome expectations survey, shortened from 60 items to 36, is based on Bandura's research and theory. Using a 5-point Likert scale, ranging from *strongly disagree* to *strongly agree*, participants are asked about their outcome expectations based on learning about cancer and its treatment, having a positive attitude, and setting goals. Graves reported alphas ranging from .62 to .82 specific to scales chosen for use in the current study (Graves et al., 2003, Graves & Carter, 2005). The nutrition and PA outcome expectation sections of Winett's *Health Beliefs Survey* were also used to measure participants' outcome expectations based on their diet and PA behaviors.

#### **Outcome variable.**

***Health behavior change (Appendix K).*** As there are currently no health behavior change questionnaires developed for use with cancer populations, previously validated health behavior change questions, based upon the *Transtheoretical Model* of behavior change

(Prochaska, 1998), were tailored for use in the current study. The large majority of these questions were used in Harper and colleagues' research detailed in "The role of social cognitive processing theory and optimism in positive psychosocial and physical behavior change after cancer diagnosis and treatment" (2007). Specifically, questions ask participants about various health behaviors with regard to nutrition and PA, and whether there have been any changes in these behaviors since their cancer diagnosis and treatment (Harper et al., 2007). Several questions were added to assess changes in duration and intensity of PA behaviors as well as specific dietary behaviors (e.g., fast-food, soft drink and candy, and alcohol consumption).

### **3.5 Procedure**

Participants completed an online survey, lasting approximately 45-60 minutes, about their cancer experience, subsequent adjustment, and lifestyle behaviors. Although all participants preferred to complete the survey online, the researcher was prepared to provide alternative options for anyone who did not have online access or wished not to complete the survey online.

In addition to the online questionnaire, the entire sample of participants were invited to participate in a 10- to 15-minute follow-up telephone interview. This telephone interview involved open-ended qualitative questions about the timing of genetic counseling, family communication, the role of health behaviors in cancer risk levels, treatment and decision satisfaction, and support group involvement. Thus, the purpose of this qualitative follow-up interview was to get a more personal, in depth snapshot of the participant's cancer survivorship experience.

Institutional Review Board (IRB) approval was obtained through GU and VT. Dr. Kristi Graves has served as a sponsor and co-investigator of the project. In regard to GU's IRB, Dr. Graves is listed as the Principal Investigator, however, Sarah Kelleher prepared the IRB

documents, which were then reviewed by Dr. Graves prior to submission. Approval at VT was not contingent upon approval at GU, therefore VT approval was sought first. The researchers also submitted a HIPAA waiver in order to ensure confidentiality and protection of participants' privacy. Following IRB approval, informed consent was obtained from each participant for completion of the online questionnaire as well as the follow-up telephone interview. Participants were compensated with a \$10 gift card to one of several vendors (i.e., Amazon.com, Borders Books & Music, Target).

## 4. Results

### 4.1 Quantitative Data

The current study is *exploratory* and the results are based on a small sample size ( $n = 20$ ). As such, higher-level statistical analyses (e.g., multiple regression) were not conducted due to a lack of fit with the current data set. Instead, conducting multiple basic analyses (i.e., correlations, *t*-tests, Analysis of Variance [ANOVA]) was deemed more appropriate to best fit the data set, sample size, and exploratory purpose of the study. Likewise, given the exploratory nature of the study, *alpha*-inflation correction procedures were not used to account for the higher likelihood of finding significance due to chance.

#### **Sociodemographics.**

Quantitative data were collected through an online survey which asked participants questions about their thoughts, attitudes, and perceptions toward their CRC diagnosis, follow-up care, and past and present health behaviors, specifically diet and PA. Sociodemographic data are presented in Table 1. The final sample included 20 participants (18 women and 2 men; 95% Caucasian and 5% Asian) between ages 33-69 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, and had an annual household income equal to or higher than \$100,001.

### **Clinical health and risk management.**

Clinical and risk management information is presented in Table 2. The average age of CRC diagnosis was 43 (Range = 29-61 years), and 6 participants (30%) reported being diagnosed with at least one other type of cancer besides CRC. The majority of the participants that reported a secondary cancer diagnosis ( $n = 4$ ; 67%) reported also being diagnosed with breast cancer. In addition, 8 participants (40%) reported a family history of CRC; four participants (20%) indicated having 2 or more relatives who had a CRC diagnosis, while another 4 (20%) reported having 1 relative with CRC. Participants age 50 or older, or with a family history of CRC, were asked about screening behaviors. 55% of these participants reported having a colonoscopy in the last 10 years. Furthermore, 25% of this subset also reported other types of surveillance in the past 5 years (e.g., flexible sigmoidoscopy, double contrast barium enema, stool DNA test, or virtual colonoscopy), with 10% reporting a fecal occult blood test (FOBT) or fecal immunochemical test (FIT) in the past year. With regard to CRC treatment, 14 participants (70%) reported receiving chemotherapy, while 3 participants (15%) indicated that they had radiation treatment. All 20 participants had HNPCC genetic counseling, and 17 participants (85%) reported undergoing genetic testing for HNPCC, however, data on genetic testing results were not systematically collected. More specifically, although many participants mentioned their HNPCC carrier status during the telephone interview, this question was not a question included in the survey measures.

Just over half (55%;  $n = 11$ ) of the participants reported that their treating oncologist worked with them to develop “Survivorship Care Plans.” When asked about health

recommendations made by the oncologist, 12 participants (60%) reported that their oncologist made recommendations regarding PA practices, and 6 (30%) indicated that their oncologist made dietary recommendations. Four participants (20%) reported that their oncologist made both PA and dietary recommendations. When asked to specify these recommendations, participants reported that their oncologists made general recommendations to “stay fit.” For example, 4 participants explicitly stated that their oncologists were “not specific” in their PA recommendations, 3 participants indicated that their oncologist recommended 30 minutes of daily exercise, and 1 participant reported that his or her oncologist suggested 45 minutes of daily PA. With regard to diet, 4 participants (20%) noted their oncologists recommended a high fiber/low fat diet. Fifteen participants (75%) reported that their oncologists did not make any recommendations regarding alcohol consumption. While 14 participants (70%) reported that they do not smoke, 2 (10%) indicated that their oncologist recommended that they quit smoking, while 2 (10%) reported that their oncologist did not make any recommendations regarding smoking.

**Psychological measures: Reliability and descriptive statistics (Tables 3 and 4).**

Reliability statistics for each of the psychosocial and social cognitive scales are presented in Table 3. Overall, the psychological measures demonstrated high internal consistency with most Cronbach’s *alpha* coefficients between .80 - .97, and the lowest being .68. Descriptive statistics (e.g., minimum, maximum, mean, standard deviation) for the social cognitive and psychosocial measures are found in Table 4.

**Pearson product moment correlations.**

Pearson product moment correlations among the social cognitive and psychosocial variables of interest are presented in Tables 5 and 6.

***Distress.*** Greater general distress was significantly ( $p$  values  $< .05$ ) related to lower scores for a number of study variables: QoL ( $r = -.749$ ), resilience ( $r = -.523$ ), self-efficacy for diet and PA ( $r = -.469$ ), self-efficacy for medical care ( $r = -.669$ ), self-regulation for a cancer diagnosis and treatment ( $r = -.543$ ), and outcome expectations regarding a cancer diagnosis and treatment ( $r = -.716$ ), indicating that a decrease in general distress is associated with an increase in these other measures. Individuals who reported less general distress also tended to exhibit greater health and well being on other related social cognitive and psychosocial constructs. In addition, cancer-related distress was significantly associated with the number of years post-CRC diagnosis ( $r = -.486$ ), suggesting that greater time since CRC diagnosis and treatment was associated with lower cancer-specific distress.

***Resilience, social cognitive variables, and quality of life.*** Significant positive correlations were found between resilience and self-regulation related to managing a cancer diagnosis and treatment ( $r = .620$ ), PA self-regulation ( $r = .621$ ), and positive outcome expectations for PA ( $r = .572$ ), indicating that greater resilience is associated with greater self-regulatory abilities and more positive outcome expectations regarding PA behaviors. In addition, significant positive correlations were found between QoL and the following variables: resilience ( $r = .603$ ), self-efficacy ( $r = .741$ ;  $r = .610$ ) and self-regulation ( $r = .726$ ) related to managing a cancer diagnosis and treatment, and positive outcome expectations regarding PA ( $r = .666$ ) and managing a cancer diagnosis and treatment ( $r = .765$ ), indicating that a higher QoL is correlated with an increase in these other psychosocial constructs. Together, these results indicate that greater well-being is associated with higher psychosocial functioning, marked by greater self-regulatory skills and confidence in one's ability to manage a cancer diagnosis and treatment, as well as more positive outcome expectations regarding management of the diagnosis and

treatment process. In contrast, a significant positive association was found between cancer-related distress and self-regulation for PA ( $r = .520$ ), suggesting that individuals who experienced greater cancer-related distress demonstrated higher self-regulatory skills for PA.

***Risk perception.*** Relationships between risk perception and the social cognitive and other psychosocial variables are presented in Table 6. Specifically, both absolute perceived risk ( $r = .707$ ) and numeric perceived risk ( $r = .663$ ) were positively correlated with distress, indicating that an increase in perceived risk for developing CRC again is associated with a significant increase in general distress. In addition, absolute ( $r = -.691$ ) and numeric perceived risk ( $r = -.548$ ) were both negatively correlated with QoL, suggesting that an increase in perceived risk for developing another CRC is associated with a significant decrease in QoL. Furthermore, absolute perceived risk was negatively correlated with resilience ( $r = -.554$ ) and self-regulation for managing a cancer diagnosis and treatment ( $r = -.502$ ), suggesting that an increase in perceived risk is associated with a significant decrease in resilience and self-regulation related to cancer diagnosis and treatment management. Comparative perceived risk - or likelihood of developing another CRC diagnosis compared with other CRC survivors - was not found to be correlated with any of the social cognitive or psychosocial variables. None of the risk perception items were significantly correlated with the number of years post-CRC diagnosis. Overall, the associations between the perceived risk items and social cognitive and psychosocial constructs indicate that the greater the perceived risk of developing another CRC, the lower the psychosocial functioning and emotional well-being.

***Social cognitive variables.*** As expected, the social cognitive variables were strongly correlated with one another. For example, self-efficacy regarding managing one's cancer diagnosis and treatment was significantly correlated with diet and PA self-efficacy ( $r =$

.622), self-regulation for a cancer diagnosis and treatment ( $r = .787$ ), and positive outcome expectations regarding a cancer diagnosis and treatment ( $r = .858$ ), diet ( $r = .809$ ), and PA ( $r = .710$ ). Specifically, an increase in self-efficacy regarding an individual's cancer diagnosis and treatment management was associated with an increase in these other social cognitive measures. In addition, significant positive correlations were found between diet and PA self-efficacy and the following variables: self-efficacy regarding medical care ( $r = .555$ ), PA self-regulation ( $r = .486$ ), and positive outcome expectations regarding an individual's cancer diagnosis and treatment ( $r = .732$ ). Self-efficacy regarding medical care was also positively correlated with positive outcome expectations regarding managing a cancer diagnosis and treatment ( $r = .759$ ) as well as positive outcome expectations for PA ( $r = .536$ ). Furthermore, self-regulation for managing a cancer diagnosis and treatment was correlated with all three positive outcome expectation measures (cancer diagnosis and treatment [ $r = .901$ ], diet [ $r = .620$ ], PA [ $r = .656$ ]). Finally, positive outcome expectations regarding an individual's cancer diagnosis and treatment were significantly positively associated with the other two positive outcome expectation measures (diet [ $r = .678$ ], PA [ $r = .841$ ]). Overall, the correlations among social cognitive variables indicate that different types of self-efficacy are associated with some forms of self-regulatory ability and positive outcome expectations, suggesting that those with higher self-efficacy also tend to demonstrate higher self-regulation and more positive outcome expectations.

#### **Health behavior change group differences across variables of interest.**

*Frequency of health behavior changes.* The frequency of health behavior change among our high-risk CRC participants was evaluated. These health behavior change variables were broken down into the following categories: (i) the amount of time engaged in PA; (ii) the intensity of PA; (iii) the number of days eating a healthful diet; (iv) the amount of alcohol

consumed each week; (v) the number of fast-food meals consumed each week; and (vi) soft drink and candy intake.

Reports of participants who indicated that they did not change their health behaviors also were assessed. Upon examination, the group reporting no change in behavior was quite heterogeneous, as reports of no change appeared to be due to a number of different reasons. For example, some participants who did not change their PA behaviors reported engaging in high levels of PA in terms of frequency both before and after their CRC diagnosis. Conversely, some of these participants reported not engaging in regular PA at any level. Because these participants were found to not be comparable in their health behaviors, analyses on this group were conducted separately (see *No Change Group Frequencies* section below).

*Physical activity.* Six participants (30%) reported *increasing* the amount of time engaged in PA and 4 participants (20%) reported *decreasing* the amount of time engaged in PA, while 10 participants [50%] reported no change in time spent engaging in PA since their CRC diagnosis (Note: 14 participants [70%] reported no change in *either* the amount of time spent engaging in PA *or* the intensity of their PA post-diagnosis).

*Diet.* Seven participants (35%) reported *increasing* the number of days they eat a healthful diet and 2 participants (10%) reported *decreasing* the number of days they eat a healthful diet (Note: 9 participants [45%] reported no change in the number of days they eat a healthful diet post-diagnosis).

*Alcohol consumption.* One participant (5%) reported *increasing* alcohol consumption post-diagnosis, while 7 participants (35%) reported *decreasing* alcohol consumption following their CRC diagnosis (Note: 12 participants [60%] reported no change in alcohol consumption post-diagnosis).

*Fast-food and soft drink and candy consumption.* No participants reported *increasing* either their fast-food or soft drink and candy consumption following their CRC diagnosis. Six participants (30%) reported *decreasing* fast-food consumption since their diagnosis, and 8 participants (40%) reported *decreasing* soft drink and candy consumption post-diagnosis (Note: 14 participants [70%] reported no change in fast-food consumption and 11 participants [55%] reported no change in soft drink and candy consumption post-diagnosis).

***Relationship of social cognitive variables to post-diagnosis behavior change.***

Independent *t*-tests were used to determine whether there were mean differences in the psychological variables between participants who *increased* positive health behaviors since their cancer diagnosis and participants who *decreased* positive health behaviors since their diagnosis.

*Physical activity.* For the amount of time spent engaging in PA, independent *t*-tests revealed no trends or significant differences between individuals who increased and those who decreased the amount of time engaged in PA across each of the psychological variables of interest. For intensity of PA, independent *t*-tests revealed a trend toward significance, indicating that individuals who increased the intensity of PA reported lower self-regulation of diet ( $M = 112.50, SD = .707$ ), while individuals who decreased the intensity of PA reported higher self-regulation of diet ( $M = 128.50, SD = 7.85$ ),  $t(4) = -2.713, p = .053$ , two-tailed test. Two participants (10%) reported increasing the intensity of PA and 5 (25%) reported decreasing (Note: 12 participants [60%] reported no change in the intensity of PA).

*Diet.* For the number of days spent eating a healthful diet, independent *t*-tests revealed no trends or significant differences across each of the psychological variables for individuals who have increased and those who have decreased the number of days eating a healthful diet.

