

**THE SALIENCE OF CANCER IN THE DIETARY BEHAVIORS OF  
PROSTATE CANCER SURVIVORS**

by

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## **ABSTRACT**

**Background.** Prostate cancer survivors are at risk for cancer recurrence, a second cancer, and other chronic conditions, including cardiovascular disease and diabetes. Some of these health risks are attributable to behavioral risk factors, including obesity, physical inactivity, and unhealthy diet. Although a cancer diagnosis is potentially a teachable moment when one might be more motivated to make behavioral changes, many prostate cancer survivors are not adhering to dietary and physical activity guidelines.

**Purpose.** This dissertation study examined influences on the healthfulness of prostate cancer survivors' diets and investigated the ways in which a prostate cancer diagnosis might impact men's dietary behaviors.

**Methods.** A purposive sample of 20 prostate cancer survivors who were at least 3 years post-diagnosis and not currently in active treatment was constructed. Over a period of approximately a month, participants completed a socio-demographic questionnaire; took part in an in-depth interview about their cancer experience and the current impact of cancer on their lives; completed three on-line dietary recalls; and participated in an in-depth interview about their dietary practices and determinants of diet. Wives/partners of eight participants were also interviewed. In-depth interviews were analyzed using a constant comparison approach. Dietary recall data were analyzed quantitatively to assess men's diet quality, and qualitatively to characterize men's dietary patterns.

**Results.** For many men, 'cancer survivor' was not a salient identity. Additionally, many men did not perceive a relationship between diet and recurrence; consequently, men described factors other than their history of cancer as more influential in their food choices. Taste and health were brought up as key determinants of food choices. Men

with healthier diets described a higher level of motivation to make healthy food choices, often for weight loss, and fewer barriers to health eating. Wives/partners were frequently described as being primarily responsible for food provision activities and therefore an important influence on the healthfulness of men's diets.

**Conclusions.** These findings suggest that health promotion programs focused on the multiple health benefits of healthy eating (e.g., weight loss, co-morbidities, longevity) might be more suitable for some men than 'cancer survivor' centered programs. Couples-based programs should also be considered.

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**CHAPTER 1**  
**INTRODUCTION**

## **INTRODUCTION**

### **Prostate cancer survivors: A growing population**

Prostate cancer is the most commonly diagnosed cancer and the second leading cause of cancer mortality in U.S. males (American Cancer Society, 2014). Fifteen percent of men in the United States will be diagnosed with prostate cancer in their lifetime (Howlader et al., 2013). In 2014, it is estimated that there will be 233,000 new cases of prostate cancer and 29,480 deaths from prostate cancer (Howlader et al., 2013). Prostate cancer is most common in older men, with 97% of prostate cancers being diagnosed in men over the age of 50 (American Cancer Society, 2014). The median age at time of diagnoses is 66 years (Howlader et al., 2013).

There are currently more than 2.7 million prostate cancer survivors in the U.S. (Howlader et al., 2013), and the vast majority (98.9%) of men with prostate cancer survive at least 5 years following their diagnosis (Howlader et al., 2013). Due to the large and growing number of prostate cancer survivors, in part attributable to the aging of the U.S. population (Edwards et al., 2002; Yancik, 2005), there is growing interest in the post-treatment health and quality of life needs of prostate cancer survivors (Harrop, Dean, & Paskett, 2011; Skolarus et al., 2014).

### **Long-term health risks of prostate cancer survivors**

The 2005 Institute of Medicine (IOM) report “From Cancer Patient to Cancer Survivor: Lost In Transition” highlighted the long lasting consequences of cancer and its treatments, and the failure of the healthcare system to effectively meet the needs of

cancer patients post-treatment (Committee on Cancer Survivorship: Improving Care, Quality of Life, Institute of Medicine, & National Research Council, 2005). Historically, the goal of oncologists in treating cancer patients was to eradicate the cancer so that patients survived (Rowland, 2006). However, as cancer patients began living longer and longer following their cancer diagnosis due to improvements in early detection and treatment, a need arose not only to focus on survival but also on the quality of life of cancer survivors following treatment (Bloom, 2002; Pollack et al., 2005). Prostate cancer survivors are at risk of long term side effects from their cancer and its treatment, both physical (e.g., urinary incontinence, impotence, and bowel dysfunction) and psychological (e.g., fear of recurrence, distress from physical side-effects) (Bloom, Kang, Petersen, & Stewart, 2007). They are also at risk of cancer recurrence, incidence of a second cancer, developing other chronic diseases, such as cardiovascular disease and diabetes, osteoporosis, and functional decline (Aziz, 2007; E. J. Davis, Beebe - Dimmer, Yee, & Cooney, 2014; Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Lassemillante, Doi, Hooper, Prins, & Wright, 2014; Weaver et al., 2013).

### **Lifestyle factors and health outcomes**

Although genetic predisposition and effects from treatment account for some of the excess health risks of prostate cancer survivors, there are also common underlying *modifiable* behavioral risk factors that contribute to their ongoing health risks, including obesity, unhealthy diet, and physical inactivity (Aziz & Rowland, 2003; Ligibel, 2012). In fact, prostate cancer survivors are more likely to die of causes other than prostate

cancer, many of which are preventable through lifestyle changes (Epstein, Edgren, Rider, Mucci, & Adami, 2012).

There is a growing body of evidence linking obesity to prostate cancer recurrence, mortality and quality of life (Demark-Wahnefried, 2007; Demark-Wahnefried et al., 2012; Joshu et al., 2011; Neugut, Chen, & Petrylak, 2004; Parekh, Chandran, & Bandera, 2012). A meta-analysis of studies published before January 5, 2010 estimated that each 5kg/m<sup>2</sup> increase in body mass index (BMI) was associated with a 15% (pooling 6 population-based cohort studies) to 20% (pooling 6 post-diagnosis survival studies) increased risk in prostate cancer mortality, and a 21% increased risk of recurrence (pooling 16 post-diagnosis survival studies) (Cao & Ma, 2011). Joshu and colleagues (2011) found that among men who had a prostatectomy, those who gained more than 2.2kg, comparing weight five years prior to surgery to weight one year post-surgery, had twice the risk of recurrence compared to men whose weight remained stable, regardless of pre-surgery BMI, also suggesting that weight gain is problematic.

A study using 2009 Behavioral Risk Factor Surveillance System data estimated that 72% of prostate cancer survivors were overweight or obese (LeMasters, Madhavan, Sambamoorthi, & Kurian, 2014). It is not yet known whether intentional weight loss following cancer treatment positively impacts cancer-related outcomes (Demark-Wahnefried et al., 2012). However, obesity is also associated with morbidity and mortality from cardiovascular disease, the leading cause of death in prostate cancer survivors (Brown, Brauner, & Minnotte, 1993; Rock et al., 2012), and diabetes, another common co-morbidity among prostate cancer survivors. Thus, weight loss might benefit

the overall health of prostate cancer survivors.

Both physical activity and healthy eating are critical to maintaining a healthy weight, which is especially important given the evidence linking obesity to prostate cancer prognosis and mortality. Based on a review of studies on lifestyle and health outcomes in prostate cancer survivors, the American Cancer Society (ACS) recommends that prostate cancer survivors “should strive to achieve and maintain a healthy weight, pursue a physically active lifestyle, and consume a diet that is rich in vegetables and fruits and low in saturated fat, with reliance on dietary sources of calcium that are within moderate levels.” (Rock et al., 2012). Physical activity is linked to slower progression of disease and reduced risk of prostate cancer specific mortality (Kenfield, Stampfer, Giovannucci, & Chan, 2011; Lemanne, Cassileth, & Gubili, 2013; Richman et al., 2011). For example, a study of 2,705 men with a history of prostate cancer found that men whose physical activity level was equivalent to three or more hours a week of walking at an average pace had 33% reduction in overall mortality and 35% reduction in prostate cancer-specific mortality compared to those whose physical activity level was equivalent to less than three hours a week of walking at an average pace; reductions were even greater for those who engaged in vigorous physical activity (Kenfield et al., 2011). Physical activity in prostate cancer survivors has been found to be associated with reduced fatigue, improved physical functioning and health related quality of life (Santa Mina et al., 2014; Thorsen, Courneya, Stevinson, & Fossa, 2008).

Dietary changes can promote weight loss, and can also reduce risk for cardiovascular disease and other obesity-related diseases. (Pekmezi & Demark-

Wahnefried, 2011; Rock et al., 2012). Currently, dietary guidelines for prostate cancer survivors reflect a heart healthy diet promoting consumption of fruits and vegetables, and restricting consumption of saturated fats. The question of whether specific foods or nutrients impact prostate cancer prognosis remains unanswered; however, there is ongoing research investigating the effects of specific foods or nutrients on prostate cancer prognosis (Berkow, Barnard, Saxe, & Ankerberg - Nobis, 2007; Demark-Wahnefried, 2007). The limited research on prostate cancer prognosis and diet suggests that saturated fat may be associated with worse survival, whereas lycopene (found e.g., in tomato-based products) and fish consumption (possibly attributable to their omega-3 fatty acid content) may be protective against prostate cancer recurrence, but these findings are inconclusive (Chan et al., 2006; Chan, Van Blarigan, & Kenfield, 2014; Richman et al., 2013).

### **Current health behaviors of prostate cancer survivors**

Studies using national data to estimate the prevalence of meeting behavioral recommendations, such as consuming at least five fruits and vegetables per day and engaging in 150 minutes or more of at least moderate intensity physical activity, find that many prostate cancer survivors are not meeting dietary and physical activity guidelines (C. M. Blanchard, Courneya, & Stein, 2008; Coups & Ostroff, 2005). Estimates using 2009 BRFSS data are that 21.5% of prostate cancer survivors meet fruit and vegetable recommendations and 46.6% meet physical activity recommendations (LeMasters et al., 2014). Furthermore, the health behaviors of cancer survivors are similar to those of adults without a history of cancer (Coups & Ostroff, 2005; LeMasters et al., 2014), which

implies that even if cancer survivors initially make changes over time they return to pre-diagnosis patterns of behavior, which in the U.S. are largely characterized by low levels of physical activity and inadequate consumption of healthy foods, such as fruits and vegetables (Kirkpatrick, Dodd, Reedy, & Krebs-Smith, 2012; Tucker, Welk, & Beyler, 2011).

### **Cancer as a Teachable Moment**

Over time, a cancer diagnosis has been conceptualized as a possible teachable moment when one is motivated to make behavioral change in an attempt to improve health, and some of these changes can be long lasting or permanent (Lawson & Flocke, 2009). Few studies have examined the extent to which prostate cancer survivors make behavioral changes following their cancer diagnosis, including changes to diet, physical activity, and supplement use (Avery et al., 2013; Maskarinec, Murphy, Shumay, & Kakai, 2001; Patterson et al., 2003; Satia, Walsh, & Pruthi, 2009). Comparing pre- and post-diagnosis food frequency questionnaires, a UK-based prospective cohort study found that 29.2% men diagnosed with prostate cancer made at least one of the following dietary changes after their diagnosis: increased intake of protein, fresh tomatoes, tomato products, or fruit/vegetable juice, or decreased consumption of red meat.

Studies examining reasons for post-diagnosis behavioral changes find that reducing the risk of recurrence, maintaining overall health or increasing wellbeing are common motivators (Demark-Wahnefried et al., 2005; Maskarinec et al., 2001; Mroz, Chapman, Oliffe, & Bottorff, 2010). For some, behavior change provides an opportunity

to exert some control in a situation (cancer diagnosis and treatment) that is otherwise out of their control (Mroz et al., 2010; Patterson et al., 2003). There has been minimal exploration of factors that differentiate prostate cancer survivors who make behavioral changes from those who do not (Mroz et al., 2010; Satia et al., 2009). Mroz and colleagues (2010) found that men's orientation towards their prostate cancer influenced whether or not they made dietary changes and the magnitude of these changes. Specifically, men who did not make changes described themselves as 'winning the war' against cancer and therefore did not see a need for such changes; men who made small dietary changes viewed cancer as a chronic condition and perceived minor dietary changes as a strategy for coping with their illness; and men who made significant changes considered their prostate cancer to be a 'turning point' that promoted them to make permanent lifestyle changes (e.g., becoming a vegetarian). In line with cancer being a 'teachable moment,' men who make behavioral changes often indicated that their physician recommended the change, while those who do not often noted that their physician never mentioned the need for such changes (Satia et al., 2009). However, the majority of prostate cancer survivors have been found not to be discussing dietary behaviors or physical activity with their physicians (C.M. Blanchard et al., 2003; Sabatino et al., 2007).

## **STUDY PURPOSE AND SPECIFIC AIMS**

Prostate cancer survivors continue to face health issues related to their cancer and are also at high-risk for obesity-related chronic diseases, such as cardiovascular disease.

However, many prostate cancer survivors are not adhering to health promoting dietary recommendations. Although a cancer diagnosis is potentially a teachable moment, little is known about the circumstances in which a cancer diagnosis might result in behavior change. The goal of this study is to add to our understanding of how prostate cancer survivors integrate their cancer experience into their overall sense of self, and how their cancer experience might impact their health behaviors, with a specific focus on healthy eating. The specific aims are:

**Aim 1:** To explore the salience of cancer in the lives of post-treatment prostate cancer survivors

- *Research question 1a:* Do prostate cancer survivors identify as “cancer survivors,” and what factors influence whether or not they view this label as applying to them?
- *Research question 1b:* How salient is being a “cancer survivor” in relation to other important identities?

**Aim 2:** To examine influences on the healthfulness of prostate cancer survivors’ diet

- *Research question 2a:* Are prostate cancer survivors’ diets consistent with dietary guidelines?
- *Research question 2b:* How do the dietary features of men with healthier diets compare to those of men with less healthy diets (e.g., what types of foods do they consume, eating patterns)?
- *Research question 2c:* What are the perceived influences on diet quality for men with healthier diets compared to men with less healthy diets?

**Aim 3:** To describe the role of wives/partners in promoting healthy eating among prostate cancer survivors

- *Research question 3a:* How (if at all) do wives/partners shape the diets of prostate cancer survivors?
- *Research question 3b:* How do couples perceive prostate cancer as having influenced their diets?
- *Research question 3c:* What role(s) do wives/partners play in dietary behavior change attempts?

## **THEORETICAL FOUNDATIONS**

### **Identity theory**

Experiencing cancer does not hold the same meaning for all people, and identity theory is a useful framework for considering if and how prostate cancer survivors might integrate their cancer experience into their overall self-concept, and how their cancer experience may influence their dietary practices. Identity theory is rooted in symbolic interactionism, a term coined by Herbert Blumer (1986). Symbolic interactionism posits that objects do not have inherent meaning, but rather meaning is socially constructed through our interactions with others, reflecting a shared understanding. As applied to identity theory, one's identity represent the social roles that a person holds, and provide socially constructed standards or expectations for how one should behave (Burke & Stets, 2009). Thus, how we 'should' behave is based on our internalized beliefs about how others think we should behave (i.e., looking glass self) (Cooley, 1902). These

expectations constitute the basis of one's self-concept.

Acting in a manner that is consistent with one's identity standards validates one's identity, which increases self-esteem (Burke & Stets, 2009; Cast & Burke, 2002). An illness, such as cancer, can limit one's ability to validate existing identities (Charmaz, 1994; Thoits, 1991). For example, men undergoing cancer treatment might value being a provider, but if their treatment is extensive, they might not be able to fulfill that role for some period of time, or permanently. A mismatch between one's actual behavior and expected behavior causes dissonance that one is then driven to resolve either through behavior change or by altering their identity standards (Burke & Stets, 2009). In the case of prostate cancer survivors, this could either lead men to adopt a new cancer-related identity that accounts for these limitations and represents a new understanding of their reality, or men could reconstruct expectations or salience of existing identities.

A 'cancer identity' is one of many identities that men who have a history of prostate cancer potentially hold. Other potential identities for such men include spouse, father, friend, golfer, fisherman, grandfather, retiree and so on. The salience of identities varies over time and situation, and when two identities are activated at the same time and provide different expectations of appropriate behavior, the expectations of the more salient identity are usually realized (Burke & Stets, 2009). For instance, in relation to health promotion, when a man is at a restaurant with friends as a cancer survivor he might be expected to make a healthy choice, but as a friend he might be expected to eat something similar to what his friends are eating. If his friends are all eating fried foods, his identity expectations would be at odds with one other, and the expectations of the

more salient identity would likely be acted upon. Thus, there is a need to understand whether men adopt a cancer identity and if they do, how their cancer identity ranks in salience compared to other important identities.

### Cancer identity

For prostate cancer survivors, their cancer identity may be of central importance during cancer treatment, but salience may wane over time. Deimling, Kahana, & Schumacher (1997) proposed four labels that represent different ways that individuals with a cancer history might internalize their illness experience – survivor, victim, patient, and ex-patient. The *survivor* label implies some sort of ownership over cancer and possibly a belief that the cancer is “cured,” while *victim* suggests a lack of control over the illness, continuing vulnerability, and possibly a fatalistic attitude; *patient* is suggestive of a reliance (or overreliance) on the medical system after the completion of active treatment; and *ex-patient* signifies a distancing of oneself from their cancer and may represent a lack of long-term impact of the illness on one’s identity (Deimling et al., 1997).

Little is known about the factors that influence the extent to which one’s cancer identity remains salient as time from diagnosis increases or the situations in which one’s cancer identity might be activated. It has been hypothesized that those who adopt a ‘cancer survivor’ identity might be more motivated to engage in health promoting activities, but this has not been empirically tested (Deimling, Bowman, & Wagner, 2007; Harwood & Sparks, 2003; Zebrack, 2000), with the exception of one study which found

no association between cancer identity type and levels of physical activity or body mass index (Chambers et al., 2011).

Most of the research on cancer identity has examined the associations between cancer identity and wellbeing/adjustment (Bellizzi & Blank, 2007; Chambers et al., 2011; Morris et al., 2014; Park, Zlateva, & Blank, 2009). While a ‘cancer survivor’ identity has been found to be associated with greater wellbeing, many cancer survivors have been found to adopt a more neutral label to describe their cancer experience, such as “a person who has had cancer,” which suggests a distancing of their cancer experience from their current sense of self. Prostate cancer survivors in particular tend to be less likely to endorse a *survivor* identity than individuals with a history of other types of cancer (Bellizzi & Blank, 2007; Deimling et al., 2007). Interestingly, in studies in which participants are able to select more than one cancer identity they often do (Deimling et al., 2007; Park et al., 2009), and they sometimes select identities that seem incompatible (e.g., survivor and victim). While a typology is useful in considering the different ways in which cancer may impact one’s identity, there is some indication that these categories are not mutually exclusive, and cannot fully account for the complex ways in which one’s cancer experience might be integrated into one’s overall sense of self.

#### Origins of ‘cancer survivor’ label

As noted above, the ‘cancer survivor’ identity has been proposed as having potential health benefits, but understanding the origins of the term ‘cancer survivor’ and the characteristics attributed to being a ‘cancer survivor’ provides insight into why this

label is not universally adopted by all people who have a history of cancer. The concept of survivorship was first applied to cancer in the 1980s (Doyle, 2008). Mullan, a physician and cancer survivor, proposed the use of the term ‘survival’ rather than ‘cure’ as an appropriate label for the post-treatment cancer experience as he argued that the expectation of being cured was unrealistic for many individuals diagnosed with cancer (1985). Mullen outlined a three-stage model of survivorship. The first phase, *acute survival*, begins at the time of diagnosis and extends throughout the time that individuals are undergoing active treatment for their cancer, and is characterized by fear and anxiety as well as pain resulting from the treatment itself. During this stage, individuals are forced to reflect on their own mortality, which is the first time for many. The next stage, *extended survival*, begins when active treatment is completed. During this phase, individuals are coping with fear of recurrence as well as the ongoing physical limitations that have been brought on by cancer and its treatment. During the final stage, *permanent survival*, the likelihood of cancer recurrence is minimal, however there are still long term consequences of cancer that survivors face, including discrimination and long term secondary physical effects of cancer (Mullan, 1985).

The term ‘cancer survivor’ was used to galvanize a community of individuals with a history of cancer. Mullan was one of the founders of the National Coalition for Cancer Survivorship, an advocacy organization established in 1986 with the goal of “chang[ing] the parlance from cancer ‘victim’ to cancer ‘survivor’” (<http://www.canceradvocacy.org/about-us/our-history.html>). Advocacy organizations tend to be inclusive and define ‘cancer survivors’ as anyone who has been diagnosed with

cancer from the day of diagnosis onwards. They also often include family members and friends who have been impacted by cancer either under the umbrella of survivors or as secondary survivors (Rowland, 2006; Twombly, 2004). The community of cancer survivors has been vital in advocating for funding and other resources for cancer-related research and programs. Cancer survivorship has been designated as a distinct field of research, focused on health and quality of life issues following active treatment, that is important enough to merit its own set of resources (Feuerstein, 2007; Rowland, 2006). The National Cancer Institute created an Office of Cancer Survivorship in 1996, and several other funding organizations have dedicated cancer survivorship research agendas (e.g., American Cancer Society, LIVESTRONG, Susan G. Komen) (Rowland, 2006).

Although the advocacy and research communities have largely adopted the term ‘cancer survivor’ as a label to describe individuals with a history of cancer, not all individuals with a history of cancer embrace the term (Khan, Harrison, Rose, Ward, & Evans, 2012; Rowland, 2008). There is also not a single agreed upon definition of what it means to be a cancer survivor (Feuerstein, 2007; Khan, Rose, & Evans, 2012), so whether or not men identify as ‘cancer survivors’ is in part predicated on how they interpret the term.

For prostate cancer survivors, the affiliation of the term ‘cancer survivor’ to the breast cancer movement, a feminized movement symbolized by the pink ribbon (Kaiser, 2008), might be another deterrent to embracing the term. However, there are efforts to replicate the pink movement for breast cancer survivors with a blue movement for prostate cancer survivors and over time this may alter the way some men conceptualize

their cancer experience (Kedrowski & Sarow, 2007).

Even among those who do not embrace the term ‘cancer survivor’ and who may not want to be defined by their cancer, cancer might remain an important part of their identity that informs their health behaviors. The extent to which one’s cancer experience remains salient over time might depend on the degree to which cancer resulted in long-term disruptions or caused one to reflect on one’s mortality for the first time (Peck, 2008). Therefore, a man who has long term side effects might integrate his prostate cancer experience into his self-concept differently than a man who has relatively few side effects, and a man who has never had a health scare before may experience cancer differently than a man with many co-morbidities. For men who are deeply affected by their cancer experience, cancer might represent a turning point in their life when they are primed to make life-altering changes (Zebrack, 2000).

#### Gender identity and masculinity

Gender is often conceptualized as a ‘master identity’ that provides context for all aspects of one’s life. Gender norms are socially constructed expectations of how men and women should behave (Hare-Mustin & Marecek, 1988), and one’s gender identity operationalizes how one internalizes these norms as applying to himself or herself. In the U.S., traditional, or hegemonic, masculinity is characterized by traits such as independence, risk-taking, power, invincibility, and being stoic (Courtenay, 2000b). It is important to recognize that there is not a single masculinity, nor is masculinity a static concept (Connell & Messerschmidt, 2005). Rather, a man’s understanding of what it

means to be a man continually evolves through his interactions with others and his interpretation of these events, as well as across the lifespan.

Below is a consideration of ways in which gender identity/masculinity beliefs shape how men process their cancer diagnosis, their current dietary behaviors, and their interest in healthy eating.

- *Cancer identity*: Men are taught to value independence and therefore have been found to be less likely than women to acknowledge having a chronic disease even if this denial results in preventable health complications (Charmaz, 1994; Courtenay, 2000a). Given that having an illness restricts a man's level of independence, masculinity norms would suggest that a man would want to detach himself from his illness identity as soon as he is able to, which is consistent with prostate cancer survivors being less likely to identify as 'survivors' than other types of cancer survivors.
- *Health behaviors*: Gender norms portray men as the more powerful gender, so it is often assumed that being male puts one at an advantage, and while this may be true in some domains, masculinity norms often put men at a disadvantage when it comes to health. Masculinity is characterized by engaging in risky behaviors and being male is one of the biggest predictors of not engaging in preventive health behaviors (Courtenay, 2000a). In the case of prostate cancer survivors, as males they are less likely to be engaging in health promoting behaviors, including healthy eating, prior to their diagnosis (Garfield, Isacco, & Rogers, 2008).
- *Gender and Food*: While masculinity and femininity are not dichotomous

descriptors, often objects and behaviors are labeled as being masculine or feminine as if they were. Foods that are low-fat (e.g., salad) are often considered to be feminine, whereas foods that are high in saturated fat (e.g., steak) are often considered to be masculine (Mroz, Chapman, Oliffe, & Bottorff, 2011b; Newcombe, McCarthy, Cronin, & McCarthy, 2012; Rothgerber, 2013; Ruby & Heine, 2011). Therefore, men can be considered to be at a disadvantage in terms of health promotion because a gendered diet means that men are eating less healthfully than women to begin with, and are also less motivated to make healthy changes that are considered feminine (e.g., dieting) (Wardle et al., 2004).

### **Ecological model of health promotion**

While a prostate cancer diagnosis presents an opportunity for a man to make healthy dietary changes, whether or not these changes occur in part depends on his existing social reality. What is the quality of his diet pre-diagnosis? What are factors that influence the healthfulness of his diet? What are barriers to healthy eating? The ecological model of health promotion is a framework that can be used to categorize determinants of healthy eating. Unlike traditional theories of health behavior that focus solely or primarily on individual level factors that influence behavior change, the ecological model of health promotion emphasizes the importance of the social environment in shaping behavior (Bronfenbrenner, 1997; McLeroy, Bibeau, Steckler, & Glanz, 1988). The ecological model of health promotion describes five levels of influence – intrapersonal factors, interpersonal processes and primary groups, institutional factors,

community factors, and public policy – that reciprocally interact to influence one’s behaviors (McLeroy et al., 1988). The main premise of this model is that the individual and his or her social environment impact one another and an individual’s behavior cannot be fully understood without understanding the social context in which the behavior is occurring. Below is a summary of the types of factors at each level that might influence prostate cancer survivors’ diets.

- *Intrapersonal factors* include knowledge, attitudes, beliefs, behaviors, and self-efficacy. For prostate cancer survivors, intrapersonal factors that may influence the quality of their diet include beliefs about diet and cancer recurrence, interest in healthy eating, knowledge of what a healthy diet entails, taste preferences and perceptions about their ability to make healthy choices (Drummond & Smith, 2006; Sobal & Bisogni, 2009; Wetter et al., 2001).
- *Interpersonal processes and primary groups* encompass the impact of social networks and social support on food choices (Sobal & Bisogni, 2009; Wetter et al., 2001). Wives play an important role in influencing the food choices of their husbands. Traditional gender roles give women primary responsibility for food purchasing and preparation, and therefore men tend to rely on women for food provision (Harnack, Story, Martinson, Neumark-Sztainer, & Stang, 1998; Lachance-Grzela & Bouchard, 2010). Men who live alone have been found to have poorer diet quality than men who live with a spouse (M. A. Davis, Murphy, & Neuhaus, 1988). Food consumption is both a gendered activity and a social

activity and the quality of a man's diet is highly impacted by his social networks (Newcombe et al., 2012; Sellaeg & Chapman, 2008). In the small body of research that has been conducted to date, wives have been identified as important in enabling prostate cancer survivors to successfully make dietary changes (Satia et al., 2009), and wives tend to maintain control over food provision following their husband's cancer diagnosis (Mroz, Chapman, Oliffe, & Bottorff, 2011a). Therefore, wives are an important consideration in any effort to change the dietary behaviors of prostate cancer survivors.

- *Institutional factors* that influence the diets of prostate cancer survivors include the types of food available and the costs of foods at venues where they purchase their food, including grocery stores, restaurants and fast food establishments (Sobal & Bisogni, 2009; Wetter et al., 2001).
- *Community factors* include that availability and accessibility of healthy foods within one's community (Sobal & Bisogni, 2009; Wetter et al., 2001). For example, someone who lives in a food desert might not have access to healthy foods and is limited by the types of food venues that they can access in their community or the surrounding areas.
- *Public policies* include local, state, and national laws and policies that influence food choice (Sobal & Bisogni, 2009; Wetter et al., 2001). For example, zoning polices dictate the types of food establishments that can be built in a community.

The relationship between the various levels of influence is not static, meaning that

a change in one level can result in changes in other levels. In the case of prostate cancer survivors, it is possible that their cancer diagnosis could impact other determinants of healthy eating. For example, more resources might become available to them to enable healthy eating or important others (e.g., physician, spouses) may recommend or facilitate healthy dietary changes. There is a need to better understand how one's cancer experience influences both motivation and capacity for healthy eating.

### **OVERVIEW OF CHAPTERS**

Chapter 2 summarizes the research methods for this dissertation study. Chapter 3 is a manuscript that addresses Aim 1, Chapter 4 is a manuscript that addresses Aim 2, and Chapter 5 is a manuscript that addresses Aim 3. The final chapter, Chapter 6, integrates the findings from the three manuscripts, discusses strengths and limitations, the implications of this research, and proposes areas for future research.

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**CHAPTER 2**  
**RESEARCH METHODS**

## RESEARCH METHODS

This dissertation is a sub-study of *Eating for Life: Dietary Behaviors Among Long-Term Cancer Survivors* (PI: Katherine Clegg Smith, PhD; NCI-OBSSR Grant #1R21CA152789-01A1) [from here on referred to as *Eating for Life*]. The *Eating for Life* study used a mixed-methods approach to explore influences on the dietary behaviors of breast cancer, prostate cancer, and non-Hodgkin's lymphoma survivors. This dissertation used data from the 20 prostate cancer survivors who participated. This chapter outlines the research methods, including sampling and recruitment, data collection methods, analysis, and data quality procedures.

### Sampling and recruitment

#### Prostate cancer survivors

A purposive sample of 20 prostate cancer survivors from the Baltimore-Washington metropolitan area was recruited to participate in the *Eating for Life* study. Minimum eligibility criteria for participation were: between the ages of 45 and 74, at least 3 years post-diagnosis and not currently in active treatment (excluding hormonal therapy). Individuals with metastatic disease or recurrent cancer were excluded. Prostate cancer survivors were recruited during follow-up oncology visits (through chart reviews), and through physician mailings, waiting room flyers, and prostate cancer organizations. Variation was sought on the following characteristics:

- *Age at diagnosis*: Men who are diagnosed with prostate cancer at an earlier age may have more aggressive disease and/or may be impacted differently by the cancer experience in terms of how it effects their everyday lives.

- *Time since diagnosis*: As time from diagnosis increases, if survivors remain cancer free, they may be less motivated to either make or maintain dietary changes that were prompted by their cancer.
- *Type of treatment*: Radiation and surgery are the primary definitive treatments for local or regional prostate cancer. Men with more aggressive disease may also be put on a regimen of hormonal therapy that can result in side effects including weight gain.
- *Race/ethnicity*: Prostate cancer incidence and mortality rates are highest among African Americans, with prostate cancer mortality rates of African American males being more than twice the national average (Howlader et al., 2013).

Whites have the second highest rates of prostate cancer, so adequate representation of both White and African American prostate cancer survivors was sought.

#### Significant others

Prostate cancer survivor participants were asked to identify a person in their life who supported them through cancer treatment and has some influence over their food choices. Participants who identified a significant other signed a permission form permitting me to contact their significant other. After signing the permission form, depending on their preference, participants either provided me with their significant others' contact information (i.e., phone number and/or email address) or were given a letter to share with their significant other that described the study, included my contact information, and requested the significant other contact me to set-up an interview time.

In cases in which permission forms were signed, but I was not contacted by significant others, I contacted prostate cancer survivor participants up to two times by phone and/or email to ascertain their significant others interest in participating in the study.

Of the 20 prostate cancer survivors, two completed the study before recruitment for the significant other sub-study began. Of the remaining 18 men, 14 signed permission forms. Men who did not sign permission forms remarked that their wives/partners would not be interested in participating. Of the 14 men who signed permission forms, interviews with nine significant others were completed – six wives, one partner, one sister, and one cousin. For the five men who completed permission forms but whose significant others were not interviewed, two indicated that their wives decided not to participate, two did not respond to follow-up requests, and one identified an individual who lived outside the Baltimore-Washington metropolitan area and an in-person interview could not be coordinated.

## **Data collection**

### Prostate cancer survivors

Figure 2-1 summarizes the data collection activities. Prostate cancer survivors completed four study contacts. Written consent was obtained from participants at the beginning of the first in-person visit (study contact 1). After consent was obtained, participants completed a structured questionnaire that captured data on health status, health behaviors (e.g., physical activity, tobacco use, alcohol use), and socio-demographic characteristics. Then, they took part in an in-depth cancer identity interview during which they were asked to describe their cancer diagnosis and treatment

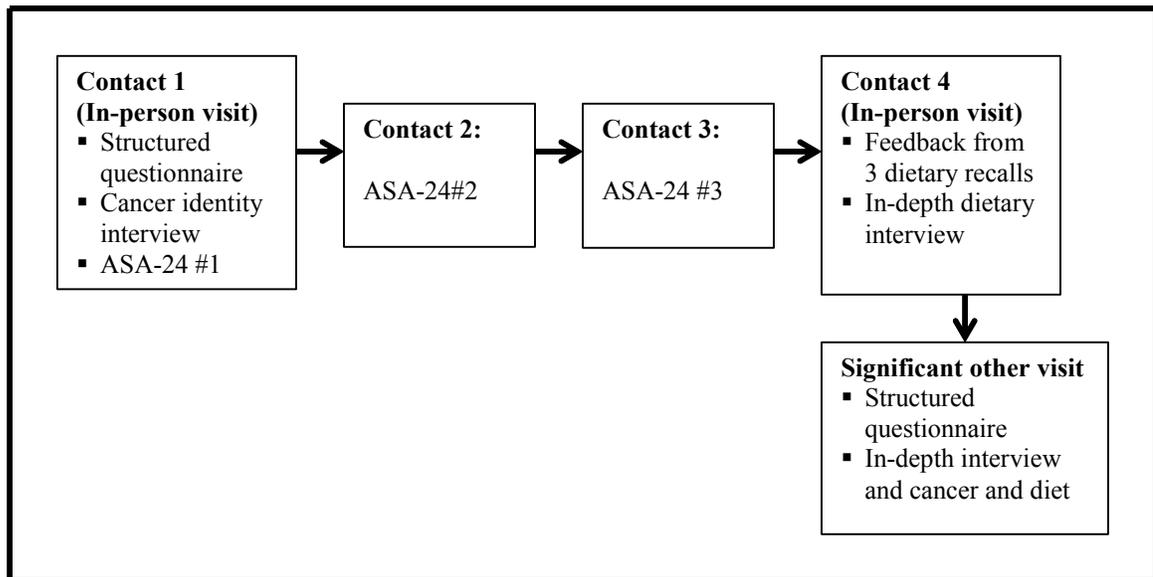
experience, reflect on how cancer has influenced their life from the time of diagnosis through the present time, and how they have integrated their cancer experience into their overall identity (e.g., adoption of a ‘cancer survivor’ identity). Finally, participants completed the first, of three, online 24-hour dietary recalls. The ASA24 (Internet-based Automated Self-Administered 24-hour Dietary Recall), an online 24-hour dietary recall developed by the National Cancer Institute, was used to collect dietary recall data (Subar et al., 2012). The study interviewer was present and available to answer questions, but participants were given written instructions and asked to complete the dietary recall unassisted if possible.

Participants were notified at the end of the first study contact, that they would be contacted on two random days over the next two weeks to complete two additional recalls. Using a standardized protocol from which usual dietary intake can be estimated (Moshfegh et al., 2008), participants completed a total of three recalls during a 14 day period, with two of the recalls collecting dietary intake data for weekdays and one for a weekend. For the second and third recalls (study contacts 2 and 3), the study coordinator contacted participants in the morning via email or by phone to request that they complete the recall by midnight. For participants who required assistance to complete the dietary recall either because they did not have access to a computer or did not feel comfortable completing the recall unassisted, the study coordinator was available to assist them either in person or over the phone.

Approximately one to two weeks after the final dietary recall, participants took part in an in-person prompted dietary discussion (study contact 4). They were given feedback from their dietary recalls and prompted to discuss typical food choices/patterns,

factors that influence their diet, dietary changes made following their cancer diagnosis, and barriers and facilitators to healthy eating. Participants were compensated a total of \$140 in cash and gift cards for completing the various study activities over the course of approximately one month.

**Figure 2-1. Data collection procedures**



### Significant others

At the end of study contact 4, prostate cancer survivors were asked to identify an important person in their life who supported them during their cancer treatment and had some influence over their dietary choices. A one-time in-person visit was scheduled with significant others. Written consent was obtained from significant others at the beginning of the in-person visit. Significant others then completed a brief survey and participated in an in-depth interview. The survey collected information on their health status, health behaviors, and demographic characteristics. The purpose of the in-depth interview was to

obtain significant others' perspectives of how cancer has impacted their lives in general, and their health behaviors specifically. Study visits with significant others were between 60 and 90 minutes, and significant others were compensated \$50 for their time. The Johns Hopkins School of Public Health Institutional Review Board (IRB) approved both the main study and the significant other sub-study.