*Alcohol consumption.* With regard to weekly alcohol consumption, independent *t*-tests revealed several significant relationships which are presented in Table 7; however, because the *increased* alcohol consumption group is comprised of just 1 participant and thus the findings should be interpreted with caution, only the most striking results will be presented. A significant difference for overall distress, indicating that individuals who increased weekly alcohol consumption reported higher general distress ( $M = 24.00$ ), while those who decreased their weekly alcohol consumption reported lower general distress ( $M = 13.29$ ,  $SD = 3.45$ ),  $t(6) = 2.905$ ,  $p < .05$ , two-tailed test. Independent *t*-tests also revealed a significant difference for self-efficacy regarding diet and PA, indicating that individuals who increased weekly alcohol consumption reported lower diet and PA self-efficacy ( $M = 38.00$ ), while those who decreased their weekly alcohol consumption reported higher diet and PA self-efficacy ( $M = 85.00$ ,  $SD = 9.21$ ),  $t(5) = -4.725$ ,  $p < .01$ , two-tailed test. In addition, independent *t*-tests revealed a significant difference for PA self-regulation, indicating that individuals who increased weekly alcohol consumption reported lower PA self-regulation ( $M = 18.00$ ), while those who decreased their weekly alcohol consumption reported higher PA self-regulation ( $M = 56.71$ ,  $SD = 12.39$ ),  $t(6) = -2.922$ ,  $p < .05$ , two-tailed test.

Overall, changes in alcohol consumption were found to be significantly associated with many of the social cognitive and psychosocial variables (i.e., general distress, QoL, self-efficacy for medical care, and diet and PA, PA self-regulation, and outcome expectations related to having a positive attitude), indicating that greater distress and poorer QoL, as well as lower self-efficacy and self-regulation, was associated with an increase in alcohol consumption post diagnosis and treatment. As noted, only one participant reported *increased* weekly alcohol consumption, therefore these results should be interpreted with caution.

*Fast-food and soft drink and candy consumption.* For weekly fast-food consumption as well as soft drink and candy consumption, independent *t*-tests could not be completed because no participants endorsed increasing either weekly fast-food intake or soft drink and candy consumption.

**No change group frequencies (Table 8).**

As noted above, participants who reported not making any health behaviors changes since their CRC diagnosis were quite heterogeneous and thus their survey responses were evaluated separately from participants who reported increases or decreases in the health behaviors. Specifically, survey responses were probed for this group of participants to determine the prevalence and frequency of their health behaviors pre-CRC diagnosis. 14 participants (70% of the total sample) reported not changing *either* the amount of time spent engaging in PA *or* the intensity of their PA since their diagnoses. Of these 14 participants, 3 (21.4%) indicated engaging in PA less than 5 times per month, 3 (21.4%) reported 6-10 times per month, 2 (14.3%) indicated 11-15 times per month, 1 (7.1%) endorsed 16-20 times per month, and 5 (35.7%) reported engaging in PA 26-30 times per month. Thus, although about 43% ( $n = 6$ ) of this no change group was already engaging in frequent PA prior to their CRC diagnosis, the majority of these individuals ( $n = 8$ ; 57%) have been engaging in PA *less than half of each month*. In addition, of the 14 participants in this no change group, approximately 7% ( $n = 1$ ) reported engaging in PA for 16-30 minutes at a time, about 43% ( $n = 6$ ) indicated engaging in PA for 31-45 minutes at a time, 36% ( $n = 5$ ) reported engaging in PA for 46-60 minutes, 7% ( $n = 1$ ) endorsed engaging in PA for 61-75 minutes at a time, and 7% ( $n = 1$ ) reported engaging in PA greater than 90 minutes. Therefore, although the majority of participants are engaging in the

recommended duration of PA (i.e., at least 30 minutes at a time), participants are falling short of the recommended frequency in which they engage in PA (i.e., 5 days per week; ACS, 2010).

For participants who reported not changing the number of days spent eating a healthful diet ( $n = 9$ ; 45% of total sample), 45.5% ( $n = 5$ ) endorsed eating a healthful diet 26-31 days per month, while 9.1% ( $n = 1$ ) indicated 21-25 days per month, 18.2% ( $n = 2$ ) reported 16-20 days per month, and another 9.1% ( $n = 1$ ) reported 6-10 days per month. Therefore, with the exception of a few participants, the majority of this no change group had already been eating a healthful diet for most days each month since before their CRC diagnosis and treatment. Finally, 60% ( $n = 12$ ) reported no change in alcohol consumption since their CRC diagnosis, while 70% ( $n = 14$ ) reported no change in fast-food consumption and 55% ( $n = 11$ ) reported no change in soft drink and candy consumption.

#### **Health behavior group comparisons across variables (Tables 9-11 & Figures 1-3).**

A one-way ANOVA was conducted to detect group differences in psychological measures across the number of times per month spent engaging in PA. The PA groups examined in this ANOVA consisted of participants who reported engaging in PA for one of the following timeframes: Less than 5 times per month, 6-10 times per month, 11-15 times per month, 16-20 times per month, 21-25 times per month, 26-30, and greater than 31 times per month. The ANOVA yielded a trend toward significance between the number of times spent engaging in PA and the emotional well-being subscale of the QoL measure,  $F(6, 13) = 2.699$ ,  $p = .063$ . Although post-hoc analyses could not be completed due to a low number of participants in a few of the cells, examination of group means on the emotional well-being subscale revealed that individuals engaging in PA greater than 31 times per month reported the lowest emotional well-being ( $M = 12.00$ ,  $SD = 0$ ) when compared to other participants who reported engaging in PA at least 6-10

times per month ( $M = 21.00$ ,  $SD = 1.00$ ) and less than 26-30 times per month ( $M = 22.20$ ,  $SD = 1.789$ ). Participants who reported engaging in PA 16-20 times per month reported the highest emotional well-being on the QoL measure ( $M = 24.00$ ,  $SD = 0$ ). No other trends or significant differences were found in psychological measures across the number of times spent engaging in PA per month.

A one-way ANOVA was also conducted to detect group differences in psychological measures across the amount of time spent engaging in PA. The results of the ANOVA yielded a significant group difference in the social and family well-being subscale of the QoL measure,  $F(4, 13) = 3.360$ ,  $p < .05$ . However, post-hoc analyses could not be completed due to at least one group category having fewer than two cases. Upon review of the group means across this social and family well-being subscale, it was found that participants who reported engaging in greater than 90 minutes of PA reported the lowest social and family well-being ( $M = 13.00$ ,  $SD = 0$ ) compared to all other group participants, whose mean scores ranged from 21.00 ( $SD = 2.828$ ; 16-20 minutes of PA) to 25.20 ( $SD = 1.924$ ; 46-60 minutes of PA). The ANOVA also yielded a significant group difference in medical care self-efficacy,  $F(4, 13) = 3.180$ ,  $p = .05$ , as well as PA self-regulation,  $F(4, 14) = 4.772$ ,  $p < .05$ . Although post-hoc comparisons could not be completed due to at least one group category having fewer than two cases, group means were examined across these social cognitive variables. Participants who reported engaging in PA for greater than 90 minutes at a time had the lowest medical care self-efficacy ( $M = 38.00$ ,  $SD = 0$ ) compared to other group participants, whose mean scores ranged from 47.00 ( $SD = 5.19$ ; 16-30 minutes) to 50.00 ( $SD = 0$ ; 61-75 minutes). Additionally, participants who reported engaging in PA for either the shortest amount of time (i.e., 16-30 minutes;  $M = 28.00$ ,  $SD = 11.136$ ) or the longest amount of time (i.e., greater than 90 minutes;  $M = 31.00$ ,  $SD = 0$ ) reported the lowest

level of PA self-regulation compared to other group participants, whose mean responses ranged from 44.71 ( $SD = 10.67$ ; 31-45 minutes) to 66.00 ( $SD = 2.83$ ; 61-75 minutes). Of note, the aforementioned results should be interpreted with caution, as only one participant reported engaging in PA for greater than 31 times per month and a different participant reported engaging in PA for greater than 90 minutes at a time.

Finally, a one-way ANOVA was conducted to detect group differences in psychological measures across the number of days per month spent eating a healthful diet. The ANOVA yielded a significant group difference in positive diet outcome expectations across the number of days per month spent eating a health diet,  $F(4, 11) = 5.497, p < .05$ . As above, post-hoc analyses could not be completed due to at least one group category having fewer than two cases; however, group means were examined for this social cognitive variable. Participants who reported eating a healthful diet for 26-31 days per month had the most positive outcome expectations regarding their healthful dietary practices ( $M = 94.00, SD = 7.52$ ) compared to other group participants, such as those who reported eating a healthful diet for approximately 16-20 days per month ( $M = 75.00, SD = 7.35$ ). No other significant group differences were detected.

#### **4.2 Summary of Quantitative Results**

The results of the quantitative survey suggest that, at the bivariate level, many of the psychosocial and social cognitive variables of interest are significantly associated with one another as well as with various health behaviors and health behavior changes. Correlational data indicate that lower distress is associated with higher psychosocial functioning, self-efficacy, and self-regulatory ability in this high-risk CRC sample. In addition, the present data also suggest that individuals with higher self-efficacy also tend to display higher self-regulation and more positive outcome expectations. Overall, participants were more likely to increase healthy

behaviors or remain consistent with healthy lifestyles practiced prior to their CRC diagnosis and treatment, and decrease unhealthy behaviors (e.g., alcohol, soft drink, candy, and fast-food consumption). This finding implies that although there are areas for growth in terms of healthy lifestyle practices, this high-risk sample of CRC survivors is a moderately health-conscious group.

No significant differences were found between individuals who increased and decreased the amount of time spent engaging in PA or the number of days spent eating a healthful diet across the variables of interest. In contrast, a trend was found for those who changed the intensity of PA—participants who increased the intensity of PA reported lower self-regulation of diet, while those who decreased the intensity of PA reported higher self-regulation of diet. Changes in alcohol consumption were found to be significantly associated with many of the psychosocial and social cognitive variables (e.g., general distress, QoL, self-efficacy for diet and PA, and PA self-regulation), indicating that greater distress and poorer QoL, as well as lower self-efficacy and self-regulation were associated with an increase in alcohol consumption post diagnosis and treatment. As noted, these results should be interpreted with caution since they are based on one participant who reported an increase in alcohol consumption post-diagnosis.

Although the majority of participants who reported no change in the time or intensity of their PA practices appear to be meeting ACS guidelines (2010) for PA duration because they reported engaging in PA for at least 30-60 minutes at a time, more than half of this group did not appear to meet the ACS recommended frequency of PA (i.e., 5 or more days per week; 2010), because they reported engaging in exercise approximately 3 times per week. Furthermore, the majority of group of participants who indicated no change in the number of days spent eating a healthful diet, reported eating a healthful diet for most days each month since before their CRC

diagnosis and treatment.

Results examining group differences in psychological measures across the number of days per month spent engaging in PA did not yield significant results, however, significant group differences were found across the amount of time spent engaging in PA and several variables of interest. Specifically, group differences for the amount of time spent engaging in PA were found across the social and family well-being subscale of the QoL measure, medical care self-efficacy, and PA self-regulation. Although post-hoc analyses could not be conducted, examination of these results revealed that participants who reported engaging in PA for a moderate number of times (e.g., 16-20 times per month) and time (e.g., 46-60 minutes) had the highest QoL (i.e., QoL regarding emotional and social and family well-being), medical care self-efficacy, and PA self-regulation. In contrast, those who reported engaging in either the least frequent/shortest duration or the most frequent/longest duration had the lowest QoL (i.e., with regard to emotional and social and family well-being), medical care self-efficacy, and PA self-regulation, resulting in an upside-down U-shaped curve. Participants who reported eating a healthful diet for most, if not all days of the month, reported the most positive outcome expectations regarding their healthful dietary practices. Taken together, these results indicate that both moderate levels of PA and higher levels of dietary adherence were associated with higher scores on several social cognitive measures.

### **4.3 Qualitative Data**

Qualitative data was collected during a follow-up telephone interview in which participants were asked open-ended questions about the timing of genetic counseling, family communication, the role of health behaviors in cancer risk levels, treatment and decision satisfaction and support group involvement. Participants' responses to open ended questions

were grouped based on identified themes, while dichotomous responses were tallied (see Table 12). Of the 20 total participants, 17 (15 women and 2 men; 100% Caucasian) individuals between the ages of 33-69 years old consented to and completed this qualitative telephone interview.

In response to the first question about the timeframe in which participants pursued HNPCC genetic counseling, all 17 participants indicated that it occurred *after* they received their CRC diagnosis. In addition, 12 participants reported that they were referred for genetic counseling by their oncologist, 2 by their surgeon, 2 by their Gastroenterologist (GI physician), 1 by a family member, and 1 by a workplace nurse.

When asked whether they discussed their cancer diagnosis and/or HNPCC risk status with family members, 9 participants indicated that they discussed these issues and events openly with all family members. Four participants reported that they discussed their diagnosis and HNPCC risk status with most family members, with the exception of elderly/ill parents/grandparents and/or young children. Three participants stated that they discussed this information with all relatives with the exception of estranged family member(s), and 1 participant reported not communicating this information to family members due to a belief that it was unnecessary or unimportant. In response to a follow-up question regarding the types of issues and/or concerns discussed with their family, participants provided 46 total responses, from which 7 themes were identified: (1) Informative, fact-based discussions; (2) Emphasis on screening behaviors; (3) Alert to possibility/reality of hereditary cancer risk; (4) Life stage issues; (5) Logistical issues; (6) Insurance/healthcare concerns; (7) Relevant research. Overall, participants' affective response to this line of questions was quite positive. Participants generally

sounded at ease describing their familial communication and appeared to candidly report on their experiences.

Of the 7 themes, 13 responses (28.3% of total responses for this theme) referred to informative, fact-based discussions of diagnosis and treatment, such as stage of diagnosis and survival rate, as well as decision-making regarding treatment options (i.e., surgery, chemotherapy). For example, one participant noted, “My family and I had ongoing discussions about the details of my diagnosis and surgical options.” Another explained, “We discussed prognosis, treatment decisions, and what to expect regarding the recovery process.” In addition, 11 responses (23.9% of responses for this theme) referred to discussions about screening behaviors (e.g., encouraging relatives to pursue screening or increase the frequency with which they get screened; Example statement: “Once I learned about my diagnosis and risks, I encouraged others in my family to increase their screening or start screening at a younger age.”). Fifteen participants (32.6% of responses for this theme) reported alerting family members to the possibility or reality of hereditary cancer risk and/or personally recommending that their relatives pursue genetic counseling/testing (Example statement: “We talked about family risk status so others would know they could be at risk.”). One response (2.2% of responses for this theme) referred to life stage issues and specifically related to discussions with a spouse about the impact of the diagnosis and treatment on plans to start a family. Three responses (6.5% of responses for this theme) referred to discussions about insurance and/or healthcare concerns, while 1 response (2.2% of responses for this theme) referred to discussions surrounding logistical issues (e.g., coordination of schedules in order to ensure attendance at medical appointments). Two participants (4.3% of responses for this theme) reported discussing relevant research findings (e.g., research about factors, such as various health behaviors, shown to prevent and reduce

cancer risk, and treatment and survival outcomes) with family members. One participant's story was particularly compelling. She described, "I talked about everything with everybody very openly. We discussed the hereditary nature of my cancer, my family's risk, surgical decisions, genetic testing, and how my course of treatment would be significantly affected by my genetic counseling and testing. Everyone was very involved with these discussions and my decision-making. We also talked a lot about life issues, like starting a family. I am fairly young and I was deciding whether to have a hysterectomy. Since that would induce menopause, there were major implications to consider. We talked about some really serious, heavy issues."