### **Data analysis**

#### Qualitative in-depth interviews:

The qualitative interview data were analyzed using a constant comparison approach (Charmaz, 2003; Glaser & Strauss, 1967). Each qualitative interview was audio-recorded and transcribed verbatim by a professional transcription company. I then reviewed the transcripts for accuracy. Coding schemes for each type of interview (i.e., cancer identity interview, in-depth dietary interview, and significant other interview) were developed inductively. First, I coded a subset of transcripts on a line-by-line basis largely retaining the terminology of respondents. Next, I developed more focused, conceptual codes to categorize patterns found across cases (Charmaz, 2003). The research questions provided boundaries for the types of codes relevant for each analysis. Throughout the development of the coding schemes, I met with the principal investigator to discuss, test, and refine draft coding schemes. Once the coding schemes were finalized, I coded the full set of transcripts in ATLAS.ti 7, a qualitative data analysis software package helpful for data management (Friese, 2013).

For Manuscript 3 (Chapter 5), in addition to analyzing data for the full sample of 20 prostate cancer survivors to investigate themes related to the roles of wives/partners in

influencing the dietary behaviors of prostate cancer survivors, interview data for pairs of prostate cancer survivors and significant others were analyzed as dyads (Boeije, 2002). Summaries were constructed for each dyad to elucidate views on role of each individual, frequency of eating together, quality of prostate cancer survivor's diet, perceptions of the relationship between diet and cancer, impact of cancer on survivor's diet, and the type of influence the significant other has on the survivor's diet. These summaries facilitated the development of conceptual codes that characterized the role of wives/partners in influencing prostate cancer survivors' diets and facilitated an assessment of the congruency of couples' views.

#### ASA24 dietary recall data

Average values for dietary variables were calculated for each prostate cancer survivor participant across the three recalls. Men's average values for the following dietary variables were compared to criteria based on 2010 Dietary Guidelines for Americans (U.S. Department of Agriculture and U.S. Department of Health and Human Services, December 2010) to assess adherence: calories, fiber, calcium, vitamin D, sodium, cholesterol, saturated fat, vitamin D, fruits and vegetables, and alcohol. These dietary variables were selected because they are consistent with the American Cancer Society recommendations for cancer survivors (Rock et al., 2012)

Healthy Eating Index-2010 scores were also calculated for an overall rating of diet quality (Guenther et al., 2013). The HEI-2010 score is made up of 12 components – adequate consumption of total fruit, whole fruit, total vegetables, green vegetables and beans, whole grains, dairy, total protein foods, seafood and plant proteins, and fatty acids;

and moderate consumption of refined grains, sodium and empty calories (i.e., added sugars, solid fats, and consumption of alcohol above moderate levels, which for men is two drinks per day). The HEI-2010 score was calculated for each participant using mean values from the three dietary recalls as an estimation of usual intake. The calculation was conducted using SAS macros available online through the National Cancer Institute (<http://appliedresearch.cancer.gov/hei/tools.html>).

Men were rank ordered using HEI-2010 scores, and an extreme case analysis with the five men with the highest quality diets and the five men with the lowest quality diets was conducted as part of Manuscript 2 (Chapter 4) (Caracelli & Greene, 1993; Creswell & Plano Clark, 2011). To identify differences in the dietary beliefs and behaviors of men with higher HEI-2010 scores and men with lower HEI-2010 scores, men's dietary data were analyzed qualitatively to identify frequently consumed foods and food consumption patterns, and in-depth interview data were explored to assess men's perceptions of typical eating patterns and perceived influences on diet.

### **Credibility**

Credibility is a concept used to assess rigor in qualitative research. Green & Thorogood (2009) propose five criteria of a rigorous qualitative analysis: transparent, maximizes validity, maximizes reliability, comparative, and reflexive. Below is a summary of how I attended to these issues in this study.

*Transparent:* Transparency is achieved by being explicit about the methods used.

Memo-writing was the primary means of tracking coding related decisions (Charmaz,

1990), and was used to document the analysis process from generating codes to brainstorming associations between codes. To further ensure transparency, reports of findings detail how the sample was constructed, data collection methods, the specific analyses conducted, and include verbatim quotes to enable the reader to draw his or her own conclusions from the data.

*Maximizes validity:* Throughout the analysis, deviant cases that challenged developing hypotheses were searched not only to disconfirm associations, but also to enable a richer understanding of the phenomenon at hand. In some instances, disconfirming evidence actually represents nuances of a complex phenomenon. In either case, all relevant findings were reported.

*Maximize reliability:* Although the analysis of the same data by a different investigator would not necessarily yield the same results as mine, I sought to improve the reliability of findings by including another researcher (the principal investigator) in the development of the coding scheme.

*Comparative:* Comparison was used throughout the analysis process to identify patterns within codes and between codes. In reports, the findings from this study are compared to the larger evidence base to assess the extent to which the findings either corroborate or contrast existing research.

*Reflexive:* This criterion embraces the fact that the research data are a product of the interaction between the researcher and participants. In recognizing that data are a research product, it is necessary to be explicit about the methodological decisions made and the theoretical assumptions framing the study. For instance, gender theory informed the design of this study, and this is explicitly acknowledged in write-ups of findings. I was initially concerned that men might be hesitant to discuss their ongoing cancer related concerns, especially those related to sexual functioning and incontinence. However, I found that men were extremely open. Some men would preface statements by asking my comfort with their discussing these topics and once I conveyed my comfort, they continued with their accounts.

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**CHAPTER 3**

**MANUSCRIPT 1:**

**CONTINUED SALIENCE OF CANCER IN MEN WITH A HISTORY OF**

**PROSTATE CANCER: FACTORS INFLUENCING ADOPTION OF A**

**‘CANCER SURVIVOR’ IDENTITY**

## **ABSTRACT**

**Background:** Experiencing cancer can disrupt one's self-concept, and adopting a 'cancer survivor' identity has been hypothesized as a positive adaptive strategy that can account for limitations caused by cancer. It has also been posited that individuals who adopt a 'cancer survivor' identity adjust better than those who espouse other cancer-related identities (e.g., victim, patient, ex-patient). However, many men with a history of prostate cancer do not identify as 'survivors.'

**Purpose:** To examine factors that influence whether men with a history of prostate cancer identify as cancer survivors.

**Methods:** In-depth interviews were conducted with 20 prostate cancer survivors. Men were first asked to provide written responses to the question "Who am I?" During the interview, which focused on men's cancer experience and the current salience of cancer in their lives, participants were asked whether they considered the term 'cancer survivor' to apply to them and their rationales. The interviews were audio-recorded and transcribed verbatim. A constant comparison approach was used to analyze the interview data, and a pile sort was conducted to categorize written "Who am I?" responses.

**Results:** Four factors emerged as influencing men's adoption of the term 'cancer survivor' – how men conceptualized the term; not wanting to be defined by their cancer experience; significance of their cancer experience in comparison to other important life events; and their perception of 'cancer survivor' as a unifying versus stigmatizing term. Men appeared not to construct their self-concept around their cancer experience but rather around family roles, other social roles, demographic and physical characteristics, religion, career, hobbies, and personality traits.

**Conclusions:** Most men in our study did not identify as cancer survivors, and those who did described it as being less salient than other important identities (e.g., family roles, career roles). For many men, cancer was portrayed as something that happened in the past and men expressed an ability to go back to life as normal after undergoing treatment. Public health programs for prostate cancer survivors need to consider the implications of designing ‘cancer survivor’ centered programs, and identify alternative strategies for engaging men who do not espouse a ‘cancer survivor’ identity.

## INTRODUCTION

There are more than 2.7 million men living with a history of prostate cancer in the United States (de Moor et al., 2013). An estimated fifteen percent of men will be diagnosed with prostate cancer in their lifetime, and almost all men (99.2%) survive at least 5 years following a prostate cancer diagnosis (Howlader et al., 2013). While historically the goal of treatment has been surviving the cancer, given that most men with prostate cancer will live many years following their diagnosis, there has been a gradual expansion in focus to health and quality of life during the post-treatment survivorship phase (Institute of Medicine & National Research Council, 2005).

Fitzhugh Mullan, a physician and cancer survivor, was the first to apply the concept of ‘survivorship’ to cancer (Mullan, 1985). He described a three-stage model of survivorship: *acute survival*, from the time of diagnosis throughout the time that individuals undergo active treatment for their cancer; *extended survival*, which commences at the completion of acute treatment; and *permanent survival*, the period during which the likelihood of cancer recurrence is minimal. Thus, what Dr. Mullan labeled as extended and permanent survival comprise what is currently referred to as the post-treatment survivorship phase.

A focus on survivorship has generated interest in how individuals with a history of cancer incorporate their cancer experience into their self-concept and the implications for their wellbeing/quality of life. There are different ways in which individuals with a history of cancer might internalize their illness experience. Deimling, Kahana, & Schumacher (1997) proposed four labels that represent different orientations towards cancer – survivor, victim, patient, and ex-patient. The *survivor* label implies some sort of

ownership over cancer and possibly a belief that the cancer is ‘cured,’ while *victim* suggests a lack of control over the illness, continuing vulnerability, and possibly a fatalistic attitude; *patient* is suggestive of a reliance (or overreliance) on the medical system after the completion of active treatment; and *ex-patient* signifies a distancing of oneself from their cancer and may represent a lack of long-term impact of the illness on one’s identity.

‘Cancer survivor’ has arguably become the dominant term to describe individuals with a history of cancer (Michael Feuerstein, 2007; Twombly, 2004). It has been posited that people who adopt a ‘survivor’ identity adjust better to having cancer than people who adopt alternative cancer-related identities (Zebrack, 2000). Most research exploring the benefits of adopting a ‘cancer survivor’ identity has focused on wellbeing; adopting a ‘cancer survivor’ identity has been found to be associated with enhanced wellbeing (Bellizzi & Blank, 2007; Chambers et al., 2011; Park, Zlateva, & Blank, 2009). It has also been hypothesized that those who adopt a cancer survivor identity might be more motivated to engage in health promoting activities that can improve their health and quality of life but this has not been empirically tested (Deimling, Bowman, & Wagner, 2007; Harwood & Sparks, 2003; Zebrack, 2000), with the exception of one study that found no association between cancer identity type and levels of physical activity or body mass index (Chambers et al., 2011).

Identity theory provides a framework for understanding the process by which a cancer diagnosis can prompt formation of a new identity (Burke & Stets, 2009). Although there are various conceptualizations of identity, I use the term identity to represent social roles that individuals hold (e.g., father, employee, etc.) that together form

the basis of their self-concept. Behavioral expectations tied to particular roles are a means by which people substantiate their self-esteem (Burke & Stets, 2009). In the case of prostate cancer, being unable to validate important identities (e.g., being a husband, being a provider) may disrupt men's self-concept (Charmaz, 1994), and lower self-esteem. Adopting a cancer-related identity enables men to account for the limitations caused by cancer. This new identity reflects a new understanding of life priorities that accompanies the illness experience and may facilitate positive adjustment (Zebrack, 2000).

Despite the potential benefits of identifying as a 'cancer survivor,' not all men with a history of prostate cancer embrace this label. In fact, they have been found to be less likely to endorse a survivor identity than individuals with a history of other types of cancer (Bellizzi & Blank, 2007; Deimling et al., 2007). Many men select more neutral labels to describe themselves in relation to their cancer, such as "a person who has had cancer," which suggests a distancing of their cancer experience from their current self-concept.

There are various factors that might influence men's identification as a cancer survivor. One consideration is men's perceptions of the gravity of their disease. While historically *cancer* has been classified as a 'life-threatening' illness, improvements in early detection and treatment have resulted in improved survival rates. With almost all men (99.2%) surviving at least 5 years following a prostate cancer diagnosis, rather than 'surviving' cancer being viewed as an accomplishment, it is possibly engaged with as the expected outcome. Certain men might still view prostate cancer as 'life-threatening' or 'life changing,' but others may not.

Another consideration is the perceived consequences of adopting such a label. Prostate cancer survivors are by definition men and therefore gender norms could play an important role in how men come to understand what it means to be a cancer survivor. In the U.S. where masculinity is characterized by being strong, independent, and in control (Connell & Messerschmidt, 2005; Courtenay, 2000), espousing a ‘cancer survivor’ identity can potentially be viewed as extending men’s association with their illness and therefore contrary to masculine ideals (Tannenbaum & Frank, 2011). Alternatively, given that prostate cancer is a sex-specific disease and potentially affects men’s sense of masculinity through its impact on sexual functioning and continence, it is possible that adopting a ‘cancer survivor’ identity can serve a coping strategy that accounts for these side effects while allowing men to preserve their sense of masculinity in other aspects of their lives.

There is no universally agreed upon definition of what it means to be a cancer survivor (M. Feuerstein, 2007; Khan, Rose, & Evans, 2012), so whether or not men identify as a cancer survivor is in part predicated on how they interpret the term. Various stakeholders have defined ‘cancer survivor’ differently. For example, advocacy groups tend to be inclusive and define survivors as anyone who has been diagnosed with cancer from the time of their diagnosis through the remainder of their lives, and some even include family members as ‘survivors’ (Twombly, 2004). Some researchers restrict the term ‘cancer survivor’ as pertaining to individuals who have completed acute treatment to differentiate cancer survivorship from other phases of the cancer trajectory (M. Feuerstein, 2007). Individuals with a history of cancer have also been found to define

‘cancer survivor’ in different and sometimes contradictory ways (Khan, Harrison, Rose, Ward, & Evans, 2012).

To meet the ongoing needs of men with a history of prostate cancer, it is important to understand how cancer impacts their self-concept. There is a need to explore how men who have completed treatment identify in terms of their cancer and whether cancer continues to be salient in the lives of these men. Given the prominence of ‘cancer survivor’ as a label for individuals who have been diagnosed with cancer and the theorized benefits of espousal of such an identity, this study examines how men with a history of prostate cancer define the term ‘cancer survivor’ and whether they perceive the ‘cancer survivor’ identity as applying to them.

## **METHODS**

### **Sample**

The men who participated in this study were recruited as part of the Johns Hopkins *Eating for Life* study, which explored cancer salience in the lives of individuals who had completed cancer treatment and the influence of cancer on their diets. While the overall study included a purposive sample of individuals with a history of breast cancer, prostate cancer, or non-Hodgkin’s lymphoma, this analysis is limited to the sub-sample of 20 prostate cancer survivors. Participants were between the ages of 45 and 74, diagnosed at least 3 years prior, and did not have metastatic cancer. Variation was sought in terms of treatment type; self-reported race; and time since diagnosis given the potential impact of these characteristics on the experience of cancer treatment and survivorship. Participants were recruited from the Baltimore-Washington metropolitan area during oncology

follow-up visits (through chart reviews), and through physician mailings, waiting room flyers, support groups, and other cancer-related organizations. This study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Table 3-1 summarizes the characteristics of the sample. Men were on average 64.2 years old and 4.5 years post-diagnosis. Men self-identified as white or black, most were married, more than half were still working, and most had at least a college degree and a household income of \$100,000 or more. Fourteen of the 20 men had at least one comorbidity, with hypertension being the most common (n=11). Sixteen men were either overweight or obese according to body mass index (BMI) calculated using self-reported weight and height.  $BMI = \text{weight (kg)} / [\text{height (m)}]^2$

<http://www.cdc.gov/en/HealthSafetyTopics/HealthyLiving/HealthyWeight/AssessingYourWeight/BodyMassIndex/AboutBMIAdults>).

**Table 3-1. Prostate cancer survivors' demographic characteristics**

	<b>Prostate cancer survivors (n=20)</b>
<b>Age</b>	64.2 (range: 50, 74)
<b>Race</b>	
Black	7
White	13
<b>Marital status</b>	
Married/living as married	15
Widowed/divorced/separated	5
<b>Occupation status</b>	
Employed	11
Retired	7
Disabled	2
<b>Educational attainment</b>	
Completed high school	2
Post-high school training	1
College graduate	5
Postgraduate	12
<b>Household income</b>	
\$10,000 to \$34,999	3
\$35,000 to \$49,999	1
\$50,000 to \$74,999	4
\$100,000 or more	10
Refused	2
<b>Self-reported health status</b>	
Excellent	5
Very good	11
Good	3
<b>Co-morbidities (# responding affirmatively)</b>	
Hypertension	11
Arthritis	5
Depression	6
Diabetes	2
Heart attack	2
Angina	1
Heart failure	1
Cirrhosis	1
Stroke	1
<b>BMI</b>	
Normal (18.5 – 24.9)	4
Overweight (25.0 – 29.9)	11
Obese (30.0 and above)	5

## **Data collection**

Participants completed a structured questionnaire, two in-depth interviews, and three 24-hour dietary recalls over a period of approximately one month. This analysis is based on data from the first in-person study visit. At the beginning of this visit, written consent was obtained from participants. Participants then completed a self-administered survey that included questions on demographic characteristics, health status, and health behaviors, and were also asked to respond to the question “Who am I?” on a sheet of paper with 10 blank spaces. Next, participants then took part in an in-depth interview about their cancer experience and the current relevance of cancer on their lives. Men were specifically asked if they identified as a ‘cancer survivor’ and the meaningfulness of this label to them. The interviews were audio recorded and professionally transcribed verbatim.

## **Analysis**

The interview transcripts were analyzed using a constant comparison approach (Charmaz, 1990). I began by reviewing the transcripts for accuracy. Then, I familiarized myself with the data by open coding, which served as the basis for inductively developing a coding scheme. The principal investigator and I met to discuss the coding scheme. We each, individually, applied the draft coding scheme to a subset of transcripts, discussed our decisions, and made revisions, including the addition of conceptual codes. Once the coding scheme was finalized, I coded the full set of transcripts using ATLAS.ti 7 (Friese, 2013). Specific codes that informed this analysis were *cancer identity* (the extent to which individuals identify as cancer survivors and

their rationales), *cancer survivor* (how participants define the term cancer survivor), and *meaningfulness* (perceptions of how meaningful one's cancer experience was in one's overall life). During the analytic process it became evident that issues of *mortality*, *comparisons to others*, and *other important life events* were central to how men identified in terms of their cancer, and therefore codes specific to these topics were incorporated into the analysis as well. Throughout the analysis, I engaged in memo writing to document my analytical process.

Pile-sorting: Participant's written responses to the question, "Who am I?" were separated and sorted into piles to identify patterns in the ways men identified themselves (Ryan & Bernard, 2003). Both identical and similar items were grouped into larger categories that represented different means by which men defined themselves.

## **RESULTS**

In men's assessment of the applicability of the term 'cancer survivor' to how they think of themselves, four primary themes emerged: (1) variation in how the term 'cancer survivor' is defined; (2) not wanting to be defined by their illness – a desire to move forward; (3) the salience of cancer relative to other defining life events; and (4) cancer survivor as a unifying vs. stigmatizing term.

### **Meaning of 'cancer survivor'**

At a fundamental level, most men responded affirmatively when asked if they were cancer survivors because they had technically 'survived' cancer. They used terms such as "beat[ing] it," being "lucky," and "surviv[ing] the Big C" to describe what it

meant to be a ‘survivor.’ Yet, their responses became more nuanced as they reflected further on what the term ‘cancer survivor’ meant. There was not a single definition of ‘cancer survivor’ that men gave. Men defined cancer survivor in terms of: being ‘cancer free’; specific timeframes; perceived risk of mortality; and extensiveness of treatment.

### Cancer free

For some men an important component of being a survivor was physical and concrete - the cancer was no longer present in their body. One man described it as “*I no longer have knowledgeable cancer in my system. I’m not being treated for it, I don’t exhibit...any symptoms of it.*” Men often referred to a low PSA score as indicative of the cancer being gone. “*...In the last 3 years based on the PSA results it’s been negative...it seems to me that that is what the doctor believes in.*” There was a sense for some that ‘survivor’ was not necessarily a permanent label. They qualified their definitions of survivor with phrases as “*so far,*” accepting the fact that the cancer could recur and their status could change. Though, most men conveyed a belief that their chance of recurrence was low.

### Timing

A few men referenced specific time frames linked to survivorship (e.g., 5 or 10 years). “*They say survivorship really takes effect after 5 years, so you’re still in the back of your mind...thinking, okay, I got to get to this milestone. But you know I’m very positive in thinking that it’s all okay...I kind of say...let’s make sure you live life and enjoy it instead of worrying about getting the five years.*” This participant heard five

years was a significant marker of being a survivor, but considered himself a survivor before reaching that point. Specific timeframes were deemed artificial because there was no guarantee of cure. As another man remarked, *“Right now they say it’s been ten years and your cured. As a physician, I don’t believe it. I mean no one’s God and we have people that after ten, fifteen years they may get some reoccurrence.”*

#### Perceived risk of mortality

Other men described being a ‘survivor’ in relation to their perceived risk of mortality. One man referred to his wife who had a history of non-Hodgkin lymphoma as a survivor *“because...she almost died,”* but did not see this term as applying to him because he did not feel at risk of dying from prostate cancer. Several other men also held this sentiment that prostate cancer was not a life-threatening disease. Comparisons were made to the experiences of individuals diagnosed with cancers that had worse prognoses, *“Well I think the term cancer survivor to most people means that you had like lung cancer...or something that’s about to zero you out. Prostate cancer is so common, that’s why I wouldn’t consider myself a cancer survivor. Although I realize it could take me out. God can take you out at any time.”* While he acknowledged the possibility of death, he did not view it as a likely outcome. Several men discounted the survivor identity because they perceived prostate cancer as common in men of a certain age. One man stated, *“I think what I’ve been told is that prostate cancer is an endemic disease and if you’re 70 years old, chances are that you’ll have prostate cancer are 70%, 80 years old an 80% chance...so I’m not horrified because the odds.”*

In contrast, there were other men who did perceive prostate cancer as a life

threatening disease because they had personal experiences with friends and family members who died from prostate cancer. Therefore, they identified as ‘survivors’ because they were cognizant that the outcome could be different. One man recounted losing a friend who had been diagnosed at the same time as him as being influential in his identification as a cancer survivor. *“Since I lost my two friends, yes, I consider myself a survivor...One of them, we were diagnosed at the same time and he said, ‘I’m not going to do anything,’ ...so that’s why I consider myself a survivor. He died last October.”*

#### Extensiveness of cancer treatment/experience

Men had prevailing notions of a ‘cancer survivor’ archetype and used this as an indicator of the applicability of the label to them. A few men commented on the relevance of treatment type in characterizing men as survivors. Men treated solely with surgery often described men who went through chemotherapy or other more involved treatments as being ‘survivors.’ As one man remarked, *“I think I would tend to think of those people that through the chemotherapy or other drugs manage to delay it or eliminate it as surviving it as opposed to those of us that were just able to go under the knife and have it excised.”* A man who had a prostatectomy likened his experience to having an appendectomy. *“I feel like it was a medical problem that had to be taken care of and we took care of it, and we were fortunate enough to catch it early, so I consider myself to be cured and don’t really view it you know as any different than somebody who goes in for another procedure for an appendectomy or something. It’s just you know you do it and move on.”* Another man portrayed men who were debilitated by the cancer experience as being the real survivors. *“A cancer survivor I think it’s somebody*

*that...was debilitated or had cancer that really affected their life...and somehow they overcome that.... It beat you or it knocked you over but you picked yourself up and moved on. And it may not be the same capacity you had before but you moved on and you beat it.”*

No single definition emerged as the predominant interpretation of what it meant to be a cancer survivor. Consequently, how men defined the term influenced whether they considered the label ‘cancer survivor’ as pertaining to them.

### **“I don’t let it define me”**

Most men, including those who self-identified as survivors, mentioned that they did not use the term ‘cancer survivor’ to describe themselves in their everyday lives. One man said, *“I haven’t, but I think I could, but like I said, I don’t talk about it. If someone would say, ‘Do you think you’re a?’ ‘Yes, I do. I am’... so far all of the PSAs have come back 0.01”* Another man spoke of an experience where he was introduced as a cancer survivor as catching him off guard. *“And just within the last year...somebody introduced me and said, ‘Oh [name’s] a cancer survivor’...I don’t think of myself that way.”*

For the most part, men viewed their cancer as something that occurred in the past and was no longer relevant to their self-concept. *“Cancer is not something I think about. I don’t carry it around as a burden. I experienced it, it did change me in certain ways but it’s not something I deal with on a daily basis or even think about on a daily basis.”* Only one participant included cancer survivor as a response when asked to write up to 10 words or phrases that described who he was; he listed survivor after “American male,”

“African American,” “happily married,” and “grandfather.” When verbally describing himself, another man described several things and ended with “*Oh, I didn’t even think about the cancer thing. Cancer survivor guy, I guess.*” The nature of the study prompted him to include this information, but it did not appear to be something he would naturally include in a description of himself.

Men’s self-concept appeared to be constructed around important social roles, accomplishments, personality traits, and physical characteristics. When asked to respond to the question “Who Am I?” participants listed important family roles they held (e.g., husband, father, grandfather, son, brother, uncle), other social roles, demographic and physical characteristics, religion, their specific careers and employment status (e.g., employed, retired), their hobbies and interests, and personality traits (Figure 3-1).

**Figure 3-1. Responses to “Who am I?” exercise (n=# of mentions)**

<p><b>Family roles (n=37)</b></p> <ul style="list-style-type: none"> <li>▪ Husband (10)</li> <li>▪ Father (12)</li> <li>▪ Grandfather (5)</li> <li>▪ Son (3)</li> <li>▪ Brother (3)</li> <li>▪ Uncle (2)</li> <li>▪ Family oriented (2)</li> </ul>	<p><b>Demographic attributes (n=19)</b></p> <ul style="list-style-type: none"> <li>▪ Name (4)</li> <li>▪ Male (4)</li> <li>▪ Race/ethnicity (3)</li> <li>▪ Human being (3)</li> <li>▪ Adult (2)</li> <li>▪ Educated (2)</li> <li>▪ Age (1)</li> </ul>	<p><b>Religion (n=4)</b></p> <ul style="list-style-type: none"> <li>▪ Christian (2)</li> <li>▪ Religious (1)</li> <li>▪ Knowledgeable about religions (1)</li> </ul>	<p><b>Career related (n=21)</b></p> <ul style="list-style-type: none"> <li>▪ Retired (=5)</li> <li>▪ Employed, employee (3)</li> <li>▪ Specific career, position (13)</li> </ul>
<p><b>Other social roles (n=7)</b></p> <ul style="list-style-type: none"> <li>▪ Friend (6)</li> <li>▪ Neighbor (1)</li> </ul>	<p><b>Physical status (n=10)</b></p> <ul style="list-style-type: none"> <li>▪ Overweight (2)</li> <li>▪ Physically active (2)</li> <li>▪ Healthy (2)</li> <li>▪ Sedentary (2)</li> <li>▪ Handsome (1)</li> <li>▪ Handicapped (1)</li> </ul>	<p><b>Hobbies/interests (n=10)</b></p> <ul style="list-style-type: none"> <li>▪ Gardener (2)</li> <li>▪ Reader (2)</li> <li>▪ Sports (2)</li> <li>▪ Traveler (1)</li> <li>▪ Stock market investor (2)</li> <li>▪ Dog lover (1)</li> </ul>	<p><b>Personality traits<sup>1</sup> (n=57)</b></p> <ul style="list-style-type: none"> <li>▪ Caring (4)</li> <li>▪ Fortunate (4)</li> <li>▪ Committed (3)</li> <li>▪ Friendly (2)</li> <li>▪ Loving (2)</li> <li>▪ Considerate (2)</li> <li>▪ Fun (2)</li> <li>▪ Funny (2)</li> <li>▪ Enjoy life (2)</li> <li>▪ Positive (2)</li> <li>▪ Determined (2)</li> </ul>

<sup>1</sup>Only listed traits with at least 2 mentions

Men’s verbal descriptions of themselves generally mirrored the written ones; however, inclusion of age or life stage was more prominent during the interviews than in the written activity. Men specified their age or reflected on where they were in their life trajectory, with statements such as “*middle aged,*” “*past middle age,*” and “*looking forward to the final stage of life.*” One participant directly compared the importance of cancer and age, specifying that it was his age, and not the cancer that “*impacts the way I live my life.*” In describing the relevance of age to their self-concept, older men especially reflected on their mortality and expressed a desire to make the most of their “*final stage.*”

One way in which prostate cancer was a potentially defining experience was through its impact on men's sense of masculinity. Almost all the men in our study suffered from issues related to sexual functioning (i.e., erectile dysfunction, no libido). Men conceptualized their inability to have sex as making them less of a man: *"I know I'm not that man I once was."* Those who underwent hormone therapy recalled that as an especially challenging time. One man commented, *"I could have been a girl, not a boy,"* to encapsulate the hot flashes and lack of desire to have sex when receiving hormone therapy. Several men also dealt with incontinence to varying degrees and had to adjust to not being able to control a bodily function. *"If anybody would tell me that at this stage at my life that I will be wearing a pull up. I would say no."*

Men rationalized that these side effects were minimal in comparison to the alternative of losing their life. *"I lost another friend I met 10 years ago...He didn't want any treatments. He said it affects your libido. He died in February."* Nevertheless, it was evident that men still struggled with these issues when they made statements like *"It would be nice to know that I could have sex whether or not I would do it or not,"* or *"I used to enjoy sex a lot, but now it's like...I'm trying to fine tune myself towards accepting reality."*

Although men continued to cope with side effects, men portrayed an ability to compartmentalize these issues and move forward with their lives. Men's other defining characteristics, including being a dad/granddad or being a provider, remained unaffected, and continued to be what men prioritized in their self-concept.

### **Salience of cancer relative to other defining life events**

Men often explained the significance of their cancer experience as being shaped by other defining life events, such as the death of a family member. One survivor remarked, *“I retired back in '95 and then my wife died. The second day of the new millennium from a asthma attack...that experience there might have prepared me for this episode with the cancer.”* Another man who lost a son said *“It [the cancer] was up there but there’s nothing worse than losing a child. That was the life changing experience because when I had that I literally became a non-person for about 15 years. I lost contact with society. That was not the effect that cancer had on me.”* Thus for these men, cancer was depicted as less traumatic, and therefore less defining, than it perhaps would have been if they had not had these experiences beforehand.

For others, cancer did compare in importance to other meaningful life events. A veteran compared experiencing cancer to being in combat. He said, *“I served in combat and after having served in war in Somalia and Mogidishu you know I said I survived that. I said I never wanted to be in combat or war again. And in 2003 I said I’m back in combat and war and this time the killer is within.”* For this man, cancer was a meaningful experience and he elevated it to the level of another defining aspect of his life – being at war.

Like being in combat, for this participant being diagnosed with cancer was a transformative experience, and it redirected his career path. He said, *“I got involved in a cancer organization and groups and going out and teaching and a year or two afterwards I was at the hospital...and a gentleman came by and said, ‘You came to my church and gave a talk and your talk was so motivating and so power that I went and had*

*my PSA and digital rectal exam and they found I had cancer but they caught it early so because of you I'm cured...So I said to myself I think that God is really wanting me to be a messenger and that's what I've been doing."* Despite the impact of cancer on his life, he described a hesitancy to lead with being a 'cancer survivor' in his day-to-day encounters outside of work. He remarked, *"I go on living my life. I don't wear it on my forehead, and I don't go out and badger people."*

### **Cancer survivor: stigmatizing or unifying?**

Although being a 'cancer survivor' was not continually at the forefront of men's self-concept, there were times, places, and situations when it became salient. For instance, when they heard a story about another survivor. One man said *"That sort of popped up when I hear about and see it on TV or something that I'm a cancer survivor. [Other than that] I really don't look at myself like a cancer survivor."*

Men talked about 'cancer survivor' being a meaningful identity when they were around other individuals with a history of cancer because it was unifying term. *"I survived the cancer so I consider myself a survivor at this time and trying to go out in the community and help other people so that they do not develop the terminal phase of this illness of prostate cancer."* Another man described an innate bond among men with a history of prostate cancer. *"I found out when I start addressing...other prostate cancer survivors, and they're like, 'Wow, he gets it. He knows.' And so, I called us the Reluctant Brotherhood. Nobody signed up for this fraternity but... once you're in it, [you're in it]."*

While some men were open with their experience and willing to share it with anyone, other men considered their cancer experience to be private, and were selective in

whom they shared this information with. It was not something they openly shared with everyone as illustrated by one man who stated: *“I think a lot of guys that I love and trust when and if they are confronted with the same outcome or same diagnosis on a case by case basis, I probably would give them good counsel. Would I necessarily be the billboard for men who disclose and they advise on the telltale signs of prostate cancer? Probably not.”*

Men who were hesitant to disclose their history of cancer provided different rationales for not doing so. Some men expressed concern that others would use their cancer experience against them. One man commented, *“I mean, people can be conniving and completely changed this whole situation around...They don’t go as far and say prostate cancer. It’s just like prostate...They could just use a little bit of information taken out of context can be devastating. They’re thinking that it’s something completely different, like it’s almost something contagious when they say that.”* Other men reported not wanting to talk about it because of prostate cancer’s association with impotence and incontinence; there was a certain amount of shame that came with experiencing prostate cancer. One man stated, *“I know this is sort of a generalization I’m about to make but I think a lot of men’s purpose in life seems to be below the waist.”*

Men who conceptualized ‘cancer survivor’ as a unifying term often told stories that illustrated the need for disclosure. *“Two years ago, when I was at [church name] and Bishop [name] said ‘All those that have been impacted by prostate cancer, please come to the altar’ and we got fifty or sixty men get up...They keep saying ‘Joe I didn’t know you had it.’ No one talks about it. It was amazing to see all these people coming to the altar.”* A few men perceived this lack of disclosure as precluding men from receiving

needed social support and preventing dissemination of important information. One man described an experience where a friend of his publicly shared his prostate cancer experience during a fraternity meeting in an effort to contest the silence around prostate cancer. He said, *“He found out there were five or six other guys in the chapter that had it and never said nothing to anybody, and we shouldn’t be doing that. We should be saving each other some steps and sharing with each other what’s going on... But that’s the kind of thing that men need to do far more of. You find out there’s a whole lot of folks out there with some issues, males that don’t talk about it.”*

## **DISCUSSION**

Men’s perception of the term ‘cancer survivor’ and its applicability to them varied considerably. This is indicative of the experience of cancer not being the same for all men. Some men described prostate cancer as not being a particularly meaningful or traumatic experience in their lives, and thus cancer would not warrant adoption of a new identity. Although cancer is currently regarded as a chronic illness (Tritter & Calnan, 2002), many men described an ability to compartmentalize their illness experience and return to their lives as normal with little to no disruption. Men’s conceptualization of prostate cancer seemed to vacillate between chronic and acute. It was acute in the sense that men, especially those treated with surgery, viewed it as being effectively treated and no longer a concern. However, men continued to be actively monitored through regular PSA testing and dealt with ongoing side effects.

It became evident that responding to the question “Do you identify as a cancer survivor?” was not as straightforward as it initially appeared. Men’s responses were

contingent on how the term was defined and were also context-specific. Previous efforts to explicate cancer survivorship have found that an experience has to be sufficiently life-altering to warrant adoption of such a label (Doyle, 2008; Peck, 2008). Men's portrayal of going back to life as usual after prostate cancer is contrary to adopting a survivor identity when it is defined in this manner. The men in our study wanted to be defined in terms of their accomplishments, such as important family roles and their careers, rather than by their illness, even if it was a transformative experience.

Men's resistance to be defined by their cancer experience can be better understood employing a masculinity lens. Sickness can be viewed as a threat to one's masculinity because it causes one to be dependent on others (Tannenbaum & Frank, 2011), and adopting a cancer related identity could be viewed as prolonging one's association with their illness. Additionally, the primary side effects of prostate cancer (i.e., impotence, incontinence) further challenge one's sense of masculinity (Chapple & Ziebland, 2002; Fergus, Gray, & Fitch, 2002; Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002). Instead of adopting a label that has a potentially negative connotation, men conveyed a desire to put their cancer behind them and move on with their lives. Men accounted for their ongoing side effects as a comparatively small price to pay to save their life, which arguably minimized the impact of ongoing side effects on their overall self-concept.

Some men recognized potential benefits of identifying as a cancer survivor and openly disclosing their history of cancer. Even though prostate cancer is so ubiquitous in older men, many men go through it alone. Our data suggest that though cancer survivor might not be an overarching or master identity that is central to one's self-concept, it may

be an important role-based identity (Thoits, 1991). Being a ‘cancer survivor’ becomes relevant when men are around other men who are recently diagnosed or have a history of prostate cancer because it allows them to connect and share experiences.

This analysis focused specifically on prostate cancer survivors, which can be viewed simultaneously as a strength and limitation. Cancer is essentially multiple diseases with different etiologies that have been grouped together because they all involve the proliferation of abnormal cells (Tritter & Calnan, 2002). Hence, the experiences of cancer survivors can vary markedly as illustrated by men in this study who often compared their experiences to the experiences of survivors of other types of cancers. Though this analysis is based solely on the experiences of men with a history of local or regional prostate cancer, it provides insight into the types of factors that may influence the illness experience and subsequent adoption of a ‘cancer survivor’ identity (e.g., perceived risk of mortality, treatment type).

Our finding of ‘cancer survivor’ meaning different things to different people is consistent with other studies that have included multiple types of cancer survivors (Deimling et al., 2007; Khan, Harrison, et al., 2012). Perceived risk of recurrence/mortality was frequently mentioned in men’s discussion of whether or not they identified as a ‘cancer survivor.’ Unfortunately, I did not collect participants’ stage or grade of disease, which is predictive of recurrence, and thus could impact men’s perceptions of severity of disease. Future research should systematically examine how factors associated with prognosis, such as stage, grade, race/ethnicity, and age, impact men’s identification as a survivor or not.