Next, participants were asked whether they have discussed the importance of health behaviors (i.e., healthful diet, regular PA) with their family members. At times, participants seemed to react somewhat sensitively to this line of questions. More specifically, it was clear that discussion of health and lifestyle behaviors is a personal issue that is not always easy to discuss openly, although participants appeared to respond with sincerity. Many admitted making significant improvements in health behaviors since their 20s and 30s. Almost all participants (n = 15) indicated that they have discussed the importance of health behaviors with family members, while 2 participants reported that they have not. One participant who denied having this discussion with family members explained, "My family is already very athletic and fit, and they pride themselves on their fitness and healthy lifestyles. No one is overweight and everyone values health. We've never really talked about it, though. It's just what we all do."

When asked about common viewpoints regarding health behaviors in participants' families, 28 total responses comprising 4 themes emerged: (1) General familial emphasis on leading healthy lifestyle; (2) Healthy lifestyle considered a form of prevention and risk reduction; (3) Ongoing struggle to close the gap between what they feel they "should" be doing

and what they are doing; (4) Emphasis on mental health and stress reduction rather than diet and exercise practices. Seventeen responses (60.7% of total responses for this theme) referred to a general familial emphasis and value on healthy lifestyle behaviors (Example statement: “Being healthy is basically a way of life for us.”; “Leading a healthy lifestyle has always just been the norm.”; “We tend to follow the motto: everything in moderation.”), while 4 responses (14.3% of responses for this theme) indicated that participants and their families view a healthy lifestyle as a form of prevention and risk reduction for future health problems, additionally noting its facilitating role in recovery from illness or injury. In addition, 6 responses (21.4% of responses for this theme) referred to an ongoing struggle to decrease the discrepancy between current lifestyle practices and what they believe they “should” be doing. For example, one participant explained, “We’ve discussed what we should be doing and we all have a mentality of encouraging healthy living, but following through is much more difficult.” Another participant stated, “We know diet and exercise are important, but we often have to discuss how we can make it happen. Although we’re generally healthy, we do have our weaknesses.” Similarly, another participant noted, “Although we’re all generally in good shape, there is some discrepancy between what we do and what we should be doing.” Furthermore, 1 participant (3.6% of responses for this theme) distinguished psychological health and stress from health behaviors through a report of greater familial concern for mental health and stress reduction (e.g., managing a busy work schedule) than for diet and exercise practices.

Participants were then asked how important they think healthy lifestyle behaviors are as related to their risk for recurrence and/or new primary diagnoses. These questions were asked based on the knowledge participants gained from their genetic counseling experience, and if applicable, their specific genetic testing results. Many participants responded to these questions

with enthusiasm and conviction. With the exception of a few who noted uncertainty and skepticism, it was apparent that most participants held fairly strong beliefs about how health behaviors could affect their risk for cancer. Comprised of 18 total responses, 4 general themes were identified in response to this question: (1) Health behaviors are very important for prevention, risk reduction, and recovery; (2) Healthy lifestyle behaviors are important, but “not the whole pie”; (3) Health behaviors are generally very important, but likely won’t impact personal risk due to a genetic predisposition; (4) Healthy lifestyles behaviors are generally important, but uncertainty remains regarding impact on risk.

Eight responses (44.4% of responses for this theme) referred to a belief that healthy lifestyle behaviors are very important for prevention, risk reduction, and/or the recovery process (Example statement: “I think healthy lifestyle behaviors are extremely important in reducing risk and minimizing the impact of treatment. If I do go through this again, I think it would lead to a speedier and stronger recovery.”), and 2 responses (11.1% of responses for this theme) indicated recognition that although healthy lifestyle behaviors are an important component in cancer risk, there are other influential factors, too (Example statement: “Among other factors, diet and exercise are important components in minimizing risk, but they’re not the whole pie. There are other environmental and biological factors, too.”). Five participants (27.8% of responses for this theme) who reported positive HNPCC genetic test results and cited the hereditary nature of their cancer appeared to hold beliefs that although healthy lifestyle behaviors are generally very important, they did not perceive that these behaviors would impact their risk level. For example, one participant reported, “Health behaviors are somewhat important, but my focus is on genetics as the primary determinant. Diet and PA are not likely to turn the tide in my case.” Another participant explained, “Healthy behaviors are important, but based on my genetic test results, I

am basically 100% likely to have a recurrence, regardless of diet and exercise, therefore it's maybe not as important in my case." Three participants (16.7% of responses for this theme) indicated that while they believed health behaviors are generally important, they admitted uncertainty about how engaging in these behaviors might affect their risk for cancer (Example statement: "Nothing is absolute. Should I be doing it regardless? Yes. How much will it matter? I don't know.").

In addition, participants were asked about treatment and decision-making satisfaction. The 17 participants who completed the telephone interview indicated that they were satisfied with the treatment they received for their cancer diagnosis, and all 17 similarly noted satisfaction with their personal decisions regarding treatment. Overall, these individuals demonstrated positive affect as they responded without hesitation and with great enthusiasm. Furthermore, many participants reported being impressed with their team of doctors and feeling grateful for the level of care and support they received throughout their surgery and treatment experiences. However, of these 17 individuals, 3 spontaneously reported dissatisfaction or disappointment with the quantity and quality of aftercare received. These 3 participants sounded somewhat disheartened as they specified that they would have liked to have received follow-up in terms of general health recommendations, "signs" to look for to detect health problems, and resources for mental health services.

Finally, participants were asked about involvement in support groups for cancer survivors. Six of the 17 participants indicated past or present involvement in a support group for cancer survivors (Note: groups were reported to be online and in person at area hospitals such as GU, Inova Fairfax, and Washington Hospital Center), including 2 participants who noted involvement in other types of support groups (e.g., a psychotherapy support group). Of the 6 who

have participated in a support group, 1 indicated that she learned of this support opportunity from a physician, 4 indicated that they learned of this opportunity through a personal search, and 1 reported a referral from a friend. Furthermore, all 6 described experiencing significant benefit as a result of their involvement in this form of support. Specifically, when asked whether it was a beneficial experience, several participants quickly endorsed feeling glad to have had this support opportunity due to its helpfulness with overall coping and adjustment. Of the 11 participants who reported no involvement, 8 indicated that they did not feel the need or were not interested in pursuing this type of support, while many cited family and friends as a beneficial and sufficient support system. In addition, 2 explained that they did not want to talk about their diagnoses any more than was already necessary. Two individuals reported interest, but a lack of involvement due to scheduling issues (e.g., time commitment, work schedule), and 2 participants noted demographic and/or individual differences as a reason for not pursuing this type of support.

#### **4.4 Summary of Qualitative Results**

Participants who completed the qualitative interview were largely pleased with the care they received during their cancer treatment; however, follow-up care was less satisfactory in a few cases, particularly as related to the absence of discussions about health and lifestyle recommendations, detection strategies, and mental health resources. Among participants in the current study, the oncologist was reportedly the most common genetic counseling referral source. Most participants cited the benefits of engaging in health behaviors, yet several believed that exercising or eating a healthful diet may not significantly impact their overall disease risk due to the hereditary basis of their cancer. In the present sample, most participants appear to have good communication amongst family members, except in cases where concerns were raised about a relative's ability to understand the information or a lack of necessity due to relatives' age.

Although the majority of this sample did not report involvement in a support group, those that did indicated a significant personal benefit. Overall, participants were well-informed about the general importance of healthy lifestyle behaviors, but several appeared to be skeptical about the potential benefits of engaging in such behaviors.

## **5. Discussion**

Global health researchers recently reported 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 as well as the dire need to increase the evidence base and enhance our understanding of the factors associated with health promotion and disease prevention in individuals at risk for cancer and other diseases. Over the past decade, behavioral health researchers have paid increased attention to health behaviors in various cancer survivor populations, with the notable exception of investigation into the factors associated with health behavior change among cancer survivors who are at increased risk due to their personal and family cancer history. Thus, the current study explored potential predictors (i.e., social cognitive and psychosocial variables) of lifestyle changes, including diet and PA behaviors, in a sample of CRC survivors at high risk of developing a second CRC and other cancers. The primary goal of this *exploratory* study was hypothesis generation. Specifically, this study aimed to generate hypotheses regarding whether and how social cognitive and psychosocial variables are related to health behavior outcomes in a sample of genetically increased risk CRC survivors. Exploring predictors of health behaviors may help enhance the understanding of psychological and health outcomes of high-risk CRC survivors.

## 5.1 Quantitative Findings

Consistent with social cognitive theory (Bandura, 1994, 1998, 2004) and research conducted in adult and general cancer survivor populations (Anderson et al., 2006, 2007; Graves & Carter, 2005; James et al., 2006; Lev, 1997; Lev et al., 2001; Merluzzi et al., 2001; Rogers, et al., 2005; Telch & Telch, 1986; Winett et al., 2007), the results of the current study indicate that higher self-efficacy, self-regulation, and more positive outcome expectations are associated with higher psychosocial functioning (e.g., high QoL, high resilience, low levels of distress) and several health behaviors (e.g., change in intensity of PA, change in alcohol consumption, frequency and duration of PA, healthful diet consumption) in high-risk CRC survivors. Individuals who demonstrate greater mastery of social cognitive skills (e.g., self-efficacy and self-regulation) are more likely to experience less distress and exhibit higher psychosocial functioning. Unfortunately, the opposite is also true: Individuals experiencing greater difficulty with social cognitive skills may experience higher levels of distress and lower psychosocial functioning.

The clinical data collected in the current study, including early age of onset of cancer, concurrent cancers and family history of disease, reflect the high-risk status of study participants. Participants' reports of PA, healthful diet, and follow-up care plans suggest that greater research and clinical attention is needed regarding provision of comprehensive post-treatment care and health behavior prescriptions to HNPCC CRC survivors. In the general population, CRC risk increases with age (Syngal, 2000) and the mean age of CRC onset is approximately 65 years. Notably, the average age of CRC onset in the current high-risk sample (i.e., age 43) is 20 years younger than people at average risk for the disease—yet closely matches the median age of onset within the larger HNPCC population (45 years; Rodriguez-Bigas et al., 1997; Vasen et al., 1999).

In addition, the frequency of additional cancer diagnoses (30% of participants reported being diagnosed with at least one other type of cancer besides CRC) combined with participants' family history of CRC (40% of participants reported a family history of CRC) highlight the high-risk nature of this HNPCC sample and the importance of gaining a thorough understanding of post-diagnosis health practices in this population.

Surprisingly, almost half of the high-risk participants do not appear to be meeting even the minimum guidelines for CRC screening for people in the general population, as outlined by the American Cancer Society (2010): (i) a colonoscopy every 10 years; (ii) a flexible sigmoidoscopy, double contrast barium enema, stool DNA test, and virtual colonoscopy every 5 years; and (iii) a fecal occult blood test (FOBT) or fecal immunochemical test (FIT) every year (ACS, 2010). Although 55% of the current sample reported having a colonoscopy in the past 10 years, only 25% reported other types of surveillance in the past 5 years (e.g., flexible sigmoidoscopy, double contrast barium enema, stool DNA test, or virtual colonoscopy), and a small 10% reported having a fecal occult blood test (FOBT) or fecal immunochemical test (FIT) in the past year. For people in families with documented HNPCC, surveillance recommendations include colonoscopy or sigmoidoscopy every 1 to 3 years until age 60, with some clinical practices also advising addition of barium enema to these endoscopic procedures (Vasen et al., 1993; Esposito et al., 2010). Of note, these findings could have implications for the prevalence of other behavioral risk factors. Prior research has found that individuals who were not adherent to screening guidelines reported having a greater number of other behavioral risk factors for CRC (e.g., smoking, low PA, low fruit and vegetable intake, obesity, and high alcohol intake) when compared to those who were adherent (Coups et al., 2007). Therefore, it is possible that the participants in the current sample who reported not meeting surveillance guidelines—nearly half

of the sample—may also be those who experience greater difficulty adopting or maintaining adequate levels of PA and consumption of a healthful diet. The surprising results that almost half of the current sample of high risk CRC survivors are not meeting the minimum guidelines for CRC screening for the general population suggests further investigation is needed to assess physicians' post-treatment recommendations. Moreover, additional investigation is needed into the prevalence and frequency of surveillance behaviors to more accurately determine adherence rates in other high-risk samples.

Although a substantial portion of the current sample reported being provided with some form of health recommendation by their oncologist (e.g., 12 participants [60%] reported receiving PA recommendations, 6 participants [30%] indicated receiving dietary recommendations), the content of these recommendations was vague—lacking specificity or prescription. This finding further highlights the need for systematic integration of specific health behavior prescriptions into post-treatment protocol including sustained behavioral follow-up procedures for CRC patients (including both average- and high-risk survivors).

Overall, correlational relationships within the data indicate that lower distress and greater well-being (e.g., QoL, resilience) were associated with higher psychosocial functioning, marked by greater diet and PA self-efficacy, self-regulatory skills and confidence in one's ability to manage a cancer diagnosis and treatment, and more positive outcome expectations regarding the proficient management of the diagnosis and treatment process. Consistent with prior research, these findings suggest that trends related to higher-level social cognitive skills as well as beliefs associated with better psychosocial functioning found in general cancer survivor populations are similar for this sample of high-risk CRC survivors (Graves & Carter, 2005; Lev, 1997; Merluzzi & Martinez Sanchez, 1997; Telch & Telch, 1986).

Interestingly, the positive correlation between cancer-related distress and self-regulation for PA indicates that individuals who experienced greater cancer-related distress demonstrated higher self-regulatory skills for PA. Perhaps individuals engage in a greater level of PA self-regulation as a means of coping with their distress (i.e., to allay their concerns/fears regarding their diagnosis and risk). Furthermore, enhanced self-regulation might provide individuals with a sense and vehicle of control in the somewhat out-of-control situation evoked by a cancer diagnosis and treatment. These results are consistent with prior research citing PA behaviors as a way to develop a greater sense of control over one's health and well-being (American Institute for Cancer Research [AICR], 2008; Milne et al., 2007). Moreover, Costanzo (2006) reported that in a sample of breast cancer survivors, participants who had higher perceptions of control over their cancer were more likely to make other positive health behavior changes. Following a cancer diagnosis, attempting to maintain or re-gain a sense of control appears to improve overall QoL (especially psychological well-being; Ferrell & Dow, 1997). Despite this interpretation, alternative explanations should be considered. For example, it is possible that given the high-risk nature of the current sample, individuals may be turning to lifestyle behaviors as a way to regulate their distress. Given the genetic basis of their disease, it could also be that higher cancer-related distress in this sample is, in fact, separate from PA self-regulation.

Also consistent with prior research and social cognitive theory (Bandura, 1998; Graves & Carter, 2005), the high level of correlation between social cognitive variables suggests that individuals who tend to exhibit higher self-efficacy also tend to display higher self-regulation, and more positive outcome expectations. These results further indicate that individuals who hold positive expectations in one area (e.g., diet, PA) are also more likely to have more positive

expectations in other areas as well (e.g., management of a cancer diagnosis and treatment; Graves & Carter, 2005).