Despite these limitations, this study provided an in-depth look into the meaning and perceived applicability of the term ‘cancer survivor’ for men with a history of prostate cancer. Furthermore, the design of the study enabled men to reflect on the salience of a ‘cancer survivor’ identity in relation to other important identities, which is important because over time the importance of one’s cancer experience may wane and other aspects of one’s self-concept may grow in salience.

The findings from this study can inform public health efforts aimed at improving the health and wellbeing of prostate cancer survivors. It is important to recognize that the experience of cancer is not homogeneous for all men. Consequently, men’s interpretation and integration of their cancer experience, and therefore their needs after completion of treatment vary. For certain men being around other men with a history of prostate cancer may be therapeutic and for them group-based ‘cancer survivor’ programs may be beneficial. Other men with ongoing issues related to side effects and/or fear of recurrence may want to work through these issues privately and may benefit more from one-on-one activities. Still others have moved on from (or successfully adjusted to) their cancer experience and the focus for them may be ensuring that they are adhering to cancer surveillance guidelines and attending to or tracking other potential co-morbidities. As the number of prostate cancer survivors in the U.S. continues to grow, so will the significance of understanding the meaning of life after cancer and how best to support men after they have completed active treatment.

## **IMPLICATIONS FOR HEALTH PROMOTION**

Previous studies have posited that individuals who identify as ‘cancer survivors’ may be more likely to engage in health-promoting activities to reduce their risk of recurrence or other health issues (Deimling et al., 2007; Harwood & Sparks, 2003). Many of the men in our study did not identify as ‘cancer survivors,’ and those who did, did not rank it as a being central to their self-concept. Furthermore, most men regarded their chance of recurrence as being relatively low. Consequently, the potential motivators to engage in health promoting activities in relation to their cancer were lacking. Men need to be made aware of health risks related to their cancer and that engaging in health behaviors, such as healthy eating and physical activity, can minimize their risks. However, programs that are formed specifically for ‘prostate cancer survivors’ might miss a considerable portion of men with a history of prostate cancer who do not identify in this way. Future research needs to identify modifiable factors that shape prostate cancer survivors’ health behaviors as well as identify strategies for increasing identity-based motivation to engage in healthy behaviors.

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**CHAPTER 4**  
**MANUSCRIPT 2**  
**INFLUENCES ON THE HEALTHFULNESS OF**  
**PROSTATE CANCER SURVIVORS' DIETS**

## **ABSTRACT**

**Background:** There is growing evidence that prostate cancer survivors can benefit from adopting a diet high in fruits and vegetables and low in saturated fats. Cancer is often conceptualized as a teachable moment when men might be more motivated to make healthy dietary changes. Despite this, many men are not adhering to dietary guidelines. There is a need to better understand the factors that influence prostate cancer survivors' diet quality.

**Purpose:** This study seeks to assess the healthfulness of prostate cancer survivors' diets and to identify diet-related factors that differentiate men with healthier diets from men with less healthy diets.

**Methods:** Twenty prostate cancer survivors completed three 24-hour dietary recalls over the course of two weeks and then participated in an in-depth dietary interview about their dietary habits. Dietary recall data were used to calculate adherence to selected dietary guidelines and overall dietary quality, as measured by the Healthy Eating Index 2010. In-depth interview data were analyzed using a constant comparison approach. An extreme case analysis was conducted to ascertain commonalities and differences between men with healthier diets and men with less healthy diets.

**Results:** There was considerable variability in the healthfulness of prostate cancer survivors' diets. Men were most likely to most likely to adhere to fruit and vegetable and alcohol recommendations, and least likely to meet fiber and sodium recommendations. Men with more healthful diets had regular eating schedules, prioritized health in food choice decisions, and incorporated a variety of fruits and vegetables into their diets while minimizing consumption of fatty foods (e.g., chips, French fries) and foods with added

sugar (e.g., cookies, ice cream); whereas men with less healthful diets either had inconsistent eating patterns or ate few meals each day, prioritized taste in food choice decisions, and were more likely to consume red meat, fatty and sugary foods, and less likely to consume fruits and vegetables. Weight loss and diet-related co-morbidities (e.g., hypertension) were mentioned as motivators for healthy eating. Men with less healthy diets described more barriers to healthy eating, including lack of time to prepare healthy foods and negative influences of significant others.

**Conclusions:** Although cancer is often conceptualized as a teachable moment that might prompt men to make healthy dietary changes, men described factors other than their history of cancer as being more influential in their food choices. Given that weight loss was frequently mentioned as a motivator for healthy eating, public health programs should consider alternative ways of framing healthy eating programs that might be more effective than a cancer-specific focus. Programs also need to attend to men's negative perceptions of healthy foods as bland and time-consuming to prepare.

## INTRODUCTION

There are more than 2.7 million prostate cancer survivors in the United States (de Moor et al., 2013). Almost all men who are diagnosed with prostate cancer (99.2%) live at least 5 years from their time of diagnosis (Howlader, Noone, & Krapcho, 2013); however, they continue to face health issues including long term side effects from the cancer and its treatment, both physical (e.g., urinary incontinence, impotence, and bowel dysfunction) and psychological (e.g., fear of recurrence, distress from physical side-effects) (Bloom, Kang, Petersen, & Stewart, 2007). Cancer survivors are also at increased risk of a second cancer, developing other chronic conditions, such as cardiovascular disease and diabetes, and functional decline compared to adults without a history of cancer (Aziz, 2007; Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005).

There is growing evidence demonstrating the positive impact that healthy diet can have on the health and quality of life of cancer survivors (Chris M Blanchard et al., 2004; Chan, Van Blarigan, & Kenfield, 2014; Demark-Wahnefried, 2007; Pekmezi & Demark-Wahnefried, 2011; Rock et al., 2012). The American Cancer Society recommends that prostate cancer survivors “should strive to achieve and maintain a healthy weight, pursue a physically active lifestyle, and consume a diet that is rich in vegetables and fruits and low in saturated fat, with reliance on dietary sources of calcium that are within moderate levels” (Rock et al., 2012). However, many prostate cancer survivors do not adhere to dietary guidelines that could improve their health (C. M. Blanchard, Courneya, & Stein, 2008; Coups & Ostroff, 2005; Mayer et al., 2007).

There are a multitude of factors that influence one’s food choices (Sobal & Bisogni, 2009); however, gender is consistently found to be an important determinant of

one's diet. Men are less likely than women to consume fruits and vegetables and high fiber foods, and are more likely to consume saturated fat, red meat, and alcohol, putting them at higher risk of diet-related diseases (Beardsworth et al., 2002; Courtenay, 2000a; Wardle et al., 2004). In the case of cancer survivors, both prostate cancer survivors and male cancer survivors in general are less likely to report making dietary changes following their diagnosis than female cancer survivors (Demark-Wahnefried et al., 2005), supporting the significance of gender in shaping one's diet and interest in making healthy dietary changes.

A social constructionist perspective provides a framework for understanding how gender, and in the case of prostate cancer survivors masculinity norms, influences one's dietary behaviors (Courtenay, 2000c; Garfield, Isacco, & Rogers, 2008). According to social constructionism, individuals learn expected behaviors through interactions with others in their social environment (Berger & Luckmann, 1992). From the time men are young boys, they are socialized to a particular understanding of what it means to be a "man." In the U.S., traditional, or hegemonic, masculinity is characterized by traits such as independence, risk-taking, power, invincibility, and being stoic (Courtenay, 2000b). There are social pressures for men to conform to gender norms (Courtenay, 2000c), and men's expression of masculinity can take the form of engaging in health-risking behaviors, including substance use, reckless driving, high-risk sexual activities, and fighting (Courtenay, 2000a; Garfield et al., 2008; Mahalik, Burns, & Syzdek, 2007).

It is important to recognize that there is not a single masculinity, nor is masculinity a static concept. Rather, a man's understanding of what it means to be a man continually evolves through his interactions with others and his interpretation of these

events (Burke & Stets, 2009). Furthermore, how one constructs their masculinity is shaped by other factors, including culture, socioeconomic status, age, and life stage (Courtenay, 2000b). For instance, older men are confronted with opportunities to reconstruct their understanding of what it means to be masculine in response to life transitions, such as retirement, widowhood, and health issues, that challenge their existing beliefs about masculinity (Gradman, 1994; Smith, Braunack-Mayer, Wittert, & Warin, 2007; Tannenbaum & Frank, 2011; Van den Hoonaard, 2007).

Specific food choices can be conceptualized as an expression of one's masculinity (Mróz, Chapman, Oliffe, & Bottorff, 2011; Newcombe, McCarthy, Cronin, & McCarthy, 2012). Men and women tend to have different objectives in constructing food choices. Women often strive to attain lean figures and select healthier foods, such as fruits and vegetables and lean sources of protein, to facilitate weight loss (Turrell, 1997; Wardle et al., 2004). Men, on the other hand, often want to bulk up or build muscle and view food as a source of fuel to do this (Wardle et al., 2004). More than any other food, red meat is a symbol of masculinity (Rothgerber, 2013; Sobal, 2005). Given that dietary guidelines tend to reflect feminine eating norms (e.g., increased consumption of fruits and vegetables, decreased consumption of red meat), rejection of these guidelines may essentially serve as an assertion of masculinity (Beardsworth et al., 2002; Gough & Conner, 2006; Mróz et al., 2011). Not surprisingly perhaps, men who hold more traditional beliefs about masculinity tend to have poorer diets than those who adopt less traditional beliefs (Courtenay, 2003).

A cancer diagnosis can represent a turning point in one's life, a time when men may be more open to making dietary changes that are inconsistent with masculine ideals

in an effort to preserve their health (Mroz, Chapman, Oliffe, & Bottorff, 2011; Sobal & Bisogni, 2009). However, as noted earlier, many prostate cancer survivors are not making changes to their diet following their diagnosis and have diets that do not conform to dietary guidelines. There is a need to better understand important influences on the quality of prostate cancer survivors' diets and the ways in which a cancer diagnosis might impact existing dietary norms, including a willingness to incorporate more 'feminized' foods into their diet. This study seeks to:

1. Assess the healthfulness of the diets of prostate cancer survivors;
2. Compare the dietary features of men with "healthier" diets to those of men with "poor" diets (e.g., eating patterns, what types of foods do they consume); and
3. Compare perceived influences on diet quality for men with "healthier" diets to men with "poor" diets.

## **METHODS**

### **Sample**

Participants were recruited as part of the Johns Hopkins *Eating for Life* study, which explored determinants of healthy eating among people with a history of breast cancer, prostate cancer, or non-Hodgkin's lymphoma. A purposive sample was constructed of individuals in the Baltimore-Washington metropolitan area who were between the ages of 45 and 75, diagnosed at least 3 years prior, completed acute treatment (excluding hormone therapy), and did not have metastatic or recurrent cancer. Variation was sought in terms of treatment type, time since diagnosis, and self-reported race because of the possible influence of these characteristics on one's experience of

cancer treatment and survivorship. Participants were recruited during follow-up oncology visits (through chart reviews), through physician mailings, waiting room flyers, support groups and cancer-related organizations. This study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

This analysis is restricted to the 20 prostate cancer survivors who participated in the overall study. Men had been diagnosed an average of 4.5 years ago (range: 3 to 10 years). Table 4-1 summarizes the demographic characteristics of the prostate cancer survivors. Men were on average 64.2 years old, self-identified as white or black, most were married, more than half were still working, and most had at least a college degree and a household income of \$100,000 or more. Fourteen of the 20 men had at least one comorbidity, with hypertension being the most common (n=11), and 16 men were classified as either overweight or obese based on body mass index calculated using self-reported weight and height.

**Table 4-1. Prostate cancer survivors' demographic characteristics**

	<b>Prostate cancer survivors (n=20)</b>
<b>Age</b>	64.2 (range: 50, 74)
<b>Race</b>	
Black	7
White	13
<b>Marital status</b>	
Married/living as married	15
Widowed/divorced/separated	5
<b>Occupation status</b>	
Employed	11
Retired	7
Disabled	2
<b>Educational attainment</b>	
Completed high school	2
Post-high school training	1
College graduate	5
Postgraduate	12
<b>Household income</b>	
\$10,000 to \$34,999	3
\$35,000 to \$49,999	1
\$50,000 to \$74,999	4
\$100,000 or more	10
Refused	2
<b>Self-reported health status</b>	
Excellent	5
Very good	11
Good	3
<b>Co-morbidities (# responding affirmatively)</b>	
Hypertension	11
Arthritis	5
Depression	6
Diabetes	2
Heart attack	2
Angina	1
Heart failure	1
Cirrhosis	1
Stroke	1
<b>BMI</b> weight(kg)/[height (m)] <sup>2</sup>	
Normal (18.5 – 24.9)	4
Overweight (25.0 – 29.9)	11
Obese (30.0 and above)	5

## **Data collection**

Participants completed study activities over the course of approximately one month. Written consent was obtained from participants at the beginning of the first in-person visit. During the first in-person visit, participants: (1) completed a structured questionnaire on demographics characteristics, health status, and health behaviors; (2) took part in an in-depth interview about their cancer experience and the current relevance of cancer in their lives; and (3) completed the first of three 24-hour dietary recalls using the Automated Self-Administered 24-hour Recall (ASA-24), a web-based self-administered 24-hour dietary recall system (Subar et al., 2012). During the next two weeks, the study coordinator contacted participants on two random days to request that they complete the dietary recall prior to midnight, for a total of three 24-hour dietary recalls. Two of the recalls collected data about weekdays and one about a weekend (Sunday) to facilitate calculation of usual intake (Moshfegh et al., 2008). One to two weeks after the final dietary recall, participants came in for a second in-person visit where they received structured feedback from their dietary recalls and took part in an in-depth interview about their eating habits. Participants received a total of \$140 in remuneration for completing study activities.

## **Analysis**

This analysis is based on data from the dietary recalls and the in-depth dietary interviews.

### 24-hour dietary recalls

Dietary recall data were used to assess the number of men meeting selected dietary recommendations. Mean values of the following dietary variables were computed for each participant: calories, fiber, calcium, vitamin D, sodium, cholesterol, saturated fat, vitamin D, fruits and vegetables, and alcohol. These variables were selected because they reflect aspects of the American Cancer Society recommendations for cancer survivors (Rock et al., 2012). The 2010 Dietary Guidelines for Americans criteria were used to assess adherence (U.S. Department of Agriculture and U.S. Department of Health and Human Services, December 2010).

The dietary data were also used to assess overall diet quality. The Healthy Eating Index 2010 (HEI-2010) score was calculated to rank the diet quality of men participating in this study (Guenther, Casavale, Reedy, et al., 2013). The HEI-2010 score is made up of 12 components – adequate consumption of total fruit, whole fruit, total vegetables, green vegetables and beans, whole grains, dairy, total protein foods, seafood and plant proteins, and fatty acids; and moderate consumption of refined grains, sodium and empty calories (i.e., added sugars, solid fats, and consumption of alcohol above moderate levels, which for men is two drinks per day). The HEI-2010 score was calculated for each participant using mean values from the three dietary recalls as an estimation of usual intake. The maximum HEI-2010 score is 100.

### In-depth dietary interviews

The in-depth, semi-structured dietary interviews were audio recorded, transcribed verbatim by a professional transcription company, and analyzed using a constant

comparison approach (Glaser, 1964). A coding scheme was developed inductively. I began by reviewing each transcript for accuracy, which facilitated familiarization with the data. I then line-by-line coded a subset of seven in-depth dietary interviews, which included three interviews with prostate cancer survivors and four with breast or non-Hodgkin's survivors who participated in the larger study. I drafted a coding scheme that included both descriptive and conceptual codes, and reviewed the draft coding scheme with two members of the study team. Incorporating feedback from study team members, I revised the coding scheme. After finalized the coding scheme, I coded the full set of transcripts using ATLAS.ti 7 (Friese, 2013).

#### Extreme case analysis

The dietary data and in-depth interviews for the five men with the healthiest diets and the five men with the least healthy diet diets [as ranked by HEI-2010] were compared to identify commonalities and differences between the two groups. Memos for each of the ten men were constructed to summarize their eating patterns and important influences on diet quality. The dietary data were analyzed qualitatively to identify frequently consumed foods and eating food patterns, and the in-depth interviews assessed men's perceptions of typical eating patterns and perceived influences on diet. Data from the ten men with middle ranking HEI-2010 scores were also analyzed to assess whether unique themes emerged from these men's data. I modeled my analysis approach after that used by Klassen et al (2009) in which a mixed-method analysis of 24-hour recall data from 156 women was conducted to enable comparisons between women with high cancer prevention diet scores and women with low cancer prevention diet scores.

## RESULTS

### Healthfulness of prostate cancer survivors' diets

Table 4-2 summarizes selected 2010 Dietary Guidelines for Americans recommendations and the extent to which the prostate cancer survivors in our study were adherent to them. Men were most likely to be adherent to alcohol (n=17) and fruits and vegetables (n=13) recommendations, and were least likely to be adherent to fiber (n=1) and sodium (n=0) recommendations. Using a liberal cutoff of 2,200 calories, only 9 of the 20 men were consuming recommended quantities of food, suggesting that in addition to dietary quality, overeating may be an issue for many men.

**Table 4-2. Prostate cancer survivors' adherence to dietary guidelines**

	<b>Dietary Guidelines for Americans, 2010</b>	<b>Average value (range)</b>	<b># meeting recommendation (n=20)</b>
<b>Calories</b>	<2,200kcal	2,455 kcal (1,458; 3,489)	9 of 20
<b>Alcohol</b>	2 drink per day maximum (28g)	9.4g (0; 49.8g)	17 of 20
<b>Fruits and vegetables</b>	2.5 cups or more	3.9 cups (1.0; 10.1)	13 of 20
<b>Cholesterol</b>	Less than 300mg	388mg (126; 854)	7 of 20
<b>Saturated fat</b>	Less than 10% of kcal	11.4% (4.2; 16.7)	6 of 20
<b>Calcium</b>	1,000mg if 45-50 years; 1,200mg if 51 years or older	991mg (466; 1,899)	5 of 20
<b>Vitamin D</b>	15mcg or more if 70 years or less; 20mcg or more if older than 70 years	7.2mcg (.97; 31.5)	2 of 20
<b>Fiber</b>	38g or more	22.4g (7.5; 63.5)	1 of 20
<b>Sodium</b>	2,300mg	4,273mg (2,668; 6,688)	0 of 20

Given that the amount of food men were eating varied substantially, I calculated men's HEI-2010 score to rank the overall healthfulness of their diets. The HEI-2010 score is calculated using the amount of food groups consumed and the ratio of unsaturated to saturated fatty acids per 1,000 calories, so it is not impacted by overall

caloric intake. The average HEI-2010 score was 56.7, with a range from 36.4 to 82.0 [maximum score: 100] (Table 4-3). This is similar to the mean score of 53.5 for the U.S. population (Guenther, Casavale, Kirkpatrick, et al., 2013).

**Table 4-3. HEI-2010 component and total scores [from highest to lowest total score]**

Rank	Total vegetables (out of 5)	Greens and beans (out of 5)	Total fruit (out of 5)	Whole fruit (out of 5)	Whole grains (out of 10)	Total dairy (out of 10)	Total protein (out of 5)	Seafood and plant protein (out of 5)	Fatty acids (out of 10)	Sodium (out of 10)	Refined grains (out of 10)	Excess calories (out of 20)	TOTAL SCORE (out of 100)
1	5.00	5.00	5.00	5.00	4.68	10.00	5.00	5.00	8.31	1.09	7.88	20.00	81.97
2	5.00	5.00	4.30	5.00	2.14	5.57	5.00	5.00	10.00	3.94	7.70	19.43	78.07
3	3.54	2.84	5.00	5.00	10.00	1.50	5.00	2.01	4.76	8.90	10.00	14.05	72.60
4	5.00	5.00	5.00	5.00	3.89	6.22	5.00	5.00	6.22	0.70	8.00	16.80	71.84
5	5.00	5.00	5.00	5.00	1.65	3.17	5.00	5.00	8.02	1.41	10.00	17.40	71.64
6	4.51	5.00	5.00	5.00	6.03	1.85	5.00	5.00	7.60	3.26	5.72	16.42	70.39
7	4.28	5.00	2.15	4.25	2.32	5.20	5.00	5.00	5.48	0.00	8.65	16.97	64.31
8	3.45	2.77	3.73	4.61	1.18	8.08	5.00	5.00	4.54	6.96	7.87	8.84	62.04
9	3.41	3.26	2.14	0.00	5.08	3.35	5.00	5.00	5.84	1.89	10.00	16.92	61.89
10	5.00	5.00	1.49	2.90	1.88	4.38	5.00	5.00	3.06	0.00	10.00	15.65	59.35
11	1.29	0.00	3.77	5.00	6.00	4.04	5.00	1.81	2.59	7.30	10.00	8.52	55.32
12	5.00	4.83	4.34	5.00	1.66	4.25	3.77	2.04	3.82	1.69	5.18	9.90	51.50
13	2.03	4.40	4.48	2.09	1.48	2.80	5.00	5.00	2.64	6.71	7.80	3.38	47.81
14	2.68	1.20	3.58	3.34	2.13	2.12	5.00	3.88	4.22	5.28	6.05	7.59	47.07
15	5.00	3.06	1.24	1.42	2.12	4.02	5.00	0.03	1.19	1.31	9.93	11.12	45.42
16	2.90	2.90	1.53	1.80	0.00	0.94	5.00	1.27	2.80	3.84	1.28	17.56	41.82
17	4.08	2.91	0.00	0.00	5.63	5.08	5.00	0.00	2.07	0.00	0.38	13.94	39.09
18	1.88	3.08	0.60	1.21	0.24	2.51	5.00	0.05	4.39	3.47	4.92	11.42	38.77
19	3.11	0.07	0.59	1.18	1.65	6.85	4.65	2.27	1.22	0.62	2.49	13.01	37.71
20	5.00	0.00	0.91	1.78	0.10	5.05	4.63	0.02	5.15	0.88	0.00	12.84	36.36

## **Distinguishing characteristics of “healthier” diets and “poor” diets**

To ascertain potential contributors to variation in diet quality, I compared the diets of the men with “healthier” diets (the five men with the highest HEI-2010 scores, ranging from 71.6 to 82.0) with the diets of men with “poor” diets (the five men with the lowest HEI-2010 scores, ranging from 36.4 to 41.8)<sup>1</sup>. The following patterns emerged in examining HEI-2010 component scores: men with healthier diets consumed more total fruit, whole fruit, green vegetables and beans, and seafood and plant-based protein than men with poor diets; the ratio of unsaturated to saturated fats was higher in men with healthier diets; and consumption of refined grains and empty calories was lower among men with healthier diets. There tended to be more variation within groups for intake of total vegetables, total dairy, whole grain, and sodium as evidenced by the variation in these HEI-2010 component scores (Table 4-3).

A qualitative assessment of dietary recall data and in-depth interviews elucidated aspects of the structure of eating occasions and the selection of specific foods that provide insight into contributors of these differences.

### Structure of eating occasions

Frequency of eating has been found to be associated with nutrient intake, with individuals who eat more frequently and those who consume breakfast, having higher nutrient intake than others (Kerver, Yang, Obayashi, Bianchi, & Song, 2006). This held true for the men in our study. Men with healthier diets were more likely to have a regular eating schedule, such as three meals or meals with snacks interspersed. As Figure 4-1

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<sup>1</sup> From this point on, “men with healthier diets” will refer to the men with the top 5 HEI-2010 scores, and “men with poor diets” will refer to the men with bottom 5 HEI-2010 scores.

illustrates, there were defined eating times and spacing between meals. Regardless of the actual schedule, a key feature was the consistency of the schedule across days. Men's interview data further supported a regular schedule with men explaining away deviations from the dominant schedule as atypical.

**Figure 4-1. Example of healthier diet (HEI-2010 score: 82.0)**

<b>Day 1</b>	
7:30 a.m.	Plain bagel, apple, 8oz yogurt, and 6oz skim milk
12:00 p.m.	Jelly sandwich on wheat bread, 8oz yogurt, and 8oz bottled water
3:00 p.m.	Apple
6:00 p.m.	Chicken breast with creamy Italian dressing, 2 cups rice, 1 $\frac{3}{4}$ cups broccoli, 1 cup salad with iceberg lettuce, artichoke hearts, tomatoes, croutons and vinaigrette dressing, and 8oz skim milk
8:00 p.m.	2 scoops Edy's ice cream, $\frac{3}{4}$ cup pretzels, and 6oz fruit juice
<b>Day 2</b>	
8:00 a.m.	2 cups Raisin Bran with milk, 5.6oz coffee with coffee mate and skim milk, and 8oz glass skim milk
11:00 a.m.	Peanut butter sandwich on whole wheat bread, apple and 6oz water
3:00 p.m.	2 Nature Valley granola bars, apple, and 17 pieces dry roasted peanuts
6:00 p.m.	6oz breaded pork chop, 1 $\frac{1}{2}$ cups baked potato with Italian dressing, 2 cups cauliflower, and 8oz skim milk
8:00 p.m.	1 $\frac{3}{4}$ cups Chex Party mix, 10 pieces Wheat Krisps, and 6oz prune juice
<b>Day 3</b>	
7:00 a.m.	Yogurt, 4oz coffee with skim milk and sugar, miniature apple bagel, and 8oz milk
12:00 p.m.	Jelly sandwich on wheat bread, apple, and 7.2oz water
3:00 p.m.	Apple
4:00 p.m.	$\frac{3}{8}$ cup dry roasted peanuts, 1 wheat cracker, and 8oz skim milk
6:30 p.m.	4oz ham luncheon meat, 1 cup baked beans, chicken hot dog, 1 $\frac{1}{2}$ cups broccoli, 1 cup salad with romaine lettuce, cherry tomatoes, onions, and vinaigrette dressing, and 8oz skim milk
8:00 p.m.	$\frac{3}{4}$ cup party mix and 3.6oz water

In contrast, men with poor diets were less likely to have a regular eating schedule and the frequency of their meals varied each day as illustrated in Figure 4-2. Those who did have a regular schedule tended to eat less frequently than men with higher scores, often limiting their food consumption to once or twice a day. Men with poor diets often ate their first meal in the mid-morning or afternoon (i.e., later than breakfast time). As shown in Figure 4-2, although this participant drank coffee early in the morning, presumably when he first woke up, his first eating occasion was many hours after that.

**Figure 4-2. Example of a poor diet (HEI-2010 score: 37.7)**

<b>Day 1</b>	
7:00 a.m.	12oz coffee
8:00 a.m.	12oz coffee
10:30 a.m.	Sports bar and 12oz coffee
12:30 p.m.	12oz coffee and 12oz water
4:00 p.m.	8.4oz coffee and 12oz water
7:15 p.m.	6 slices meat pizza and 12oz coffee
<b>Day 2</b>	
5:45 a.m.	12oz coffee
6:00 a.m.	12oz coffee
9:00 a.m.	12oz coffee and 8oz water
10:45 a.m.	Oatmeal raisin cookie and 9.6oz coffee
12:01 p.m.	12oz coffee and 8oz water
2:00 p.m.	1 ½ cup beef chili and 8oz water
3:00 p.m.	1 piece Strawberry shortcake, 9.6oz coffee, and 8oz water
7:30 p.m.	2 cups cereal (unknown kind) with ½ cup skim milk and 12oz coffee
<b>Day 3</b>	
8:45 a.m.	9.6oz coffee and 12oz coffee
1:30 p.m.	4 blueberry pancakes with ¼ cup lite Log Cabin syrup, 3 slices pork bacon, and 12oz coffee
4:00 p.m.	12oz coffee
6:30 p.m.	1 cup spaghetti with meat sauce, 1 slice bread, 1 cup parmesan chicken with ½ cup tomato sauce, 5.6oz wine, and 12oz beer
8:30 p.m.	½ cup chocolate pudding with ¼ cup light whipped cream, and 12oz coffee

### Selection of specific foods

In addition to the structure of eating patterns, the specific foods and food groups that men's diets were comprised of contributed to differences in diet quality scores.

- ***Men with healthier diets got more of their protein from lean sources, such as chicken and seafood.*** Though most men in both groups received the maximum score for total protein intake, men with healthier diets ranked higher in terms of seafood and plant-based protein consumption. Men with poor diets got more of their protein from red meat, while those with healthier diets obtained more of their protein from fish or chicken. Men's interview data revealed that limited consumption of red meat was intentional for many. One man with a healthier diet who professed his love for red meat reduced his consumption due to the negative impact it had on his cancer risk. *"Before I had cancer...I wasn't conscious of what I ate, I just ate anything, anything and everything...Like I love red meat, I ate a lot of red meat...So now I'm conscious of red meat. That has changed a lot."* Others described reducing consumption of red meat in an effort to combat co-morbidities, such as cardiovascular disease. Men with poor diets conveyed a knowledge that too much red meat was not good for them, and some even expressed a desire to reduce their intake, but they continued to consume more red meat than other types of proteins.
- ***Men with healthier diets consumed fewer refined grains.*** Several men in both groups articulated an interest in reducing their intake of grains, but men with healthier diets often selected whole grains instead of refined grains (e.g., whole wheat bread, high fiber wraps), while men with poor diets ate more refined grains (e.g., white bread, white rice, pasta, muffins). In interviews, men with healthier diets described

deliberately seeking out whole wheat and high fiber products. *“When I look at the food labels, I’m looking for fiber...so fiber’s something that’s important to me because it’s good for you, and it also fills you up.”* One man with a poor diet who tried to reduce his refined grain intake described cost as a barrier to consistently using multigrain bread in place of white bread. He noted, *“the price of that [multigrain bread], you could buy three loaves of [white] bread, or at least two. It was expensive...I’ll take it for sandwiches, but I did have white bread.”*

- ***Snacking patterns contributed to men with poor diets consuming more foods with empty calories (i.e., foods with solid fats or added sugars), and men with healthier diets consuming more fruits and nuts.*** While men in both groups enjoyed foods with empty calories, men with poor diets ate greater amounts in part because their snacks consisted almost entirely of these foods. Men with healthier diets alternated between snacking on these items and healthier choices, such as nuts and fruits. Thus, men’s snacking patterns also contributed to a higher intake of fruit among men with healthier diets. Men with healthier diets voiced pleasure in eating fruit. One man with a healthier diet described his ideal day as *“two chicken sandwiches and a whole bunch of fruit.”* Alternatively, several men with poor diets described an aversion to fruit. *“It’s messy. It’s dirty. It sticks. Hands get all slopped up. My parents love fruit but I never liked fruit.”*
- ***Men with poor diets were more likely to drink alcohol at levels above moderate consumption.*** Most of the men in this study were either non-drinkers or drank moderately, but men with poor diets were more likely to drink alcohol at levels above moderate consumption and also to drink alcohol more frequently. One participant

with a poor diet described consumption of wine as a regular part of his and his partner's diet, "*We'll drink a bottle of wine a night.*"

### **Perceived influences on diet quality**

Men described taste and health as the two primary factors influencing their food choices. Men's specific motivations for healthy eating and perceived capacity to eat healthy impacted whether taste or health was prioritized in their food choices.

#### Taste versus health

During interviews men described overarching influences on their food choices. The key conundrum emerging from interviews was a dilemma between selecting foods that tasted good and foods that were healthy. Men in both groups often viewed foods that were good for them and foods that were tasty as mutually exclusive. In fact, one man conceptualized a healthy diet as, "*probably a very boring one.*" Men with healthier diets emphasized health-related factors as influencing their food choices (e.g., low fat items, high antioxidant levels, etc.). "*So I guess I got kind of this internal thing and I look at it and I gauge whether I think it's healthy or not, and if I think it's not healthy, then more consideration goes into whether I eat it or not.*" When men with healthier diets discussed the types of foods they ate they often used phrases such as "*supposed to be good for me,*" and voiced the proposed benefits of the specific foods they were consuming. For example, one man incorporated black rice into his diet because of its high antioxidant levels. "*I'm into this black rice now and it supposedly has more*

*antioxidants than even blueberries and blackberries, and actually it's pretty good.*" He emphasized the health benefits and secondarily commented on its taste.

In contrast, men with poor diets described prioritizing taste in the selection of foods they ate: *"I'd have blueberry pancakes every morning and then I would have pizza every night."* Though they often portrayed an awareness of the healthfulness, or lack thereof, taste preferences often won out. *"Most of the time it's probably chicken and spaghetti. Spaghetti, I shouldn't be eating that much spaghetti, you know, with all the calories in it, but I love it."*

Even men with healthier diets who prioritized health over other considerations conveyed a need to include treat or "cheat" foods. *"My only problem time is eating after dinner, like most people I afford myself ice cream, you know, why not?"* They also wanted sufficient variety in their diet to prevent boredom. A survivor who reported making significant changes following his cancer diagnosis commented, *"This [sticking to his healthy eating regimen] is a lot of discipline. I think it was good. It was good for a while, but I'm getting bored with it."*

Some men presented being fortunate in their preferences towards healthy foods such that they struggled less with the choice between taste and health benefits. *"I just prefer – what I like is coincidentally healthy."* However, more often in constructing their diet, men had to make compromises between eating the foods they like and the foods that were good for them.

### Motivators for healthy eating

Considering the tension between healthy foods and tasty foods, for men to choose healthy options, they have to perceive benefits of doing so. Although cancer is often thought of as a teachable moment or turning point when men might adopt lifestyle behaviors, such as healthy eating, to reduce their risk of recurrence, for the men in our study this was not frequently cited as a motivation for healthy eating. There was a lack of consensus on the effectiveness of healthy eating in reducing risk of recurrence. It was the men who perceived a relationship between diet and recurrence that reported making changes. More commonly, men did not perceive themselves to be at risk of recurrence. *“It’s gone. That’s it. It’s not like I went through any period of like chemotherapy or anything. They cut it out and that was gone. I was okay, and it has been like 10 years I guess, something like that.”*

By far the primary motivator for healthy eating cited was weight loss, particularly for men with poor diets. They viewed healthy eating with a focus on portion control, often in conjunction with exercise, as an effective strategy for weight loss. *“I really want to lose weight and I have lost and I’m continuing to lose weight. And I know that eating the right foods can help me do that.”* Most men also had co-morbidities, such as hypertension, and described other lifestyle related diseases they had as motivators for healthy eating.

More often than not, men described a cumulative effect in which healthy eating became more of a priority as the number of diet-related issues they faced increased. As one man put it, *“I said my luck’s not good. I had a heart attack and then I had cancer...so why don’t you pay attention to you eating. I mean that kind of was it. I*

*mean it's like, alright, you know, you want to stay around a while longer, pay attention to what you're eating."*

#### Perceived capacity to eat healthy

Both those with healthier diets and those with poor diets talked about healthy eating as being within their control and a matter of willpower. One man with a poor diet commented, *"I don't think there's anything really to prevent me from eating healthier. It's a choice isn't it? ...It's a choice and I try to make the right choice, but it's not always done."* Part of this was related to the taste versus health deliberation. The unhealthy options were often viewed as more appealing and this temptation often thwarted men efforts to make healthy choices. In general, men with healthier diets were more apt to discuss facilitators of maintaining a healthy diet, whereas men with poor diets described difficulties with willpower or other barriers to healthy eating.

Healthy eating was viewed as time consuming by certain men. Lack of time led some men to rely heavily on eating out, and they acknowledged the choices available to them were less healthy than if they prepared their own food at home. One man with a busy work and extracurricular activity schedule went to Subway or a similar establishment daily for lunch, and had a sandwich, drink and either cookies or chips. Then, on the weekends he was regularly on the go and relied on fast food or restaurants for his meals as well. He was coming upon retirement and portrayed retirement as a period when he would have more time to dedicate to healthy eating and regular exercise. *"What I'm looking forward to is I know when I'm [retired]...I'll eat at home. I won't go out and eat, and then I'll eat on a more regular basis."* Men in both groups highlighted

the need for simplicity and desired healthy foods that they could just “*walk in and pick it up and eat it.*”

Interestingly, although men conceptualized healthy eating as being within their control, several men described their wives or partners as influencing the healthfulness of their diet. Men with healthier diets often described a positive influence that simplified healthy eating. One man praised his wife’s actions as essential to making healthy eating the default option. “*Well, the first thing is, what [wife’s name] cooks and so she cooks very healthy. And I think that’s probably the primary thing...The food she buys at the store make a big difference in what’s around, and so I would say that’s the main thing. What you bring home.*” On the other hand, men with poor diets often placed the blame in part on the behaviors of their wives/partners. “*I don't want to blame her but she likes those things. She likes to eat, so I go along with it. I don't want to cause a problem, but if I could just change some of the things that way I could eat healthier. It's not a big deal. She's changing slowly. If she understood why I need to change more clearly, maybe she would change some things.*” Even men who did not “blame” their wives/partners for their unhealthy eating habits acknowledged the principal role they played in making food-related decisions. “*And [girlfriend name]’s pretty good. She wants to eat healthy. So, if I went and said, ‘Oh, we need to have sweet potatoes, more sweet potatoes,’ or whatever it is, then she would build it in.*” Thus, although the taste versus health choice seemed to be at the forefront of men’s food choices, men also described their capacity to eat healthy as being shaped by other factors, most notably time constraints and the food-related behaviors of the primary food preparer.