Similar to prior research in average-risk CRC survivors (Mullens et al., 2004), the results of the correlational data examining perceived risk indicate that for a high-risk sample of CRC survivors, greater perceived risk of developing another CRC is associated with lower psychosocial functioning and well-being. Specifically, individuals who perceive themselves at higher risk for developing another CRC are more likely to experience greater general and cancer-related distress as well as lower QoL. Novel to the present study is evidence of the association between resilience and perceived risk; individuals who perceive themselves at higher risk for another CRC also tend to exhibit less resilience. Participants with higher perceived risk of recurrence also tended to have lower self-regulatory ability with regard to management of a cancer diagnosis and treatment. Thus, individuals who believe they are at a high risk for developing CRC again may experience on-going worry or fear, potentially inhibiting their daily psychosocial functioning and emotional health.

Similar to prior research with cancer patients, associations were identified between more positive health behaviors and better QoL (Blanchard et al., 2008), greater distress and poorer QoL, and lower self-efficacy and self-regulation and increased alcohol consumption post-diagnosis and treatment. Although the findings related to alcohol consumption should be interpreted with caution because only one participant reported increasing alcohol consumption, perhaps people with greater psychological distress turn to maladaptive coping behaviors, such as alcohol consumption. Furthermore, individuals may be more likely to develop poor coping behaviors (e.g., increased intake of alcohol) as a form of avoidance, numbing, and escape, if they feel less confident in their ability to engage in healthy behaviors and less able to employ self-

regulatory strategies. On the other hand, individuals who decrease alcohol intake following a CRC diagnosis appear to experience less distress, greater emotional health and well-being, and higher psychosocial function.

As recommended by national oncology organizations for post-treatment behavior, and consistent with previous research (Alfano et al., 2009), participants were more likely to increase health behaviors or remain consistent with moderately healthy lifestyles practiced prior to their CRC diagnosis and treatment, and decrease unhealthy behaviors. Most study participants who reported not making any changes in the time or intensity in which they engage in PA reported engaging in PA for 30-60 minutes at a time but not for more than 15 days per month. Although these participants are fairly active, they are not meeting full ACS guidelines for PA of at least 30 minutes of moderate to vigorous PA for 5 or more days a week (2010). In contrast, participants who reported no change in the number of days spent eating a healthful diet appear to meet recommendations, with reports of eating a healthful diet for the majority of every month. Of note, participants were only given general guidelines as to what constitutes a healthful diet (e.g., a diet high in fruits and vegetables, whole grains, and leaner sources of protein); therefore, additional research is needed to more accurately assess participants' dietary practices to better gauge the frequency with which they consume a healthful diet.

Taken together, findings suggest that adopting and maintaining a healthful diet is likely an easier feat than adoption and maintenance of adequate levels of PA. These results in the current sample of high-risk CRC survivors are supported by prior findings in other cancer populations, including average-risk CRC samples, which found higher percentages of survivors making positive dietary changes compared to those making positive PA changes (Alfano & Rowland, 2009; Alfano et al., 2009; Harper et al., 2007; Mullens et al., 2004). Fatigue and/or

pain may be limiting factors in the adoption/maintenance of PA; therefore, a challenge becomes how to design PA interventions for cancer survivors that ensure the feasibility and likelihood of successful adoption and maintenance of PA.

This area has received growing interest and attention over the past several years, as researchers have begun developing randomized controlled trials examining the feasibility and effectiveness of health behavior interventions in cancer survivor populations (Courneya, 2008; Courneya et al., 2008). Unfortunately, current health behavior interventions targeting cancer survivor populations are highly time and resource intensive as well as expensive (Irwin, 2006, 2008). Despite the intensive nature of these programs, key findings in the areas of weight management and health behavior interventions for all adults indicate that higher dose supervised interventions are most effective. As a result, this evidence-based practice should be considered standard care for adults and should be paid for by insurance (Balducci et al., 2010; Courneya, 2008; Sigal & Kenny, 2010). The same should be true for cancer survivors. Thus, as evidence develops regarding the impact of health behaviors on disease risk reduction, these high-dose supervised interventions should become an essential component of the prescribed health behavior treatment for cancer survivors.

Group comparisons across each of the social cognitive and psychosocial variables revealed that there may be an *optimal* level of PA (e.g., approximately 16-25 times per month, for about 46-75 minutes at a time) for this sample of high-risk CRC survivors as indicated by the reportedly higher psychosocial functioning (i.e., higher QoL, medical care self-efficacy, and PA self-regulation) in these group participants. Furthermore, extreme amounts of PA (i.e., less than 5 times per month/16-30 minutes at a time or greater than 31 times per month/greater than 90 minutes per time) were found to be associated with lower psychosocial functioning in this

sample of high-risk CRC survivors. Thus, participants who are meeting or just exceeding ACS guidelines for PA are likely to be the most well-adjusted, while those engaging in extremely high or low levels of PA may be employing more maladaptive coping strategies and could potentially be characterized as less well-adjusted. Not surprisingly, participants who reported eating a healthful diet for most, if not all days of the month also reported the most positive outcome expectations regarding their healthful dietary practices. Individuals who engage in healthy behaviors would also expect positive outcomes to result from those healthy practices. Similarly, individuals might be more likely to engage in healthy lifestyle behaviors if they expect more positive outcomes to result.

## **5.2 Qualitative Findings**

The results of the qualitative telephone interviews suggest that although there appear to be open channels of communication between family members, the opportunity exists for healthcare providers to further encourage a high frequency and quality of communication in all families, particularly in families in which the potential for a genetic risk exists. This word of mouth communication between relatives and/or direct physician recommendations can have important implications for implementation of appropriate screening behaviors in at-risk individuals. Although communication styles are largely based on individual differences, personal choice, and family dynamics, researchers who have examined hereditary disease risk and communication issues through a legal and ethical “duty to warn” perspective assert that healthcare providers have a professional responsibility to “encourage but not to coerce” patients to share genetic information with family members (DeMarco & McKinnon, 2007; Offit et al., 2004).

Perhaps most importantly, the qualitative results suggest that an increase in education is needed to inform high-risk CRC patients of the potential benefits of engaging in health behaviors. This teachable moment could be of great benefit if included as a component of the care patients receive following completion of treatment. Although only a minority of participants noted some level of dissatisfaction with the after-care received, these reports hold significant weight due to their relevance in recovery. That is, it is believed that the quantity and quality of aftercare is likely to impact a cancer survivors' mental and physical recovery process.

Attention to care during cancer survivorship is a critical issue, likely impacting a cancer survivors' long-term physical and psychological health (Hewitt & Ganz, 2006). Cancer survivors would significantly benefit from an increase in the quantity and quality of specific follow-up care recommendations provided to them by their physicians. Growing attention has been dedicated to survivorship care issues as shown by various prominent national organizations, such as NCI, IOM, ASCO, ACS, and NCCS, who have created offices; task forces and committees; and sponsored conferences, workshops, and symposia devoted to increasing our understanding and awareness of cancer survivors' post-treatment needs (Hewitt & Ganz, 2006; Jacobs et al., 2009; Rowland et al., 2006). These institutions have similarly highlighted the need for physicians to adopt and implement survivorship care models in order to develop appropriate, effective, and individualized aftercare plans for their patients (Jacobs et al., 2009). Overall, as researchers have suggested (Irwin, 2009; Irwin & Mayne, 2008), physicians and/or members of the oncology care team should become aware of the benefits of healthy lifestyle behaviors and familiarize themselves with current health guidelines in order to provide their patients with appropriate and effective prescriptions and referrals as well as high caliber survivorship care.

Attempts to ensure a high quality of follow-up care for cancer survivors can be seen through the increasing presence of “survivorship clinics” at major cancer institutions (e.g., The Connecticut Challenge Survivorship Clinic at Yale Cancer Center, and Survivorship Clinics at Dana Farber Cancer Institute, Fox Chase Womens Cancer Center, Sloan Kettering and MD Anderson Cancer Centers). Specifically, 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, QoL, 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. These healthcare professionals assist patients in creating survivorship treatment plans, which can include 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 (Yale Cancer Center, 2010). 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 have begun to join forces to create transdisciplinary resources for cancer survivors post-treatment.

### **5.3 Synthesis of Quantitative and Qualitative Findings**

Results of the quantitative and qualitative data suggest that although patients report a high degree of satisfaction with their healthcare team throughout their CRC treatment, post-treatment patient care is lacking in terms of specific recommendations, or prescriptions, for health behaviors. While participants reported that their oncologists have made various health

recommendations, they are typically general in nature and not prescriptive. In addition, although many patients reported creating survivorship care plans with their oncologists, several did not. Notably absent from these survivorship plans are specific health behavior recommendations, or prescriptions. Thus, while it is important that oncologists are broaching the topic of health behaviors with their patients, these lifestyle discussions need to become significantly more focused (i.e., health behavior prescriptions) as well as a more standardized component of CRC treatment and/or post-treatment. Care can also be improved through routine implementation of survivorship care plans as use of these plans should become the norm for all patients post-treatment.

In addition, although a moderate number of participants are engaging in healthy lifestyle practices, several are not meeting guidelines and additionally, as reported during the telephone interview, may not appreciate the potential benefits of healthy behaviors. These findings are consistent with quantitative results suggesting that there may be an *optimal* level of PA in this high-risk sample of CRC survivors. Several high-risk CRC survivors may be limiting their engagement in PA to moderate dosages, as many reported believing that healthy behaviors can only impact risk levels so much. Thus, although it is encouraging that only a minority of participants increased unhealthy behaviors post-diagnosis, a critical challenge in this cancer survivor population involves the following three issues: (i) education of high-risk CRC survivors regarding the potential benefits of health behaviors on general cancer prevention and survival issues (e.g., QoL); (ii) motivation to adopt and maintain health behaviors that meet or just exceed evidence-based guidelines; and (iii) development of health behavior interventions (especially for PA) that ensure the feasibility of successful adoption and maintenance of health behaviors that meet evidence-based guidelines.

Although there is a wealth of knowledge documenting the significant benefits of the adoption and maintenance of health behaviors in general cancer populations (i.e., non-high risk cancer survivors), more evidence is needed to determine the impact of health behaviors on patient-reported and overall health outcomes in high-risk populations (NCI, 2010). Currently, little is known about whether protective factors (e.g., healthful diet, regular PA) are as influential in genetically increased risk cancer populations, such as HNPCC CRC survivors (NCI, 2010). For example, one study found PA, energy level, and vegetable intake to be significantly associated with CRC risk in individuals without a family history of CRC, but not for those with a familial predisposition (La Vecchia et al., 1999). These findings identify the uncertain impact of environmental factors on CRC risk for high-risk individuals (LaVecchia et al., 1999). That is, genetic predisposition may either dampen or even negate the influence of environmental factors (e.g., healthful diet, regular PA) on CRC risk levels. Thus, a critical next step in this line of research is examination of the short and long-term impacts of health behaviors on QoL and other health-related outcomes in this HNPCC population.

## **6. Strengths and Limitations**

The current study has several strengths. These strengths include: (i) the mixed-methods approach; (ii) use of a hard to reach clinical population; (iii) use of social cognitive theory with in-depth assessment of theoretically-based behavior change precursors; (iv) use of an online survey; and (v) the high rate in which eligible individuals consented to participate (i.e., 100% agreement rate for the online survey and 85% agreement rate for the telephone interview). Although the qualitative interview data may not be generalizable to a wider HNPCC population, qualitative measurement is a commonly used exploratory method which therefore matches the purpose of the current study. Furthermore, this mixed-methods design is believed to have

provided a more complete understanding of the cancer survivorship experiences of the current sample.

Despite the various strengths of the present study, several limitations should be discussed. First, results may not be generalizable due to sample size and sample characteristics. That is, the sample is fairly small ( $n = 20$ ) and homogenous, as participants are primarily Caucasian, female, highly educated, and report a high socioeconomic status. As a result, findings of the current study may not be applicable to other, more diverse populations of HNPCC survivors.

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 health behavior change, social cognitive and psychosocial constructs over time (i.e., before the diagnosis, during treatment, after completion of treatment) could allow for examination of changes in patterns of health behavior across the continuum of the cancer experience.

A fourth limitation can be considered the inclusion of several measures which were adapted by the Investigator. Although the scales generally demonstrated very good internal consistency, more research is needed to examine the reliability and validity of these adapted scales within larger samples. A fifth and final limitation of the current study is the use of multiple analyses and the lack of *alpha*-level correction procedures to avoid Type 1 error; however, the multiple analyses were considered best suited to the exploratory purpose of the study.

## 7. Future Directions

A vital next step in this line of research is to increase the evidence-base examining the short- and long-term impact of adoption and maintenance of health behaviors in high-risk cancer populations (e.g., HNPCC and *BRCA1/2* carriers). Although further research examining predictors of health behavior change/maintenance and health behavior interventions is warranted, research must first be done to improve our understanding of the effects of health behaviors on cancer risk levels in genetically high-risk populations.

Following development of the knowledge base regarding the impact of health behaviors in high-risk cancer populations, more research is needed to 1) examine the most effective way to deliver specific health behavior prescriptions (e.g., QoL Clinics, Survivorship Clinics, genetic counseling sessions, trained oncology nurses), 2) determine how best to integrate and standardize these focused health behavior discussions, and 3) enhance development of high-dose supervised health behavior interventions for cancer survivors.