### **Findings from men with middle-ranking HEI-2010 scores**

The themes that emerged from the data of men with the ten middle ranking HEI-2010 scores were similar to those identified in the extreme case analysis. Most of the men with middle scores questioned the association between cancer recurrence and diet, and thus, few made changes to their diet because of the cancer. Weight loss was the most mentioned motivator for healthy eating; a couple of men also mentioned diet-related comorbidities as motivators. Taste and time appeared to be key influences on men's perceived capacity to eat healthy. Men perceived healthy foods to be bland, and several remarked that their busy work schedule prevented them from eating as healthfully as they would like.

### **DISCUSSION**

There was substantial variation in the diet quality of the prostate cancer survivors participating in this study. This sample was not constructed to be representative of all prostate cancer survivors, but rather to enable exploration of factors that may contribute to differences in diet quality. Comparing the diets of men with healthier diets to the diets of men with poor diets shed light on areas that could be targeted in efforts to promote healthy eating among prostate cancer survivors. For example, men with healthier diets had regular eating schedules, and incorporated a variety of fruits and vegetables in their diets while minimizing consumption of foods with saturated fats (e.g., chips, French fries) and foods with added sugar (e.g., cookies, ice cream). In contrast, men with less healthy diets either had inconsistent eating patterns or ate few meals each day, and their

meals were more likely to include red meat, and less likely to include fruits and vegetables; snacks were more likely to contain fatty or sugary foods.

The mixed method design of this study allowed men to react to their dietary recall data and articulate their rationales and perceived influences for specific food choices and dietary patterns. The data suggest that men with healthier diets were eating healthy either because they had a natural affinity for these foods or because they were prioritizing health above other factors in selecting particular foods. Men with poor diets prioritized taste in the selection of their foods and described healthy foods as being bland or boring. Therefore, efforts to promote healthy eating among prostate cancer survivors would likely benefit from a concerted focus on making healthy eating appealing. Men in both groups also discussed the importance of integrating their favorite foods into their diets. Men still wanted to occasionally eat red meat and indulge in foods that consisted of empty calories (e.g., ice cream, cookies), so programs that are too restrictive are not likely to be appealing.

The premise of this study was that a cancer diagnosis might be an impetus for healthy eating among prostate cancer survivors. Our findings suggest that for many survivors cancer plays little, if any, role in their dietary decision-making. Currently the evidence linking diet to health and quality of life in prostate cancer survivors is inconclusive (Chan et al., 2006); as the evidence evolves and the data become more conclusive, thought needs to go into how to best disseminate this information to survivors and how to frame messages about healthy eating. Interestingly, the strongest evidence links obesity/weight gain to poorer outcomes in prostate cancer survivors (Demark-Wahnefried, 2007; Joshi et al., 2011; Neugut, Chen, & Petrylak, 2004), and weight loss

(unrelated to cancer) was a primary motivator for healthy eating for many men in our study. Therefore, one strategy would be to frame reduced risk of recurrence as another potential benefit of losing weight.

Most men had other diet-related comorbidities, including hypertension and diabetes, so holistic messaging around healthy eating may be warranted, especially since prostate cancer survivors are more likely to die of heart disease than from their cancer (Epstein, Edgren, Rider, Mucci, & Adami, 2012). Furthermore, men portrayed an interest in exercising along with healthy eating to facilitate weight loss, signifying a potential need for programs that address both healthy eating and physical activity.

Despite cancer not being the primary motivator for many, given the interest in healthy eating, prostate cancer survivors may represent a motivated group that could benefit from targeted intervention since a majority are not adopting a healthier diet following their diagnosis (Avery et al., 2013). Their motivation might stem from an intersection of gender and age/life stage that makes healthy eating more salient and acceptable. Prostate cancer survivors are by definition older men; prostate cancer survivors are on average 66 at their time of diagnosis (Howlader, Noone, Krapcho, et al., 2013). They are often dealing with multiple health issues and concerns about mortality may be more prominent than when they were younger. While younger men may portray their masculinity through a denial of health issues, older men come to a point where denial is not possible because of the growing impact their health concerns are having on their day-to-day life (Tannenbaum & Frank, 2011). Adopting healthy eating habits can represent a positive adaptive strategy that enables them to preserve or improve their health (Wethington, 2005). For example, many of the men in this study mentioned red

meat, a masculinized food, as one of their favorite foods, but several noted that they were trying to cut down on their consumption of red meat because of their perceptions of the health risks associated with eating too much red meat.

Though motivated, men acknowledged barriers to healthy eating that for some superseded motivation, most notably lack of time, which is consistent with findings from previous studies of healthy eating in men (Gough & Conner, 2006). A focus on foods to avoid can make healthy eating seem restrictive and cumbersome. An emphasis on the wide range of foods one can and should eat, and strategies for simplifying healthy eating may be a more effective strategy (Popkin, Haines, & Patterson, 1992).

Efforts could also benefit from including wives/partners because they are often the primary food preparers. Men who are married or living with a partner generally have healthier diets than men who live alone (Davis, Murphy, Neuhaus, Gee, & Quiroga, 2000); however, wives/partners can sometimes be a negative influence on diet quality, so optimal approaches for involving them need to be ascertained.

This study had both strengths and limitations. The primary strength of this study was the multiple data sources. Men completed three 24-hour dietary recalls over the course of two weeks and then participated in an in-depth dietary interview. The three 24-hour dietary recalls enabled me to estimate men's usual dietary intake more accurately than I could have with a single recall. Participants also received feedback from their dietary recalls during the in-depth interview so they could reflect on the extent to which the three days depicted their typical eating patterns, as well as discuss important influences on their food choices. The qualitative and quantitative data were not only

analyzed separately, but also using an integrated approach that resulted in a deeper exploration and interpretation of the data.

This study sought to understand the role of both cancer and masculinity in shaping the diets of prostate cancer survivors. We did not collect data on men's cancer stage and grade, which might impact men's motivation to make lifestyle changes to reduce their risk of recurrence. We also did not assess men's masculinity beliefs, and I, therefore, had limited ability to directly explore relationships between participants' masculinity beliefs and dietary behaviors.

Nonetheless, the findings from this study shed light on factors that could be targeted in efforts to promote healthy eating among prostate cancer survivors. Given that cancer was not portrayed as a primary motivator for healthy eating, these findings might be applicable to older men in general, who suffer from higher rates of diet-related comorbidities than their younger counterparts. Future research is warranted with both prostate cancer survivors specifically, and older men more generally, to evaluate different strategies for promoting healthy eating (e.g., masculinity informed approaches, couples-based approaches), and to assess the impact of dietary changes on health outcomes.

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**CHAPTER 5**  
**MANUSCRIPT 3:**  
**THE INFLUENCE OF WIVES/PARTNERS ON THE DIETARY BEHAVIORS**  
**OF PROSTATE CANCER SURVIVORS**

## **ABSTRACT**

**Introduction:** The American Cancer Society recommends that prostate cancer survivors consume a diet high in fruits and vegetables and low in saturated fat. However, many prostate cancer survivors are not following these dietary guidelines. Prostate cancer survivors mention wives as integral to their ability to eat healthy. Women are typically responsible for food purchasing and preparation, and accordingly, wives/partners could facilitate healthy dietary changes among prostate cancer survivors. Yet little is known about the ways in which a prostate cancer diagnosis impacts the dietary practices of couples.

**Purpose:** This study seeks to understand how prostate cancer survivors perceive their wives/partners as shaping their diets, and the role(s) wives/partners play in prostate cancer survivors' attempts to make healthy dietary changes.

**Methods:** In-depth interviews were conducted with a purposive sample of 20 prostate cancer survivors. For a subset of survivors (n=8), wives/partners were also interviewed. Interview data were analyzed using a constant comparison approach, and summary memos were constructed for dyads.

**Results:** Most men described their wives/partners as being primarily responsible for food-related household tasks, and portrayed their wives/partners food choices and preparation methods as impacting the healthfulness of their diets. Couples that expressed a belief that there was a connection between diet and cancer recurrence were the ones who reporting making post-diagnosis dietary changes. Survivors were credited with initiating dietary changes by suggesting foods that could be added to or eliminated from

their diet, but wives/partners continued to maintain primary control over food-related household tasks, and thus were integral to implementing and sustaining dietary changes.

**Conclusions:** These findings highlight the important role that wives/partners play in shaping the diets of prostate cancer survivors. Couples-based strategies should be utilized to encourage healthy eating among prostate cancer survivors. Given that many survivors are not making dietary changes following their cancer diagnosis, there is a need to inform couples of the relevance of healthy eating to healthy survivorship.

## **INTRODUCTION**

Prostate cancer survivors are at risk for recurrence and are at higher risk for lifestyle related diseases, such as cardiovascular disease and diabetes, than men without a history of cancer (Aziz, 2007; Bloom, Kang, Petersen, & Stewart, 2007; Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). A cancer diagnosis is often thought of a teachable moment when men might be more motivated to make behavioral changes that could reduce their overall long-term health risks (Lawson & Flocke, 2009). However, national-level data reveal that many prostate cancer survivors are not meeting dietary guidelines (Blanchard, Courneya, & Stein, 2008; Coups & Ostroff, 2005). Prostate cancer survivors mention social support, especially that provided by wives (e.g., changes in cooking, making similar changes), as integral to their ability to make healthy dietary changes (Satia, Walsh, & Pruthi, 2009). However, little research has examined the ways in which a prostate cancer diagnosis might impact the dietary practices of couples (Mroz, Chapman, Oliffe, & Bottorff, 2011a).

### **Gender and diet**

In general, men have less healthful diets than women (Mroz, Chapman, Oliffe, & Bottorff, 2011b; Wardle et al., 2004). Though there are a multitude of factors that influence food choice and thus variability in the healthfulness of diet among both men and women (Sobal & Bisogni, 2009; Wetter et al., 2001), women have consistently been found to be more likely to meet dietary guidelines than men. Women are more likely to eat fruits and vegetables and high fiber foods, and less likely to eat fatty foods (Turrell, 1997; Wardle et al., 2004). They are also more likely to report liking the taste of healthy

foods, believing in a connection between food and health, and making dietary changes to lose weight (Beardsworth et al., 2002; Turrell, 1997). In contrast, men are more likely to prefer foods that are inconsistent with dietary guidelines (e.g., foods high in saturated fat) and are less likely to want to make changes to conform to guidelines (Gough & Conner, 2006; Wardle et al., 2004).

### **Gender relations and food**

Expectations of who is responsible for food-related household tasks (e.g., shopping, cooking) are also gendered. Among heterosexual couples, women traditionally have been, and for the most part continue to be, primarily responsible for food provision activities (Harnack, Story, Martinson, Neumark-Sztainer, & Stang, 1998; Lachance-Grzela & Bouchard, 2010). Men are less likely to be involved in food-related work, less experienced with cooking, and when they do cook, often restrict the types of cooking they do (e.g., grilling) (Harnack et al., 1998; Sobal, 2005). Perhaps not surprisingly, given gendered eating patterns, married men have consistently been found to have healthier diets than their single counterparts (Davis, Murphy, Neuhaus, Gee, & Quiroga, 2000). Men who live alone are more likely to miss meals, including breakfast, and also rely more on eating out, both of which negatively impact the nutritional quality of their diets (Davis, Murphy, & Neuhaus, 1988; Kerver, Yang, Obayashi, Bianchi, & Song, 2006).

## **Couples as a target for dietary behavior change**

Cohabiting couples tend to have similar diets, in part because they frequently eat meals together (Sobal & Nelson, 2003). The food choices of the family food preparer have been found to predict the diets of the families (i.e., similar levels of fruit and vegetable consumption, similar intake of high fat foods) (Hannon, Bowen, Moinpour, & McLerran, 2003). However, it is important to recognize that the primary food preparer (often the woman) is not making food-related decisions independently. In fact, husbands' preferences have been found to supersede the preferences of wives' when preferences are not consistent, so men also play a considerable role in shaping family food choices (Beagan & Chapman, 2004; Schafer, 1978). Given that women are more likely than men to prioritize nutrition rather than taste, diet quality tends to be healthier when wives' preferences prevail (Schafer, 1978; Wardle et al., 2004).

Because of the interconnectedness of co-habiting couples' diets, a change in one partner's behaviors can inadvertently impact the other's diet quality (Sexton et al., 1987; Shattuck, White, & Kristal, 1992). For example, wives of men participating in a coronary heart disease risk-factor intervention program reported higher nutrition-related knowledge and had more healthful diets than wives of husbands' in the control condition post-intervention even though they were not the intended target of the intervention (Sexton et al., 1987). Findings such as these led to the development of interventions that specifically targeted couples.

Interdependence theory is an explanatory model for understanding how behavior change occurs in couples (Deutsch, 1949; Johnson & Johnson, 2005; Lewis et al., 2006). The premise of this theory in relation to health behavior change is that an individual's

behavioral outcomes can be influenced both by his/her own actions (actor effect) and his/her partner's actions (partner effect), signifying multiple potential mechanisms of change. This theory emphasizes the importance of relational factors and posits that change is most sustainable when both partners engage in a behavior and experience both actor and partner effects. A health issue, such as a cancer diagnosis, can activate "communal coping," which refers to a couple having a shared understanding and working collaboratively to address a health threat (Lewis et al., 2006). This concept may be particularly relevant in the case of prostate cancer because cancer is a disease that impacts not only the individual, but also the couple as an entity (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Miller & Caughlin, 2013). In this case, healthy dietary changes might be initiated if a couple conceptualized it as a strategy to reduce prostate cancer-related risks.

Interestingly, couples-based interventions to promote behavior change for weight loss or other health issues (e.g., cardiovascular disease) have generally been less successful than anticipated (Lassner, 1991; Lewis et al., 2006). Lassner (1991) postulated that inconsistent findings with respect to efficacy were attributable to variability in the operationalization of social support. She hypothesized that programs that integrated significant others as primary participants and focused on relational factors influencing the selected behavior would be more effective than those that included significant others tangentially.

Social support and social control are two mechanisms by which significant others can influence partners' behaviors (Helgeson, Novak, Lepore, & Eton, 2004; Rook & Ituarte, 1999; Tucker, 2002; Tucker & Anders, 2001). While these are theorized as

facilitating behavior change, not all attempts by partners to encourage behavior change are embraced (Goldsmith, Lindholm, & Bute, 2006). In some cases, social control attempts have been viewed as challenging one's autonomy and can cause distress or lead to the opposite behavior (Lewis, Butterfield, Darbes, & Johnston-Brooks, 2004; Tucker & Anders, 2001).

To help determine how to best integrate wives/partners in efforts to promote healthy eating among prostate cancer survivors, this study seeks to understand: (1) how prostate cancer survivors perceive their wives/partners as shaping their diets, and (2) the role wives/partners play in prostate cancer survivors' attempts to make healthy dietary changes.

## **METHODS**

Twenty prostate cancer survivors were recruited as part of the Johns Hopkins *Eating for Life* study, which explored dietary behaviors among long-term prostate cancer, breast cancer, and non-Hodgkin's lymphoma survivors. Men were between the ages of 45 and 74, had been diagnosed at least 3 years ago, and had completed acute treatment. Men with metastatic or recurrent cancer were excluded. Men were recruited from the Baltimore-Washington metropolitan area during oncology follow-up visits (through chart reviews) and through waiting room flyers, physician mailings, and prostate cancer organizations.

Participants completed study activities over a period of approximately a month. Men completed a structured demographic questionnaire, an in-depth interview about their cancer experience and the current salience of cancer in their lives, three online 24-hour

dietary recalls, and an in-depth interview on their diet and factors that influence their food choices. This analysis focuses on data from the in-depth dietary interview.

At the end of the final study visit, men were asked to identify a person in their life who supported them during their cancer treatment and had some influence over their dietary choices. Men were given the latitude to identify any important person in their life who met these criteria. Nine men identified significant others who consented to participate in the study – six wives, one non-live in partner, one sister, and one cousin. Significant others took part in a one time in-person study visits during which they completed a demographic questionnaire and participated in an in-depth interview about their family member's prostate cancer experience and diet. Given the focus of this paper on couples, the sister and cousin dyads were excluded from this analysis. However, data from one couple where both the man and his wife participated in the main study (both were cancer survivors) were included, for a total of eight couple dyads.

Tables 5-1 and 5-2 summarize the demographic characteristics of 20 prostate cancer survivors and the eight couple dyads, respectively. Men had been diagnosed an average of 4.5 years ago (range: 3 to 10 years). Table 5-1 summarizes the demographic characteristics of the prostate cancer survivors. Men were on average 64.7 years old, self-identified as white or black, most were married, more than half were still working, and most had at least a college degree and a household income of \$100,000 or more. Fourteen of the 20 men had at least one comorbidity, with hypertension being the most common (n=11), and 16 men were classified as either overweight or obese using body mass index calculated from self-reported weight and height. The subset of men in the

dyad analysis were slightly younger, all had at least a college education, and self-reported their overall health to be excellent or good.

**Table 5-1. Prostate cancer survivors' demographic characteristics**

	<b>Prostate cancer survivors (n=20)</b>
<b>Age</b>	64.2 (range: 50, 74)
<b>Race</b>	
Black	7
White	13
<b>Marital status</b>	
Married/living as married	15
Widowed/divorced/separated	5
<b>Occupation status</b>	
Employed	11
Retired	7
Disabled	2
<b>Educational attainment</b>	
Completed high school	2
Post-high school training	1
College graduate	5
Postgraduate	12
<b>Household income</b>	
\$10,000 to \$34,999	3
\$35,000 to \$49,999	1
\$50,000 to \$74,999	4
\$100,000 or more	10
Refused	2
<b>Self-reported health status</b>	
Excellent	5
Very good	11
Good	3
<b>Co-morbidities (# responding affirmatively)</b>	
Hypertension	11
Arthritis	5
Depression	6
Diabetes	2
Heart attack	2
Angina	1
Heart failure	1
Cirrhosis	1
Stroke	1
<b>BMI</b>	
Normal	4
Overweight	11
Obese	5

**Table 5-2. Dyad demographic characteristics**

	<b>Prostate cancer survivors (n=8)</b> [A subset of the 20 men in Table 1]	<b>Wives/partners (n=8)</b>
<b>Age</b>	62.8 (range: 50, 74)	61.6 (range: 44, 73)
<b>Race</b>		
Black	3	3
White	5	5
<b>Marital status</b>		
Married	7	7
Divorced/widowed	1	1
<b>Occupational status</b>		
Employed	5	6
Retired	3	2
<b>Educational attainment</b>		
Completed high school	0	1
College graduate	3	3
Postgraduate	5	4
<b>Household income</b>		
\$50,000 to \$74,999	1	0
\$75,000 to \$99,999	0	1
\$100,000 or more	6	5
Refused	1	2
<b>Self-reported health status</b>		
Excellent	5	1
Very good	3	6
Good	0	1
<b>Co-morbidities</b>		
Hypertension	4	4
Arthritis	1	2
Depression	2	0
Diabetes	1	1
Heart attack	1	0
Cirrhosis	1	0
<b>BMI</b> weight(kg)/[height(m)] <sup>2</sup>		
Normal (18.0 – 24.9)	0	3
Overweight (25.0 – 29.9)	7	3
Obese (30.0 or above)	1	2

The in-depth interviews with survivors and significant others (conducted separately) were audio recorded and professionally transcribed. I first reviewed

transcripts for accuracy. I then inductively developed coding schemes. I began by open-coding a subset of the transcripts. Then, I met with the principal investigator to review the coding scheme and made revisions based on these discussions. Once the coding scheme was finalized, I coded the full set of transcripts using ATLAS.ti 7 (Friese, 2013). Interviews were analyzed using a constant comparison approach (Charmaz, 1990), with a focus on codes related to food-related responsibilities and decision-making, the impact of cancer on diet, and the roles of others in the eating habits of participating prostate cancer survivors. These codes included *grocery shopping* (who does the grocery shopping and what types of factors influence their purchasing decisions), *food decision-making* (who does the cooking and how are decisions about what to prepare made), *post-cancer dietary changes* (the impact of cancer on existing eating habits), *eating with others* (how often prostate cancer survivors eat with other members of their households) and *important influences* (discussions of individuals that either positively or negatively influence men's eating habits).