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### Study Flow Chart

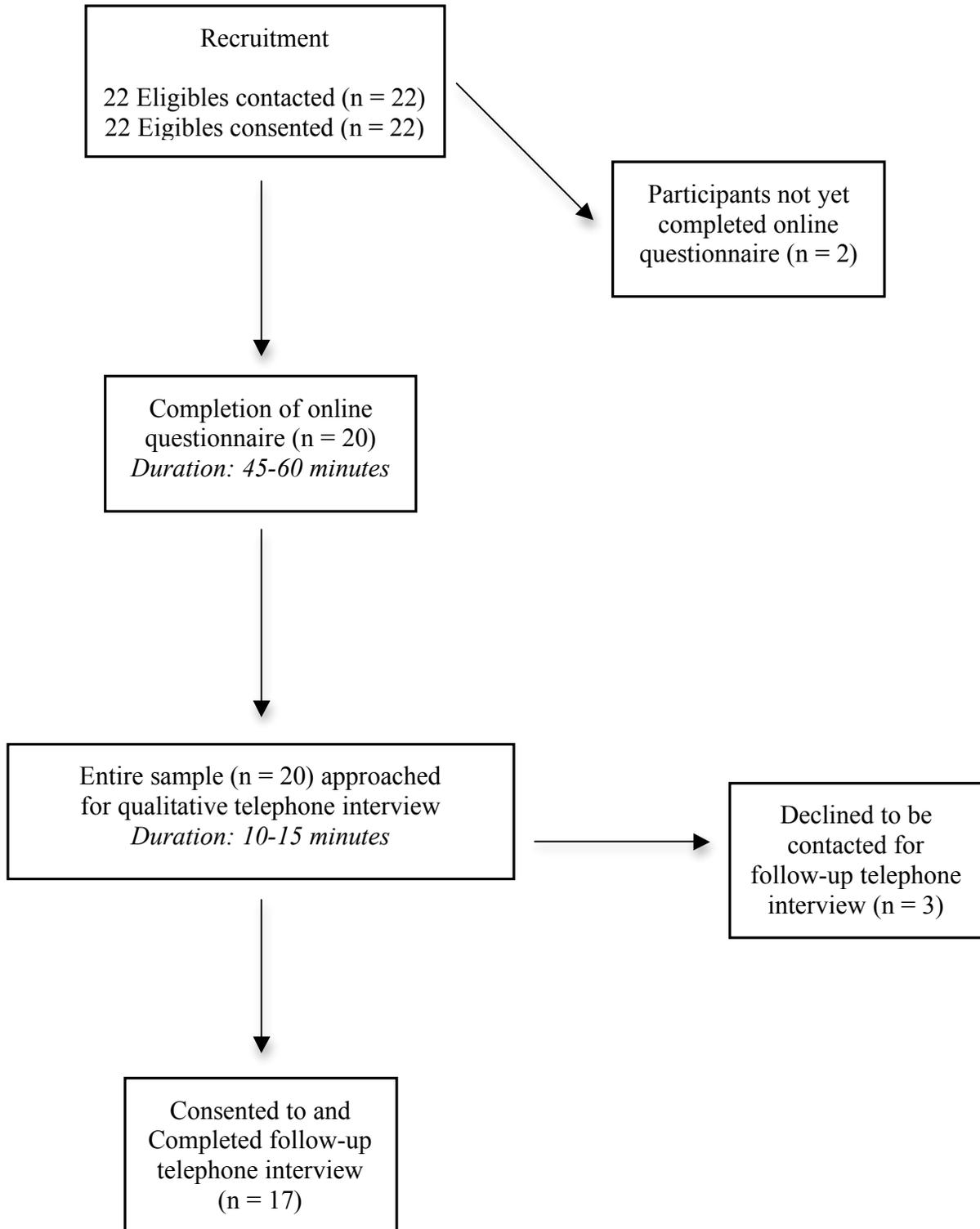


Table 1. *Sociodemographic Data*

<b>Demographic Variable</b>		<b>Number of Participants</b>	<b>%</b>
<b>Age</b>			
	30-40	7	35%
	41-50	4	20%
	51-60	6	30%
	61-70	3	15%
<b>Gender</b>			
	Male	2	10%
	Female	18	90%
<b>Adopted</b>			
	No	20	100%
<b>Ethnicity</b>			
	Not Hispanic or Latino	20	100%
<b>Racial Background</b>			
	White	19	95%
	Asian	1	5%
<b>Marital Status</b>			
	Married	16	80%
	Divorced or separated	4	20%
<b>Education</b>			
	High school graduate, or GED	1	5%
	Some college	1	5%
	College graduate or beyond	18	90%
<b>Religion</b>			
	Catholic	8	40%
	Protestant	5	25%
	Jewish	1	5%
	Atheist/Agnostic/None	4	20%
	Other	2	10%
<b>Employment</b>			
	Not employed	9	45%
	Full-time employed	4	20%
	Part-time employed	2	10%
	Retired	1	5%
	Student	2	10%
	Receiving Disability	2	10%
<b>Household Income</b>			
	Under \$25,000	1	5%
	\$25,001-\$50,000	1	5%
	\$50,001-75,000	1	5%
	\$75,001-100,000	2	10%
	\$100,001-\$150,000	7	35%
	Over \$150,000	6	30%
	Prefer not to answer	1	5%

Table 2. *Clinical Health and Risk Management Information*

<b>Variable</b>	<b>Number of Participants</b>	<b>%</b>
<b>Age of CRC diagnosis</b>		
29-40	8	40%
41-50	7	35%
51-70	5	25%
<b>Other cancer diagnoses</b>		
Yes	6	30%
No	14	70%
<b>Family history of CRC</b>		
Yes	8	40%
No	12	60%
<b>Colonoscopy in last 10 years</b>		
Yes	11	55%
No	9	45%
<b>Chemotherapy</b>		
Yes	14	70%
No	6	30%
<b>Radiation</b>		
Yes	3	15%
No	17	85%
<b>Genetic testing for HNPCC</b>		
Yes	17	85%
No	3	15%
<b>“Survivorship Care Plan” developed with oncologist</b>		
Yes	11	55%
No	7	35%
Don’t Know	1	5%
<b>Oncologist made physical activity recommendations</b>		
Yes	12	60%
No	5	25%
N/A	3	15%
<b>Oncologist made dietary recommendations</b>		
Yes	6	30%
No	9	45%
N/A	5	25%
<b>Oncologist recommended changes in alcohol consumption</b>		
Yes	-	-
No	15	75%
N/A	5	25%
<b>Oncologist recommended quit smoking</b>		
Yes	2	10%
No	2	10%
N/A	14	70%

Table 3. *Reliability Statistics for Social Cognitive & Psychosocial Measures*

	<b>Cronbach's <i>alpha</i></b>
<b>BSI (General Distress)</b>	.861
<b>IES (Cancer-Related Distress)</b>	.801
<b>FACT-C (QoL)</b>	.676
<b>Resilience</b>	.813
<b>Self-Efficacy: Dx &amp; Tx</b>	.828
<b>Self-Efficacy: Diet &amp; PA</b>	.787
<b>*Self-Efficacy: Medical Care</b>	--
<b>Self-Regulation: Dx &amp; Tx</b>	.912
<b>Self-Regulation: Diet</b>	.969
<b>Self-Regulation: PA</b>	.946
<b>Outcome Expectations: Dx &amp; Tx</b>	.934
<b>Outcome Expectations: Diet</b>	.777
<b>Outcome Expectations: PA</b>	.910

Note. QoL = Quality of Life; Dx & Tx = Diagnosis & Treatment; PA = Physical Activity

\*Reliability could not be calculated for this scale because it had zero variance (i.e., all participants responded uniformly).

Table 4. *Descriptive Statistics for Social Cognitive & Psychosocial Measures*

	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>Average Number of Years Post-Diagnosis</b>	20	.43	12.64	5.43	3.50
<b>BSI</b> (General Distress, out of 44)	20	11.00	24.00	14.45	4.48
<b>IES</b> (Cancer-Related Distress, out of 75)	19	.00	42.00	14.63	11.84
<b>FACT</b> (QoL, out of 136)	15	81.00	122.00	102.87	10.18
<b>Resilience</b> (out of 100)	18	63.00	94.00	78.11	8.64
<b>SE: Dx &amp; Tx</b> (out of 297)	18	195.00	284.00	233.83	23.25
<b>SE: Diet &amp; PA</b> (out of 90)	18	38.00	100.00	79.50	14.57
<b>SE: Medical Care</b> (out of 50)	18	38.00	50.00	47.78	3.72
<b>SR: Dx &amp; Tx</b> (out of 110)	17	64.00	110.00	90.59	13.50
<b>SR: Diet</b> (out of 155)	16	64.00	153.00	112.94	28.36
<b>SR: PA</b> (out of 70)	19	18.00	68.00	46.26	14.93
<b>OE: Dx &amp; Tx</b> (out of 180)	11	98.00	172.00	136.00	21.71
<b>OE: Diet</b> (out of 105)	18	65.00	100.00	83.17	9.06
<b>OE: PA</b> (out of 650)	17	272.00	634.00	417.35	110.13

Note. QoL = Quality of Life; SE = Self-Efficacy; Dx & Tx = Diagnosis & Treatment; PA = Physical Activity; SR = Self-Regulation; OE = Outcome Expectations

Table 5. *Pearson Product Moment Correlations Between Variables of Interest.*

	# Yrs Post-Dx	General Distress	Cancer Distress	QoL	Resilience	SE: Dx & Tx	SE: Diet & PA	SE: Medical Care	SR: Dx & Tx	SR: Diet	SR: PA	OE: Dx & Tx	OE: Diet	OE: PA
# Yrs Post-Dx	-													
General Distress	.155	-												
Cancer Distress	-.486*	.296	-											
QoL	.128	-.749**	-.391	-										
Resilience	-.051	-.523*	.083	.603*	-									
SE: Dx & Tx	-.163	-.444	-.134	.741**	.463	-								
SE: Diet & PA	-.340	-.469*	.166	.469	.413	.622**	-							
SE: Medical Care	.245	-.669**	-.028	.610*	.420	.493	.555*	-						
SR: Dx & Tx	.131	-.543*	-.025	.726**	.620**	.787**	.484	.449	-					
SR: Diet	.103	-.059	.400	.124	.413	.219	-.118	.181	.331	-				
SR: PA	-.197	-.243	.520*	.245	.621**	.167	.486*	.394	.360	.277	-			
OE: Dx & Tx	.133	-.716*	.162	.765*	.569	.858**	.732*	.759*	.901**	.218	.492	-		
OE: Diet	.049	-.089	.151	.484	.336	.809**	.182	.395	.620*	.486	-.040	.678*	-	
OE: PA	.262	-.370	.004	.666**	.572*	.710**	.145	.536*	.656**	.311	.425	.841**	.471	-

Note. # Yrs Post-Dx = Number of Years Post-Diagnosis; QoL = Quality of Life; SE = Self-Efficacy; Dx & Tx = Diagnosis & Treatment; PA = Physical Activity; SR = Self-Regulation; OE = Outcome Expectations

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

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

Table 6. *Pearson Product Moment Correlations Between Variables of Interest.*

	<b>Absolute Perceived Risk</b>	<b>Numeric Perceived Risk</b>	<b>Comparative Perceived Risk</b>
<b>Number of Years Post-Diagnosis</b>	.947	.442	.419
<b>General Distress</b>	.707**	.663**	.435
<b>Cancer Distress</b>	-.088	.077	.035
<b>QoL</b>	-.691**	-.548*	-.534*
<b>Resilience</b>	-.554*	-.372	-.289
<b>SE: Dx &amp; Tx</b>	-.212	-.004	-.182
<b>SE: Diet &amp; PA</b>	-.381	-.249	-.235
<b>SE: Medical Care</b>	-.461	-.345	-.374
<b>SR: Dx &amp; Tx</b>	-.502*	-.377	-.400
<b>SR: Diet</b>	-.067	.159	.072
<b>SR: PA</b>	-.427	-.324	-.127
<b>OE: Dx &amp; Tx</b>	-.526	-.346	-.386
<b>OE: Diet</b>	-.252	.001	-.406
<b>OE: PA</b>	-.357	-.314	-.329

Note. QoL = Quality of Life; SE = Self-Efficacy; Dx & Tx = Diagnosis & Treatment; PA = Physical Activity; SR = Self-Regulation; OE = Outcome Expectations

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

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

Table 7. Means and Standard Deviations of the Increased and Decreased Alcohol Consumption Groups, and Independent T-Test Values Assessing Group Differences Across Social Cognitive And Psychosocial Variables.

	<b>Overall Distress</b>	<i>t</i> value	<b>QoL: Physical Well Being</b>	<i>t</i> value	<b>SE: Diet &amp; PA</b>	<i>t</i> value	<b>SE: Medical Care</b>	<i>t</i> value	<b>SR: PA</b>	<i>t</i> value	<b>OE: Ca Dx Tx – Positive Attitude Subscale</b>	<i>t</i> value
	Mean (SD)	<i>p</i> value	Mean (SD)	<i>p</i> value	Mean (SD)	<i>p</i> value	Mean (SD)	<i>p</i> value	Mean (SD)	<i>p</i> value	Mean (SD)	<i>p</i> value
<b>Increased Alcohol Consumption</b> ( <i>n</i> = 1)	24.00	2.905	5.00	-4.223	38.00	-4.725	41.00	-3.024	18.00	-2.922	23.00	-4.095
<b>Decreased Alcohol Consumption</b> ( <i>n</i> = 7)	13.29 (3.45)	<i>p</i> <.05	22.17 (3.76)	<i>p</i> <.01	85.00 (9.21)	<i>p</i> <.01	49.00 (2.45)	<i>p</i> <.05	56.71 (12.39)	<i>p</i> <.05	52.57 (6.75)	<i>p</i> <.01

Note. QoL = Quality of Life, SE = Self-Efficacy, PA = Physical Activity, SR = Self-Regulation, OECaDxTx = Outcome Expectations for a cancer diagnosis and treatment

Table 8. *No Change Group Frequencies*

<b>Health Behavior Variable</b>	<b>Number of Participants</b>	<b>%</b>
<b>No change in amount of time <i>or</i> intensity of PA</b>	<b>14</b>	<b>70%</b>
<b>Frequency of PA</b>		
< 5 times per month	3	21.4%
6-10 times per month	3	21.4%
11-15 times per month	2	14.3%
16-20 times per month	1	7.1%
21-25 times per month	-	-
26-30 times per month	5	35.7%
> 31 times per month	-	-
<b>Duration of PA</b>		
16-30 minutes	1	7.1%
31-45 minutes	6	42.9%
46-60 minutes	5	35.7%
61-75 minutes	1	7.1%
75-90 minutes	-	-
> 90 minutes	1	7.1%
<b>No change in number of days eating a healthful diet (per month)</b>	<b>9</b>	<b>45%</b>
6-10 days per month	1	9.1%
11-15 days per month	-	-
16-20 days per month	2	18.2%
21-25 days per month	1	9.1%
26-31 days per month	5	45.5%
<b>No change in alcohol consumption</b>	<b>12</b>	<b>60%</b>
<b>No change in fast-food consumption</b>	<b>14</b>	<b>70%</b>
<b>No change in soft drink and candy consumption</b>	<b>11</b>	<b>55%</b>

Table 9. Means and Standard Deviations of Groups for Amount of Time Engaged in PA per Month, and One-Way ANOVA Values Assessing Group Differences Across Social Cognitive and Psychosocial Variables.

	<b>QoL: Emotional Well-Being Subscale</b>	<i>F</i> value
	Mean (SD)	<i>p</i> value
<b>Less than 5 times per month</b> ( <i>n</i> = 4)	19.25 (4.43)	
<b>6 - 10 times per month</b> ( <i>n</i> = 3)	21.00 (1.0)	
<b>11 - 15 times per month</b> ( <i>n</i> = 4)	20.50 (1.91)	
<b>16 - 20 times per month</b> ( <i>n</i> = 1)	24.00 (0)	2.70
<b>21 - 25 times per month</b> ( <i>n</i> = 2)	20.50 (0.71)	<i>p</i> = .063
<b>26 - 30 times per month</b> ( <i>n</i> = 5)	22.20 (1.79)	
<b>Greater than 31 times per month</b> ( <i>n</i> = 1)	12.00 (0)	

Note. QoL = Quality of Life

Table 10. Means and Standard Deviations of Groups for Time Spent Engaging in PA, and One-Way ANOVA Values Assessing Group Differences Across Social Cognitive and Psychosocial Variables.

	<b>QoL: Social &amp; Family Well-Being Subscale</b>	<i>F</i> value	<b>SE: Medical Care</b>	<i>F</i> value	<b>SR: PA</b>	<i>F</i> value
	Mean (SD) ( <i>n</i> )	<i>p</i> value	Mean (SD) ( <i>n</i> )	<i>p</i> value	Mean (SD) ( <i>n</i> )	<i>p</i> value
<b>Less than 15 minutes of PA</b> ( <i>n</i> = 0)	-		-		-	
<b>16 - 30 minutes of PA</b>	21.00 (2.83) ( <i>n</i> = 2)		47.00 (5.19) ( <i>n</i> = 3)		28.00 (11.14) ( <i>n</i> = 3)	
<b>31 - 45 minutes of PA</b>	23.63 (3.93) ( <i>n</i> = 8)		47.83 (2.64) ( <i>n</i> = 6)		44.71 (10.67) ( <i>n</i> = 7)	
<b>46 - 60 minutes of PA</b>	25.20 (1.92) ( <i>n</i> = 5)	3.36	49.00 (2.45) ( <i>n</i> = 6)	3.18	53.17 (12.34) ( <i>n</i> = 6)	4.77
<b>61 - 75 minutes of PA</b>	23.00 (0) ( <i>n</i> = 2)	<i>p</i> < .05	50.00 (0) ( <i>n</i> = 2)	<i>p</i> = .05	66.00 (2.83) ( <i>n</i> = 2)	<i>p</i> < .05
<b>76 - 90 minutes of PA</b> ( <i>n</i> = 0)	-		-		-	
<b>Greater than 90 minutes of PA</b>	13.00 (0) ( <i>n</i> = 1)		38.00 (0) ( <i>n</i> = 1)		31.00 (0) ( <i>n</i> = 1)	

Note. QoL = Quality of Life; SE = Self-Efficacy; SR = Self-Regulation; PA = Physical Activity

Table 11. Means and Standard Deviations of Groups for Number of Days Eating a Healthful Diet per Month, and One-Way ANOVA Values Assessing Group Differences Across Positive Diet Outcome Expectations.

	<b>OE: Diet</b>	<i>F</i> value
	Mean (SD)	<i>p</i> value
<b>Less than 5 days per month</b> ( <i>n</i> = 1)	84.00 (0)	
<b>6 - 10 days per month</b> ( <i>n</i> = 1)	80.00 (0)	
<b>11 - 15 days per month</b> ( <i>n</i> = 0)	-	5.50
<b>16 - 20 days per month</b> ( <i>n</i> = 4)	75.00 (7.35)	<i>p</i> < .05
<b>21 - 25 days per month</b> ( <i>n</i> = 5)	81.00 (3.67)	
<b>26 - 31 days per month</b> ( <i>n</i> = 5)	94.00 (7.52)	

Note. OE = Outcome Expectations

Table 12. *Qualitative Results*

Survey Item	Response / Identified theme
1. (a)	HNPCC Genetic Counseling occurred <u>after</u> receipt of diagnosis (n = 17)
1. (b)	Referral from: <ul style="list-style-type: none"> <li>● Oncologist (n = 12)</li> <li>● Surgeon (n = 2)</li> <li>● GI (n = 2)</li> <li>● Family member (n = 1)</li> <li>● Workplace nurse (n = 1)</li> </ul>
2. (a)	Discussions about diagnosis and HNPCC risk status with: <ul style="list-style-type: none"> <li>● All family members openly (n = 9)</li> <li>● All family members, with exception of parents/grandparents who are elderly/in poor health and/or young children. (n = 4)</li> <li>● All family members, with exception of estranged family member(s) (n = 3)</li> <li>● No communication with family members (n = 1)</li> </ul>
2. (b)	Informative, fact-based discussions about diagnosis, prognosis and treatment (e.g., stage of diagnosis, survival rate), as well as decision making (e.g., surgery, chemotherapy; n = 13) Importance of screening behaviors (e.g., encouraging relatives to pursue screening or increase frequency with which they get screened; n = 11) Alerting family to possibility/reality of hereditary risk; recommending GT (n = 15) Life stage issues (e.g., impact of surgery on plans to start a family; n = 1) Logistical issues (e.g., coordination of schedules to ensure attendance at medical appointments; n = 1) Insurance/healthcare concerns (n = 3) Latest research (n = 2)
3. (a)	Discussed importance of health behaviors with family (n = 15) Have not discussed health behaviors with family (n = 2)
3. (b)	Family emphasizes and values a healthy lifestyle (e.g., “way of life”, “everything in moderation”; n = 17) Healthy lifestyle viewed as a form of prevention and risk reduction, also affects recovery from illness or injury (n = 4) Struggle to close gap between current practices and what they feel they <i>should</i> be doing (n = 6) Mental health and stress reduction is of greater concern than diet and exercise practices (n = 1)
4.	Role of health behaviors in future cancer risk: <ul style="list-style-type: none"> <li>● Very important for prevention, risk reduction, and/or recovery process (n = 8)</li> <li>● Important component, but “not the whole pie” (n = 2)</li> <li>● Generally very important, however, likely won’t impact my risk (due to my “+” GT result; n = 5)</li> <li>● Generally important, but uncertain regarding impact on risk (n = 3)</li> </ul>
5. (a)	Satisfied with treatment received (n = 17)
5. (b)	Satisfied with personal decisions regarding treatment (n = 17) Note: <i>Inadequate after-care</i> (n = 3)
6. (a)	Past or present involvement in a support group for cancer survivors (n = 4) Involvement in other type of support group (i.e., not specifically for cancer) (n = 2) No involvement in a support group (n = 11)
6. (b)	Involvement: <ul style="list-style-type: none"> <li>● Physician (n = 1)</li> <li>● Personal search (n = 4)</li> <li>● Friend (n = 1)</li> <li>● Found to be beneficial (n = 6)</li> </ul> <i>No involvement:</i> <ul style="list-style-type: none"> <li>● Did not feel the need or was not interested (e.g., family and friend as a beneficial and sufficient support system) (n = 8)</li> <li>● Did not want to talk about it any more than was already necessary (n = 2)</li> <li>● Scheduling conflicts (e.g., time commitment, work schedule) (n = 2)</li> <li>● Demographic and individual differences (n = 2)</li> </ul>

Figure 1. *Differences in Emotional Well-Being Across Physical Activity Frequency Groups*

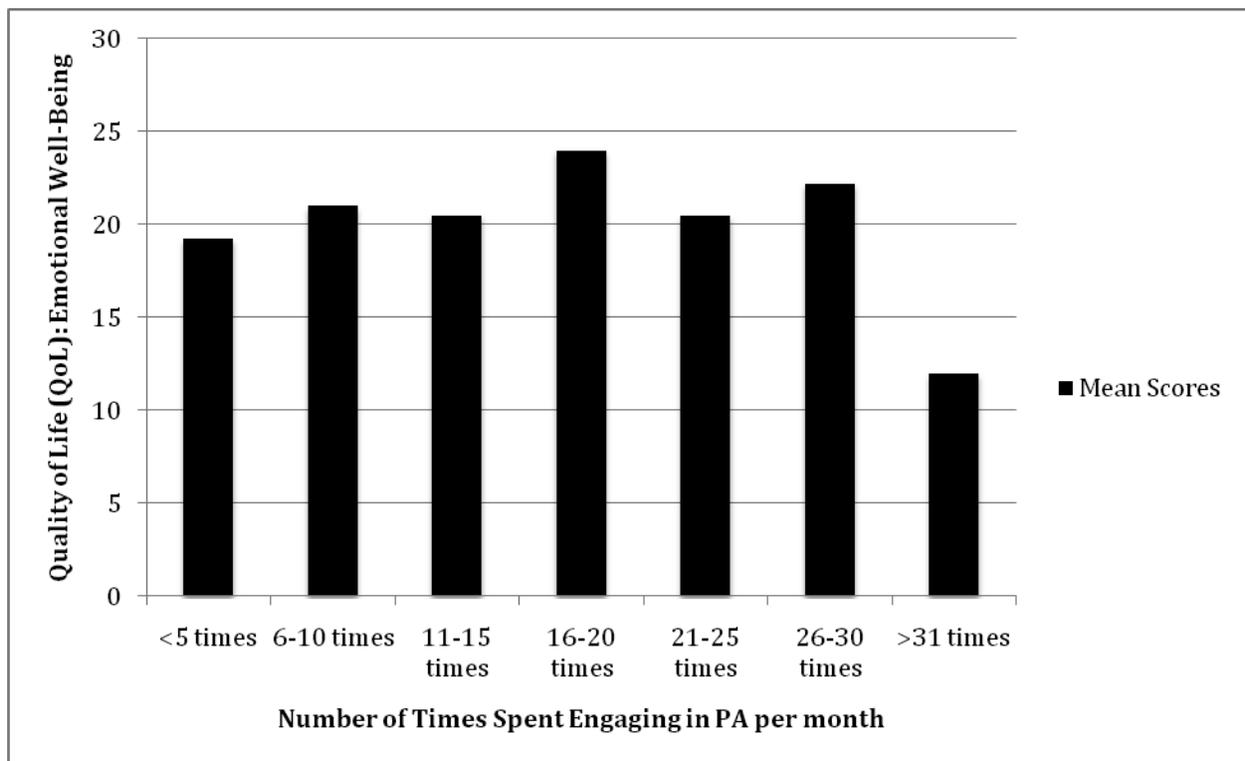


Figure 2. *Differences in Psychological Variables Across Physical Activity Duration Groups*

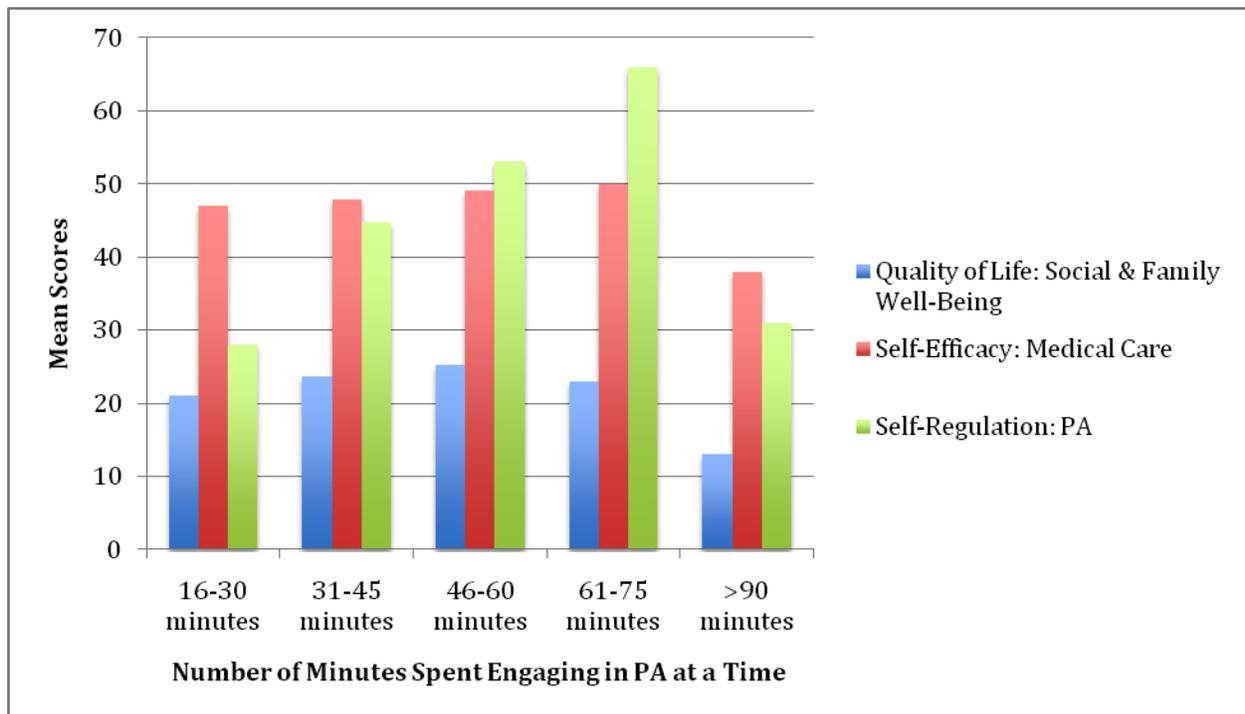
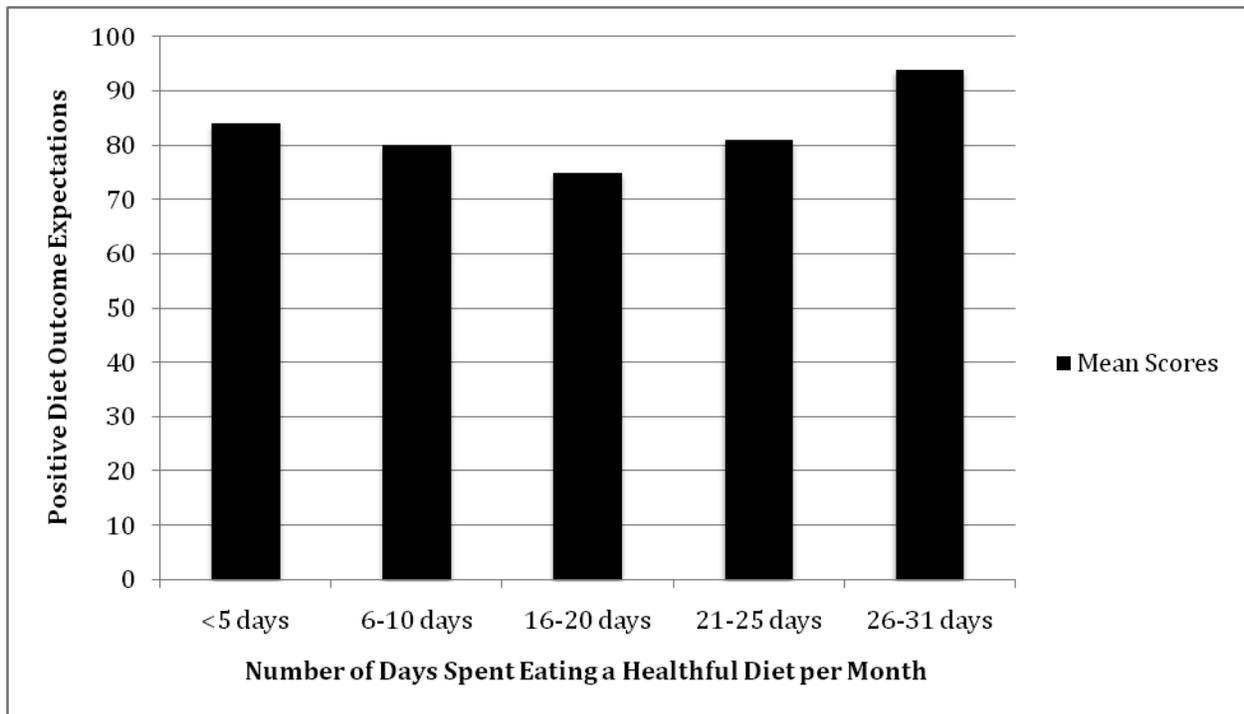


Figure 3. *Differences in Diet Outcome Expectations Across Healthful Diet Frequency Groups*



## Appendix A

### 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.

<b>1. What is your date of birth?</b> Month _____ Day _____ Year _____	
<b>2. What is your age?</b> _____ years	
<b>3. What is your gender?</b>	
<input type="checkbox"/>	(1) Male
<input type="checkbox"/>	(2) Female
<b>4. What is your height and weight?</b>	
	<b>Height:</b> _____ (feet) & _____ (inches)
	<b>Weight:</b> _____ (pounds)
<b>5. Since this time last year, is your weight...</b>	
(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)	
<b>6. Are you adopted?</b>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
<b>7. What is your ethnicity?</b>	
<input type="checkbox"/>	(1) Hispanic or Latino
<input type="checkbox"/>	(2) Not Hispanic or Latino
<b>8. What is your racial background?</b>	
<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
<input type="checkbox"/>	(6) Other (Please Specify) _____
<input type="checkbox"/>	(7) More than One Race (Please Specify) _____

<b>9. Which of the following describes your current marital status?</b>	
<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
<b>10. How many years of school have you completed?</b>	
<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
<b>11. What is your religious background?</b>	
<input type="checkbox"/>	(1) Catholic
<input type="checkbox"/>	(2) Protestant
<input type="checkbox"/>	(3) Jewish
<input type="checkbox"/>	(4) Atheist/Agnostic/None
<input type="checkbox"/>	(5) Other (Please specify) _____
<b>12. Are you currently employed for salary or wages?</b>	
<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
<b>13. What was your annual household income before taxes last year?</b>	
<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
<b>14. Do you have health insurance?</b>	
<input type="checkbox"/>	(1) Yes

<input type="checkbox"/>	(0) No
--------------------------	--------

**15. If there are other studies for which you may be eligible, may we contact you to tell you about them? You would be free to participate or decline at that time.**

<input type="checkbox"/>	(1) Yes
--------------------------	---------

<input type="checkbox"/>	(0) No
--------------------------	--------

## Appendix B

### CLINICAL 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).

<b>16. Have <u>you</u> been diagnosed with any type of cancer?</b>	<b>Indicate Type(s) of Cancer(s)</b>	<b>Age at Diagnosis</b>
<input type="checkbox"/> (1) Yes <input type="checkbox"/> (0) No		
<b>17. Have any of your family members been diagnosed with <u>Colon Cancer</u>? (check all that apply)</b>		<b>Age at Diagnosis</b>
_____ Mother		
_____ Father		
_____ Sister(s)		
_____ Brother(s)		
_____ Daughter(s)		
_____ Son(s)		
_____ Maternal Aunt(s)		
_____ Paternal Aunt(s)		
_____ Maternal Uncle(s)		
_____ Paternal Uncle(s)		
_____ Maternal Grandmother		
_____ Paternal Grandmother		
_____ Maternal Grandfather		
_____ Paternal Grandfather		

If you are 50 years old or older, or if you or anyone else in your family has been diagnosed with colon cancer, please answer the following questions about your colon cancer screening history.

If you are under 50 years of age without a family history of colon cancer, please check here:

*You do not need to fill out the questions on this page if you have checked this box.*

<b>18. Have you ever had a discussion about colon cancer screening with your doctor or other health professional?</b>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
<b>19. Within the last 10 years, have you had a colonoscopy?</b>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
<b>20. Within the last 5 years, have you had a flexible sigmoidoscopy, double contrast barium enema, stool DNA test, or virtual colonoscopy?</b>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No
<b>21. Within the last year, have you had a fecal occult blood test (FOBT) or fecal immunochemical test (FIT)?</b>	
<input type="checkbox"/>	(1) Yes
<input type="checkbox"/>	(0) No

## Appendix C

### RISK MANAGEMENT

Next we are interested in learning more about your treatment for colon cancer and about your continued medical care after your colon cancer treatment is over.

1. Did you have any part of your colon removed (colectomy) after your diagnosis? Please describe: \_\_\_\_\_
2. Did you have chemotherapy?
  - a. Yes. If Yes, please indicate what type of chemotherapy you had: \_\_\_\_\_
  - b. No
3. Did you have radiation?
  - a. Yes
  - b. No
4. Did your physician provide you with a plan for your care after your treatment was over? These plans are sometimes called “survivorship care plans” and are usually written documents that tell you about the treatment you had and what you should do in the future.
  - a. Yes
  - b. No
  - c. Don’t know
5. Did your physician recommend that you exercise?
  - a. Yes. If yes, please describe: \_\_\_\_\_
  - b. No
  - c. Don’t know
  - d. Not applicable, I already exercise the recommended amount
6. Did your physician recommend any changes to what you eat?
  - a. Yes. If yes, please describe: \_\_\_\_\_
  - b. No
  - c. Don’t know
  - d. Not applicable, I already eat a healthy diet.
7. Did your physician recommend any changes to your alcohol consumption?
  - a. Yes. If yes, please describe: \_\_\_\_\_
  - b. No.
  - c. Don’t know
  - d. Not applicable, I don’t drink alcohol

8. Did your physician recommend that you quit smoking?
- a. Yes. If yes, please describe: \_\_\_\_\_
  - b. No.
  - c. Don't know
  - d. Not applicable, I don't smoke.
9. When was your most recent appointment with your physician?  $\frac{\quad}{\text{MM}} / \frac{\quad}{\text{DD}} / \frac{\quad}{\text{YY}}$
10. When was your most recent colonoscopy?  $\frac{\quad}{\text{MM}} / \frac{\quad}{\text{DD}} / \frac{\quad}{\text{YY}}$
11. How often do you go in for check-ups with your physician?
- a. Every 3 months
  - b. Every 6 months
  - c. Once a year
  - d. Once every 2 years
  - e. Other: \_\_\_\_\_
12. How often are you supposed to have a colonoscopy?
- a. Once a year
  - b. Every other year
  - c. Every 3 years
  - d. Every 5 years
  - e. Every 10 years
  - f. Other: \_\_\_\_\_

## Appendix D

### DISTRESS

#### GENERAL PSYCHOLOGICAL DISTRESS: BSI

Below are a list of problems and complaints that people sometimes have. Please tell me how much discomfort that problem has caused you in the last two 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: Impact of Event Scale

Below is a list of comments made by people after stressful life events. Using the following scale, please indicate how frequently each of these comments were true for you DURING THE PAST SEVEN DAYS.

	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 E

### QUALITY OF LIFE

#### FACT-C (version 4.0)

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.**

<b><u>PHYSICAL WELL-BEING</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
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

<b><u>SOCIAL/FAMILY WELL-BEING</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
GS1	I feel close to my friends .....	0	1	2	3	4
GS2	I get emotional support from my family .....	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness.....	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4

Q1 *Regardless of your current level of sexual activity, please answer the following question.*   
*If you prefer not to answer it, please mark this box and go to the next section.*

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

**Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
<b><u>EMOTIONAL WELL-BEING</u></b>						
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

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

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<b><u>ADDITIONAL CONCERNS</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
C1	I have swelling or cramps in my stomach area.....	0	1	2	3	4
C2	I am losing weight.....	0	1	2	3	4
C3	I have control of my bowels.....	0	1	2	3	4
C4	I can digest my food well.....	0	1	2	3	4
C5	I have diarrhea (diarrhoea).....	0	1	2	3	4
C6	I have a good appetite.....	0	1	2	3	4
C7	I like the appearance of my body.....	0	1	2	3	4
Q2	Do you have an ostomy appliance? (Mark one box)	<input type="checkbox"/>	No	or	<input type="checkbox"/>	Yes
	If yes, please answer the next two items:					
C8	I am embarrassed by my ostomy appliance.....	0	1	2	3	4
C9	Caring for my ostomy appliance is difficult.....	0	1	2	3	4

## Appendix F

### RESILIENCE

#### The Connor-Davidson Resilience Scale

Please indicate how true each of the following statements are for you.

	Not at all true	Rarely true	Sometimes true	Often true	True nearly all the time
Able to adapt to change					
Close and secure relationships					
Sometimes fate or God can help					
Can deal with whatever comes					
Past success gives confidence for new challenge					
See the humorous side of things					
Coping with stress strengthens					
Tend to bounce back after illness or hardship					
Things happen for a reason					
Best effort no matter what					
You can achieve your goals					
When things look hopeless, I don't give up					
Know where to turn for help					
Under pressure, focus and think clearly					
Prefer to take the lead in problem solving					
Not easily discouraged by failure					
Think of self as strong person					
Make unpopular or difficult decisions					
Can handle unpleasant feelings					
Have to act on a hunch					

	<b>Rarely true</b>	<b>Rarely true</b>	<b>Sometimes true</b>	<b>Often true</b>	<b>True nearly all the time</b>
Strong sense of purpose					
In control of your life					
I like challenges					
You work to attain your goals					
Pride <i><u>in your achievements</u></i>					

## Appendix G

### RISK PERCEPTION

The following questions are about your attitudes and opinions about colon cancer.

1. In your opinion, how likely is it that you will develop colon cancer again? Would you say...

- Not at all likely..... 1
- A little bit likely..... 2
- Somewhat likely.....3
- Very likely.....4
- Definitely..... 5

2. On a scale from 0 to 100, where 0 means that you definitely won't get colon cancer again and 100 that you definitely will, how likely is it that you will develop colon cancer again sometime in your life? \_\_\_\_\_

3. Compared to other people who have had colon cancer, how would you rate your chances of having a recurrence?

- Much less..... 1
- A little bit less..... 2
- About the same.....3
- Quite a bit greater.....4
- Much greater.....5

## Appendix H

### SELF-EFFICACY

#### The Cancer Behavior Inventory

*This questionnaire 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 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 read each numbered item. Then rate that item on how confident you are that you can accomplish that behavior. Circle a number on the scale. If you circle a "1," you would be stating that you are not at all confident that you can accomplish that behavior. If you circle 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	

1. Maintaining independence.	1	2	3	4	5	6	7	8	9
2. Maintaining a positive attitude.	1	2	3	4	5	6	7	8	9
3. Accepting that I have cancer.	1	2	3	4	5	6	7	8	9
4. Maintaining work activity.	1	2	3	4	5	6	7	8	9
5. Asking nurses questions.	1	2	3	4	5	6	7	8	9
6. Remaining relaxed throughout treatments and not allowing scary thoughts to upset me.	1	2	3	4	5	6	7	8	9
7. Seeking support from people and groups outside the family.	1	2	3	4	5	6	7	8	9
8. Maintaining a daily routine.	1	2	3	4	5	6	7	8	9
9. Asking technologists questions.	1	2	3	4	5	6	7	8	9
10. Coping with hair loss.	1	2	3	4	5	6	7	8	9
11. Using denial.	1	2	3	4	5	6	7	8	9
12. Remaining relaxed throughout treatment (chemotherapy, radiation).	1	2	3	4	5	6	7	8	9
13. Coping with physical changes.	1	2	3	4	5	6	7	8	9

14. Ignoring things that cannot be dealt with.	1	2	3	4	5	6	7	8	9
15. Actively participating in treatment decisions.	1	2	3	4	5	6	7	8	9
16. Sharing feelings of concern.	1	2	3	4	5	6	7	8	9
17. Remaining relaxed while waiting at least one hour for my appointment.	1	2	3	4	5	6	7	8	9
18. Expressing personal feelings of anger or hostility.	1	2	3	4	5	6	7	8	9

19. Seeking information about cancer or cancer treatments.	1	2	3	4	5	6	7	8	9
20. Expressing negative feelings about cancer.	1	2	3	4	5	6	7	8	9
21. Keeping busy with activities.	1	2	3	4	5	6	7	8	9
22. Finding an escape.	1	2	3	4	5	6	7	8	9
23. Reducing any anxiety associated with getting my blood drawn.	1	2	3	4	5	6	7	8	9
24. Maintaining a sense of humor	1	2	3	4	5	6	7	8	9
25. Accepting physical changes or limitations caused by cancer treatment.	1	2	3	4	5	6	7	8	9
26. Seeking consolation.	1	2	3	4	5	6	7	8	9
27. Reducing any nausea associated with treatment (chemotherapy, radiation).	1	2	3	4	5	6	7	8	9
28. Maintaining hope.	1	2	3	4	5	6	7	8	9
29. Asking physicians questions.	1	2	3	4	5	6	7	8	9
30. Doing something, anything.	1	2	3	4	5	6	7	8	9
31. Managing pain.	1	2	3	4	5	6	7	8	9
32. Managing nausea and vomiting.	1	2	3	4	5	6	7	8	9
33. Controlling my negative feelings about cancer.	1	2	3	4	5	6	7	8	9

## Self-Efficacy Scale - Modified (Diet and Physical Activity)

We are interested in knowing how confident you feel about various health behaviors. Please rate how confident you are that you can do the behaviors listed below. Use the scale provided below and indicated the number that describes your level of confidence for that behavior.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	
Not at all confident				Moderately confident			Extremely confident			

The following questions ask about your confidence in behaviors related to your overall health.

How confident are you that you can...

1. Reduce soft drinks and candy intake?	1	2	3	4	5	6	7	8	9	10
2. Reduce candy intake?	1	2	3	4	5	6	7	8	9	10
3. Reduce fast food consumption?	1	2	3	4	5	6	7	8	9	10
4. Follow a healthy diet (i.e., fruits, vegetables, whole grains, low-fat dairy, low sodium, high fiber)	1	2	3	4	5	6	7	8	9	10
5. Drink 6-8 glasses of water per day?	1	2	3	4	5	6	7	8	9	10
6. Not smoke at all?	1	2	3	4	5	6	7	8	9	10
7. Not drink more than 2 alcoholic drinks per week?	1	2	3	4	5	6	7	8	9	10
8. Exercise 4 to 5 times per week?	1	2	3	4	5	6	7	8	9	10
9. Exercise for at least 30 to 45 minutes per workout?	1	2	3	4	5	6	7	8	9	10
10. Exercise at a moderate to high level of intensity?	1	2	3	4	5	6	7	8	9	10

Click here if you do not smoke

Click here if you do not drink

**SE Scale - Modified, continued.**

The following questions ask about your confidence in behaviors related to your medical care.

Again, please use the following scale to answer the questions below.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	
Not at all confident				Moderately confident			Extremely confident			

How confident are you that you can...

10. Keep your regularly scheduled doctors appointments?	1	2	3	4	5	6	7	8	9	10
11. Report any changes in symptoms to your physician as soon as you notice them?	1	2	3	4	5	6	7	8	9	10
12. Take your medications each day as prescribed?	1	2	3	4	5	6	7	8	9	10
13. Follow your physician's advice and treatment plan to manage symptoms related to your medical treatment?	1	2	3	4	5	6	7	8	9	10
14. Have a colonoscopy every 3 to 5 years after the first year out from diagnosis?	1	2	3	4	5	6	7	8	9	10

If you have an ostomy:

15. Change your ostomy bag every 3-5 days?	1	2	3	4	5	6	7	8	9	10
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## Appendix I

### SELF-REGULATION

#### Graves' Self-Regulation Scale for Medical Care

Please tell us how much the statements below describe you. Use this scale to tell us **how well the statement describes you**:

1	2	3	4	5
Does Not Describe Me		Describes Me Somewhat		Describes Me Very Well

	How well does this describe you? (1 – 5)
1. I plan ways to make my treatment sessions (or appointments with my cancer doctor) more bearable.	
2. If I have negative emotions about something, I try to make them more positive.	
3. I set goals for myself (related to managing my illness).	
4. I write down questions I have about my illness or treatment so I can ask the doctor or nurse.	
5. I know how to recognize when I have a negative thought about something.	
6. I look for information I need to make decisions about my cancer treatment.	
7. I try to think about problems in a ways that makes them easier to handle.	
8. If my health keeps me from doing something I want to do, I know that I can plan it for another time.	
9. If I have a question the doctor hasn't answered, I know how to ask him or her in a way so that I find out what I want to know.	
10. I try to realize when a negative thought affects the way I feel and act.	
11. I try to relax when I am feeling stressed or worried about something.	
12. I try to realize when I need to take a break and rest.	

Please tell us how much the statements below describe you. Use this scale to tell us **how well the statement describes you**:

1	2	3	4	5
Does Not Describe Me		Describes Me Somewhat		Describes Me Very Well

	How well does this describe you? (1 – 5)
13. I try to communicate with my doctor and nurses so that we talk about any questions and/or worries I have.	
14. I try to communicate well with my family on issues related to my illness.	
15. I try find activities that I enjoy doing most of the time.	
16. I try to take the time I need to take care of myself.	
17. When I have a question about something, I try to find the answer.	
18. If I reach a goal I have set, I do something to reward myself.	
19. I know when I start to get upset about something that I will be able to deal with it.	
20. I know that I am in charge of my feelings related to my illness.	
21. I consider all the options when I make a decision about my treatment.	
22. I try to keep track of all of my medical appointments and feel in control of my care.	

### Modified from Health Beliefs Survey: Self-Regulation for Diet

Please, tell us what you have done in the past 3 months to eat healthier foods.

Use this scale to tell us how often in the past 3 months you did the following:				
1 Never	2 Seldom	3 Occasionally	4 Often	5 Repeatedly
<b>In the past 3 months how often did you:</b>				<i>How Often (1-5)</i>
1. Remind yourself that high-fat foods have more calories than low-fat foods.				
2. Tell yourself that every calorie counts.				
3. Remind yourself that “fat-free” does not mean “calorie-free.”				
4. Tell yourself that fruits and vegetables are low in calories.				
5. Remind yourself that whole grain foods will help you feel full and satisfied.				
6. Tell yourself that whole grain foods, fruits and vegetables are good substitutes for high calorie and high fat foods.				
7. Work toward the goal to eat more whole grain foods.				
8. Work toward the goal to eat more fruit and vegetables.				
9. Work toward the goal to pay closer attention to serving sizes.				
10. Keep track of how many high-fat foods you eat each day.				
11. Work toward the goal to eat smaller portions.				
12. Work toward the goal to avoid ice cream and other high-fat dairy foods.				
13. Work toward the goal to avoid high-fat beef.				
14. Work toward the goal to eat low-fat toppings for potatoes and other vegetables.				
15. Work toward the goal to eat low-fat salad dressing.				
16. Work toward the goal to choose low-fat foods in fast-food and other restaurants.				
17. Work toward the goal to eat regular meals everyday day.				
18. Work toward the goal to eat fruits and vegetables for snacks.				

Use this scale to tell us how often in the past 3 months you did the following:				
1 Never	2 Seldom	3 Occasionally	4 Often	5 Repeatedly
In the past 3 months how often did you:				<i>How Often (1-5)</i>
19. Plan to eat only a certain number of calories a day.				
20. Keep track of the number of calories in the foods you eat.				
21. Plan to eat 5 or more servings of fruits and vegetables each day.				
22. Keep track of how many servings of fruits and vegetables you eat each day.				
23. Plan to eat 3 servings of whole-grain foods each day.				
24. Keep track of how many sweet snacks and desserts you have each day.				
25. Plan to eat fewer sweet snacks and desserts.				
26. Keep track of how many servings of whole-grain foods you eat each day.				
27. Plan to eat fewer high-fat foods at meals.				
28. Keep track of how many sodas and other sugared beverages you have each day.				
29. Plan to drink fewer sodas and other sugared beverages.				
30. Plan to eat fewer high-fat chips and crackers.				
31. Keep track of how many servings of high-fat chips and crackers you eat each day.				

### Modified from Health Beliefs Survey: Self-Regulation for Physical Activity

Please, tell us what strategies you have used in the past 3 months to successfully walk or do other exercise.

Use this scale to tell us how often in the past month you did the following:				
1 Never	2 Seldom	3 Occasionally	4 Often	5 Repeatedly
<b>In the past month how often did you:</b>				<i>How Often (1-5)</i>
1. Set aside time each day to walk or do other exercise?				
2. Make a plan to walk or do other exercise?				
3. Keep or make a new plan based on how well you were doing with your walking or other exercise?				
4. Set a goal for the number of days you walked or exercised each week?				
5. Keep track of how many steps you take each day?				
6. Keep track of the number of days you walked or exercised each week?				
7. Keep track of how long your walks or exercise sessions were?				
8. Plan to walk or exercise 5 days a week?				
9. Plan to make your walking or exercise sessions a little longer?				
10. Set goals for how long your walking or exercise sessions will be?				
11. Plan your walking or other exercise sessions so they are enjoyable?				
12. Get together with someone else to walk or do other exercise?				
13. Keep track of how much you enjoy your walking or other exercise?				
14. Keep track of how fast you walked or how hard you did other exercise?				

## Appendix J

### OUTCOME EXPECTATIONS

#### Modified from Graves' Outcome Expectations for Medical Care

People deal with cancer in different ways. Please tell us how much you agree or disagree that the following would happen.

Use this scale to tell us <b>how much you agree</b> :				
1	2	3	4	5
Strongly Disagree		Not Sure		Strongly Agree

<i>If I learned about my cancer and its treatment...</i>	How much do you agree? (1 – 5)
... I would not worry about the physical changes in my body.	1.
... I would be able to manage any nausea I experience.	2.
... I would know it is ok for me to do activities I enjoy.	3.
... I would be able to set proper limits for myself.	4.
... I would worry about not getting better.	5.
... I would worry that I could not meet the needs of my family.	6.
... I would be able to communicate with others about my illness.	7.
... I would feel better about my relationship with my doctor.	8.
... I would know that my feelings and thoughts were normal.	9.
... I would feel that I am doing what I can to manage my cancer and treatment.	10.
... I would be able to maintain hope in the fight against my illness.	11.
... I would be more able to accept changes in my body from treatment (hair loss, fatigue, etc).	12.

<u>Use this scale to tell us <b>how much you agree:</b></u>				
1 Strongly Disagree	2	3 Not Sure	4	5 Strongly Agree
<i><b>If I looked at the positive side of having cancer...</b></i>				How much do you agree? (1 – 5)
... I would be giving myself false hope.				13.
... I would be giving my family false hope.				14.
... I would be able to communicate with others about my illness.				15.
... I would make it easier for my family to be around me.				16.
... I would be able to take advantage of each day.				17.
... I would feel foolish.				18.
... I would not worry about the future as much.				19.
... I would be better able to relax.				20.
... I would not be facing reality.				21.
... I would feel closer to my family and friends.				22.
... I would know that it is ok to sometimes have less positive feelings about cancer.				23.
... I would be better able to maintain a sense of humor.				24.
... I would not feel as alone.				25.

Use this scale to tell us <b>how much you agree</b> :				
1	2	3	4	5
Strongly Disagree		Not Sure		Strongly Agree

<i><b>If I talked to my doctor about my illness...</b></i>	How much do you agree? (1 – 5)
... I would feel too pushy.	26.
... I would be able to get the information I need.	27.
... I would feel disrespectful.	28.
... I would be proud of myself.	29.
... I would feel like a difficult patient.	30.
<i><b>If I set goals related to my illness...</b></i>	How much do you agree? (1 – 5)
... I would feel like I could handle things better.	31.
... I would be pretending to control things I can't control.	32.
... I would be able to make problems less overwhelming.	33.
... I would be setting myself up for failure.	34.
... I would be taking things one step at a time.	35.
... I would set an example for other cancer patients.	36.

### Modified from Health Beliefs Survey: Outcome Expectations for Diet

Now, tell us what you expect will happen when you eat healthier foods.

Use this scale to tell us if you agree the following will happen:				
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i> <i>Strongly Agree</i>
If I eat healthier foods every day, I expect:				Do you agree? (1-5)
1. I will decrease my risk of recurrence.				
2. I will decrease my chance of becoming ill or disabled.				
3. I will lose weight.				
4. I will feel healthier and happier.				
5. I will live longer.				
6. I will feel better in my clothes.				
7. I will be hungrier.				
8. I will be unhappy and irritable.				
9. My health will improve.				
10. I will miss eating the foods I love.				
11. I will have healthier skin, hair, or teeth.				
12. I will be less likely to get cancer or heart disease.				
13. Shopping for healthy foods will be a lot of trouble.				
14. I will be bored with what I have to eat.				
15. I will have to change a lot of my favorite foods.				
16. I won't be able to eat the same foods as the rest of my family.				
17. I will have to spend too much time keeping track of what I eat.				
18. The food I eat will not taste good.				
19. It will take too long to prepare meals and snacks.				
20. I will have to plan my meals too far in advance.				
21. I will be more attractive.				

### Modified from Health Beliefs Survey: Outcome Expectations for Physical Activity

These questions ask about what you expect will happen *if you were take a walk or do other exercise most days of the week*. They also ask about how much it would matter to you for these things to happen.

Use this scale to tell us how much it will matter:				
1	2	3	4	5
It will not matter at all				It will matter very much
If I slowly and steadily build up to walking or doing other exercise most days of the week, I expect I will ...			Do you agree? (1-5)	Will it matter? (1-5)
1. decrease my risk of recurrence.				
2. decrease my chance of becoming ill or disabled.				
3. have to give up some of my normal activities.				
4. have to take more time than usual to plan my day.				
5. have one more thing to worry about getting done.				
6. not have enough time for other things I want to do.				
7. have to change my normal routine.				
8. sleep better.				
9. have less time to spend with my family.				
10. have less time to spend with my friends.				

Use this scale to tell us how much it will matter:				
1	2	3	4	5
It will not matter at all		It will matter very much		
If I slowly and steadily build up to walking or doing other exercise most days of the week, I expect I will ...			Do you agree? (1-5)	Will it matter? (1-5)

11. feel less stress.		
12. be less irritable.		
13. enjoy it.		
14. feel bored.		
15. dislike it.		
16. find it pleasurable.		
17. be no fun at all.		
18. be very energizing.		
19. make me feel depressed.		
20. be happier.		
21. feel good physically.		
22. feel very invigorated.		
23. feel exhilarated.		
24. not want to do anything else.		
25. be very absorbed by it.		
26. feel refreshed.		

## Appendix K

### HEALTH BEHAVIOR CHANGE

#### Diet & Physical Activity

- 1) I currently **regularly** engage in physical exercise such as walking, bicycling, swimming, or jogging.

\_\_\_\_\_ NO (Go to question #2)

\_\_\_\_\_ YES

- 1a) If yes, I have been **regularly** engaging in physical exercise since **before** my cancer diagnosis and treatment:

\_\_\_\_\_ NO

\_\_\_\_\_ YES

- 2) Do you *currently* resistance train (also called strength training) twice per week?

\_\_\_\_\_ NO

\_\_\_\_\_ YES

- 3) During the past month, **how often** have you engaged in physical exercise such as walking, bicycling, swimming or jogging?

\_\_\_\_\_ Times

- 3a) When you have engaged in physical exercise during the past month, **how long** have you typically exercised?

\_\_\_\_\_ Minutes

- 4) Has the amount of time you spend engaged in physical exercise changed since **your cancer diagnosis and treatment**?

\_\_\_\_\_ It has increased; I now typically spend more time engaged in physical exercise.

\_\_\_\_\_ It has decreased; I now typically spend less time engaged in physical exercise.

\_\_\_\_\_ It has not changed; I now typically spend the same amount of time engaged in physical exercise.

**5) Has the intensity of your physical exercise changed since your cancer diagnosis and treatment?**

\_\_\_\_\_ It has increased; I now typically engage in a higher intensity physical exercise.

\_\_\_\_\_ It has decreased; I now typically engage in a lower intensity physical exercise.

\_\_\_\_\_ It has not changed; I now typically engage in the same level of intensity in physical exercise.

**6) During the next six months, I intend to regularly engage in physical exercise.**

Strongly Disagree    1    2    3    4    5    Strongly Agree

**7) During the next 30 days, I intend to regularly engage in physical exercise.**

Strongly Disagree    1    2    3    4    5    Strongly Agree

**8/9) For me, regularly engaging in physical exercise would be:**

Positive                    1    2    3    4    5    Negative

Unpleasant                1    2    3    4    5    Pleasant

**10) Most of the people who are important to me would recommend that I regularly engage in physical exercise.**

Strongly Disagree    1    2    3    4    5    Strongly Agree

11) If I wanted, I could regularly engage in physical exercise.

Strongly Disagree    1    2    3    4    5    Strongly Agree

12) For me, regularly engaging in physical exercise would be ...

Very Difficult    1    2    3    4    5    Very Easy

13) I currently regularly eat a healthy diet, that is, a diet low in fat and high in fiber, fruits and vegetables.

\_\_\_\_\_ NO    (Go to question #2)

\_\_\_\_\_ YES

13a) If yes, I have been regularly eating a healthy diet since before my cancer diagnosis and treatment:

\_\_\_\_\_ NO

\_\_\_\_\_ YES

14) During the past month, how many days have you eaten a healthy diet?

\_\_\_\_\_ Days

15) Has the number of days that you eat a healthy diet changed since your cancer diagnosis?

\_\_\_\_\_ It has increased; I now typically have more days in which I eat a healthy diet.

\_\_\_\_\_ It has decreased; I now typically have fewer days in which I eat a healthy diet.

\_\_\_\_\_ It has not changed; I now typically have the same number of days in which I eat a healthy diet.

16) **Has the amount of alcohol you consume each week changed since your cancer diagnosis?**

\_\_\_\_\_ It has increased; I now typically drink more alcohol each week.

\_\_\_\_\_ It has decreased; I now typically drink less alcohol each week.

\_\_\_\_\_ It has not changed; I now typically drink the same amount of alcohol each week

17) **Has the number of fast food meals that you eat each week changed since your cancer diagnosis?**

\_\_\_\_\_ It has increased; I now typically eat more fast food meals each week.

\_\_\_\_\_ It has decreased; I now typically eat fewer fast food meals each week.

\_\_\_\_\_ It has not changed; I now typically eat the same number of fast food meals each week.

18) **Has your soft drink and candy intake changed since your cancer diagnosis?**

\_\_\_\_\_ It has increased; I now typically consume more soft drinks and candy each week.

\_\_\_\_\_ It has decreased; I now typically consume fewer soft drinks and candy each week.

\_\_\_\_\_ It has not changed; I now typically consume the same amount of soft drinks and candy each week.

19) **During the next six months, I intend to regularly eat a healthy diet.**

Strongly Disagree    1    2    3    4    5    Strongly Agree

20) **During the next 30 days, I intend to regularly eat a healthy diet.**

Strongly Disagree    1    2    3    4    5    Strongly Agree

21/22) For me, regularly eating a healthy diet would be....

Positive	1	2	3	4	5	Negative
Unpleasant	1	2	3	4	5	Pleasant

23) Most of the people who are important to me would recommend that I regularly eat a healthy diet.

Strongly Disagree	1	2	3	4	5	Strongly Agree
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24) If I wanted, I could regularly eat a healthy diet.

Strongly Disagree	1	2	3	4	5	Strongly Agree
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25) For me, regularly eating a healthy diet would be...

Very Difficult	1	2	3	4	5	Very Easy
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26) We hope to speak with a small number of participants via telephone following completion of this online questionnaire. This interview will last approximately 30 minutes and is optional. Would you be willing to be contacted for a brief follow-up telephone interview? *You would be free to participate or decline at that time.*

\_\_\_\_\_ YES

\_\_\_\_\_ NO

27) For participants who may be interested in learning about the results of this study, a brief general report will be available 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?

\_\_\_\_\_ YES

\_\_\_\_\_ NO