For the subsample of men who identified a wife/partner to participate in the study an additional analysis of dyadic data was conducted (Boeije, 2002). Summaries were constructed for each dyad to elucidate views on role of each individual, frequency of eating together, quality of prostate cancer survivor's diet, perceptions of the relationship between diet and cancer, impact of cancer on survivor's diet, and the type of influence the significant other has on the survivor's diet. These summaries facilitated the development of conceptual codes that characterized the role of wives/partners in influencing prostate cancer survivors' diets and facilitated an assessment of the congruency of couples' views.

## RESULTS

I first discuss how men conceptualized their wives/partners as influencing their food choices, using data from the full sample of 20 prostate cancer survivors. Then, using the dyadic data I explore whether couples' adapted their diets in response to prostate cancer, and the roles wives/partners played in implementing dietary changes.

### **Roles of wives/partners in shaping the diets of prostate cancer survivors**

Prostate cancer survivors generally credited their wives with doing the majority of food-related household tasks. Some men described taking a very hands-off approach, as one man pronounced, *"She cooks, so I just eat what she cooks."* However, other men reported a sharing of responsibilities. Retirement sometimes marked a shift in responsibilities for food-related household tasks, particularly for retired men whose wives/partners were still working. A few retired men described increasing their involvement in food shopping and/or cooking. When asked who prepares the majority of the meals, one man responded, *"I do now since I'm retired, and she's still working...It's been two years, I've been doing everything."* Even in these cases, wives/partners retained some level of involvement. For example, although the man quoted above commented that he had been doing everything for the past two years, he later clarified that he was responsible for weekday cooking, but his wife still did the grocery shopping and cooked on the weekends.

Consistent with previous research citing wives as positive influences on men's diets (Allen, Griffith, & Gaines, 2013) and the benefits of being married on men's diet quality (Conklin et al., 2014; Deierlein, Morland, Scanlin, Wong, & Spark, 2014), men

often referred to their wives/partners as facilitators of healthy eating. As one man put it, *“Well, the first thing is, what [wife’s name] cooks and so she cooks very healthy, and I think that’s probably the primary thing...I just think that just the food that [wife’s name] cooks and the food she buys at the store make a big difference in what’s around, and so I would say that’s the main thing, what you bring home.”* In addition to the particular foods that wives/partners purchased and prepared, men described them as being valued sources of advice on how to eat healthier. One man who touted his girlfriend as his motivation for healthy eating, said *“She would say don’t eat too much, eat a balanced, don’t eat ice cream, eat this...all the things that we know are less good for you.”* Men sometimes positioned their wives as experts on healthy eating and food provision activities, and deferred to them in these areas. *“I mean, she’s an excellent cook and she’s very health conscious...She’s good at planning diet and food preparation.”*

Wives/partners were often characterized as being healthy eaters and sometimes their food preferences and choices unintentionally impacted men’s diets. Men frequently described their wives preference for lean meats, such as fish and chicken, as a reason for their reduced consumption of red meat. In an more extreme examples of this, one man recounted how his wife’s decision to adopt a vegetarian diet a few years ago significantly reduced the amount of red meat in his own diet. *“My wife is a vegetarian, so that impacts on how food is prepared, which means she doesn’t eat any red meat. I tend to eat much less red meat that probably I ordinarily would if she wasn’t a vegetarian.”* He made it clear that he had no intention to become a vegetarian himself and remarked *“We don’t necessarily see eye-to-eye on that [the benefits of a vegetarian diet]. We’ve been married 35 years...You can have those kinds of disagreements.”* This illustrates the

interdependence of couples' diets and how a decision by one partner can impact the other.

Conversely, a few men described their wives/partners' food choices as causing them to make less healthy choices than they otherwise would. One man resolved that his food choices were less healthy when he ate with his girlfriend because his choices mirrored her unhealthy eating habits. *"We have our separate apartments...but just recently from time to time she'll stay over more than not...I find that when she's not here I eat healthier...She just has a negative view of life and that's reflected in the way that she eats...But just living with her, I have the tendency of doing the wrong thing."* Another man perceived his wife's food choices/preparation methods to be unhealthy, but appeared hesitant to suggest healthier options. *"I don't want to blame her but she likes those things [unhealthy foods]. She likes to eat, so I go along with it. I don't want to cause a problem, but if I could just change some of the things that way I could eat healthier."* In this case, the husband expressed a desire to make healthier food choices, but perceived food-related decisions as being under his wife's purview. Both these men took ultimate responsibility for their food choices, but noted that it was more difficult to eat healthy when their partners were not.

### **The impact of prostate cancer on couples' diets**

Using Lewis et al.'s interdependence and communal coping approach as a framework (2006), an antecedent of behavior change following a prostate cancer diagnosis would be couples' perceptions of the relationship between diet and prostate cancer recurrence and/or mortality. Consistent with this, the four couples that reported

making dietary changes perceived a connection between diet and cancer. One wife remarked, *“We were definitely red meat eaters all the time, eating a lot of junk food, I mean, not in excess. We would eat our three basic meals but dessert would always be ice cream. Even the type of milk we drank it wasn’t organic...Now we are drinking almond milk...We both feel like that [eating habits] played a major role, could have played a major role in how it [cancer] develops.”* Her husband voiced a similar belief. In contrast, the four couples that reported not making any changes to their diet either attributed cancer to other causes (e.g., genetics) or questioned the strength of the evidence linking diet to recurrence. In response to whether there was a relationship between cancer recurrence and diet, a wife commented, *“I hear it all the time...but I don’t pay too much attention. You know the antioxidants or eat beta-carotene, you know, carrots and tomato, and almonds. So I hear that. I don’t put a whole a lot of credence because how much of it do you have to eat, to have it make a difference?”*

### **The role of wives/partners in facilitating dietary change**

Couples voiced analogous beliefs regarding the association between diet and cancer except for one case in which the prostate cancer survivor believed there was an association and initiated dietary changes – primarily reducing his consumption of red meat and cheese. His wife, on the other hand, portrayed a fatalistic view and did not see a connection between diet and cancer recurrence; however she was supportive of his changes and remarked *“I support him in anything he wants to do...this is how the relationship works...I have learned that if it’s in the best interest of us, I’m more vocal. If it’s about him I step back, whatever you do is fine.”*

Similarly, the other three couples that reported making dietary changes recounted a scenario in which the prostate cancer survivor initiated changes and the wife played a supportive role. The importance of the wife being supportive should not be understated. Although in all four cases the prostate cancer survivor was credited with initiating changes, these changes did not alter the existing food responsibility arrangements; the wives were still primarily the ones purchasing and preparing foods. Wives described integrating their husbands' preferences into their food practices. *"So yeah, I mean it's changed [our diet], and I try for him too. I mean it's hard. It's not as hard as it was in the beginning. In the beginning all he ate was salads and chicken. When he came out from the hospital all he ate was salads and chicken. I was never so sick of salad in all my life."* Although this wife found her husbands' dietary changes to be rather restrictive, she described following them in support of her husband's efforts.

Changes initiated by prostate cancer survivors impacted family members' diets to varying degrees. One wife noted that she ate healthier in the house but continued to make unhealthy choices when she was outside the home. *"If I was alone, I would probably bring in food, high fat, high caloric, or make a sandwich...So because I'm with him, whatever he is into, I sort of do, so I guess I'm eating a little healthier. Yeah, but all at school I eat, it's terrible."* For another couple that still had young children living at home, the wife described the prostate cancer diagnosis as an impetus to make healthier food choices for the whole family. *"Even with the girls, what we have them eat. I'm like nope. Can we have this? No. I want you to have some fruits. I want you to drink more water...so it definitely has impacted...what we eat."*

There was some evidence that wives' involvement may be essential to sustainability of dietary change. Wives' decisions to adopt similar dietary changes likely made it easier for men to adhere to these changes. And in some instances, wives took on a regulatory role to help their partners maintain these changes. For one couple, in which both partners described a recent backtrack in their efforts to eat healthy, the wife described her efforts to moderate their consumption of unhealthy foods. *"We all kind of slipped like he's eating sherbet now when he really wasn't even doing that, junk food like chips...It's okay in moderation because I said, 'well should we get some more Pringles?' and he was like, 'yeah.' I was like, well, remember the serving size is 16. You can have 6. You don't need to have 16 of them."*

Though wives seemingly had an important role in facilitating healthy eating, they conveyed limits to their ability to influence their husbands' dietary choices, especially when husbands ate out a lot. They noted that the extent of their influence was limited to what their husbands' were eating inside the home. *"I cannot control what he is eating outside. I mean when he is not home. Yeah...I am cooking what I want, but he pretty much is always eating what I choose."* Another wife described taking a more proactive role in encouraging her husband to eat healthy, but did not believe that her advice was always heeded. She encouraged him *"to take care of himself a little better, not run himself into the ground, eat a little better, exercise a little bit more. Yeah, I try. Yes, I try, I try very hard."* She described how her husband prioritized his work and extracurricular activities at the expense of his health sometimes, and without a modification to his schedule his diet continued to suffer. Her husband's account substantiated how prioritization of work and extracurricular activities monopolized his ability to eat as

healthy as he would like. *“And it’s so hard right now to control my time. And so then [when I] do, [I] race to go out, and...I’m going to get a sandwich. I’m getting out of here. But it’s not the healthiest thing in terms of food, right?”*

### **Couples’ dynamics around dietary behavior change**

The four couples that reported making post-diagnosis dietary changes described the survivor initiating the change, and the wife supporting the change. This is not, however, the only manner in which behavior change can occur. Couples that did not make post-diagnosis changes shed light into how they approached dietary changes in the context of weight loss. In one case, the wife and husband had different perspectives on her influence on his weight loss efforts and this seemed to thwart his efforts. The wife voiced frustration because when she tried to support his weight loss efforts, she found him to be unreceptive. *“I can’t do anymore coddling to my husband. You know what, I’m at an age where I don’t feel like going out buying something special, and plus he says he doesn’t have time to eat a salad. Like a couple of days, we had something leftover and I said you take this, just stick it in the microwave. No, he didn’t want to do that.”* The husband’s perspective, on the other hand, was that his wife sometimes sabotaged his efforts, whether intentional or not. *“And I could swear that if I said to my wife, ‘well I think my stomach is getting bigger, so I’m going to stop,’ it’s like she goes out and gets something that I know puts some weight on my stomach. But, it’s not a copout, but that, I mean some of it’s part of that.”* This highlights the importance of couples having a shared vision in behavior change attempts of how they can support each other.

For another couple, rather than playing the supportive role, the female partner was portrayed as the initiator of healthy dietary changes. She stated *“I got after him about how he ate. He was overweight and didn’t get much exercise, and you know I just nag. Although they say it’s not going to help, but at some point he just decided [to make changes].”* While she characterized herself as a nagger, her partner expressed appreciation for her efforts and cited her as his primary motivation for losing weight, because *“she doesn’t like men with stomachs.”*

These examples demonstrate that not all couples approach behavior change the same way and highlight the importance of understanding relationship dynamics in efforts to promote healthy dietary change.

## **DISCUSSION**

These findings highlight the importance of wives/partners in shaping the healthfulness of prostate cancer survivors’ diets, and the interdependence of couples’ diets. When prostate cancer prompted couples’ to make dietary changes, women were depicted as maintaining primary control of food-related household tasks. This is consistent with other research that has found that wives remain in charge of food provision activities after a prostate cancer diagnosis (Mroz et al., 2011a). Hence, for men in relationships, successful behavior change likely requires involvement from both the prostate cancer survivor and his partner.

Couples that made dietary changes described doing so to reduce risk of recurrence. Interestingly, while many wives described taking a proactive role caring for husbands and working as a team to get through treatment, this mentality did not

necessarily extend into survivorship. This perhaps signifies a belief that the ‘health crisis’ is over. Even wives/partners who believed there was an association between diet and recurrence assessed their husbands’ risk of recurrence to be low.

Therefore, it appears that there is a need to inform couples of the relevance of health promotion (e.g., healthy eating, physical activity) to healthy survivorship. Given that couples are primed to work as a team during the prostate cancer treatment process (Berg et al., 2008; Gray et al., 2000; Harden et al., 2002; Maliski, Heilemann, & McCorkle, 2002), it could be a natural next step for couples to take on health behavior change, if it is framed as beneficial for survivorship. While studies associating diet to risk of recurrence and mortality are inconclusive (Berkow, Barnard, Saxe, & Ankerberg - Nobis, 2007; Chan, Van Blarigan, & Kenfield, 2014; Demark-Wahnefried, 2007), there is growing evidence regarding the association between weight/obesity and cancer outcomes (Joshu et al., 2011; Neugut, Chen, & Petrylak, 2004). Furthermore, prostate cancer survivors are at increased risk for diet-related health conditions, such as cardiovascular disease and diabetes. Consistent with a “communal coping” approach (Lewis et al., 2006), dietary behavior change can be framed as a strategy that couples can undertake to reduce both cancer-related and general health risks.

These findings can inform efforts to integrate wives/partners into health promotion programs for prostate cancer survivors. Couples-based health promotion programs need to consider how relationship factors might influence behavior change efforts. First, there is a need to understand couples’ existing arrangement around food-related household tasks and the roles that each person would have in implementing dietary changes. Second, couples need to be provided with communication strategies to

facilitate behavior change. It was evident that some men in this study felt more comfortable broaching the topic of dietary change/healthy eating with their partners than others. Previous studies have underscored the importance of communication in either facilitating or derailing attempts to make lifestyle changes (Beverly, Miller, & Wray, 2007; Goldsmith, Bute, & Lindholm, 2012; Goldsmith et al., 2006; Kärner, Dahlgren, & Bergdahl, 2004). For the couples in our study, the survivors, for the most part, were the ones initiating dietary changes. Prostate cancer survivors' receptivity to their partners' initiating or encouraging them to make behavioral changes may be predicated on how they receive the message (e.g., an act of genuine concern versus an attempt to restrict their autonomy). In addition, wives/partners receptivity to making changes to their food-related practices may be dependent on how they conceptualize these changes (e.g., an opportunity to make healthy changes that can be mutually beneficial versus an attack on healthfulness of their current food practices). The experiences of these couples' demonstrate the variability in how couples address behavior change.

A limitation of this study was that I was unable to recruit as many wives/partners or other significant others as I had planned. However, the wives/partners I did recruit shed light on how couples approach behavior change, and important considerations in efforts to promote behavior change in couples. Additionally, I was able to obtain feedback from the full sample of 20 men on how they perceived their wives/partners as influencing the healthfulness of their diet. Future studies need to identify specific strategies that are most effective in facilitating couples-based behavior change.

Also, for prostate cancer survivors who are not in relationships, and even for some who are in relationships, there may be other members of their social networks who

could facilitate their behavior change. Prostate cancer survivors are on average 66 years at the time of diagnosis (Howlader et al., 2013), and therefore, are at a life stage when their social roles might be changing (e.g., retirement, widowhood), which impacts the composition of their social network (Antonucci & Akiyama, 1987; Wrzus, Hänel, Wagner, & Neyer, 2013). Social network members can influence diet in various ways, such as by providing social support, acting as behavioral role models, or serving a regulatory function by exerting social control (Nestle et al., 1998; Rook & Ituarte, 1999; Salvy, Jarrin, Paluch, Irfan, & Pliner, 2007; Tucker, 2002). A study of older adults found that in addition to spouses, immediate family members were most likely to be perceived as agents of social control followed by extended family and friends (Tucker, 2002). A few men in this study discussed the influence their daughters or daughter-in-laws had in encouraging them to eat healthy (e.g., exposing them to healthy foods), and men appeared to be receptive to their daughters' advice. Future studies should investigate which social network members are most influential and the role these individuals could play in promoting healthy behavior change in prostate cancer survivors.

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**CHAPTER 6**  
**INTEGRATIVE SUMMARY AND DISCUSSION**

## SUMMARY OF FINDINGS

The overall goal of this dissertation study was to explore influences on the healthfulness of prostate cancer survivors' diets and to generate a better understanding of the ways in which a prostate cancer diagnosis might influence men's dietary behaviors. Together, the three papers depict the complexity of factors that impact the healthfulness of prostate cancer survivors' diets, and highlight important factors that need to be considered in efforts to promote healthy eating among prostate cancer survivors.

**Paper 1** examined the extent to which men with a history of prostate cancer adopted a 'cancer survivor' identity. Individuals have multiple identities that together constitute their self-concept. Identities provide behavioral expectations for how one should act, and accordingly more salient identities are more influential in shaping one's behavior (Burke & Stets, 2009). It has been posited that identifying as a 'cancer survivor' reflects better adjustment to diagnosis than alternative cancer-related identities [e.g., victim, patient, ex-patient, a person who has had cancer] (Zebrack, 2000). A defining characteristic of being a 'survivor' might be engaging in health promoting activities to reduce risk of recurrence or of getting a second cancer (Deimling, Bowman, & Wagner, 2007; Harwood & Sparks, 2003). The men in our study described non-cancer identities, such as family roles, career roles, and hobbies, as being more salient to their self-concept than being a 'cancer survivor'. Consistent with previous research, men in our study often rejected the label 'cancer survivor,' because they did not want to be defined by their cancer. Many men articulated a lack of concern about recurrence and/or an inability to reduce their risk; thus, the link that would motivate them to engage in health promoting behaviors in relation to their cancer experience was lacking. This

suggests that identities other than being a ‘cancer survivor’ may be more instrumental in shaping men’s health promotion beliefs and behaviors.

Within our small sample of 20 prostate cancer survivors, there was great variation in the healthfulness of men’s diets. In many cases, men were eating too much food and an unhealthy mix of foods. Dietary data indicated that men struggled most with consuming adequate amounts of fiber and with controlling the amount of sodium in their diet. Despite this, some men were making healthier dietary choices than others, and **Paper 2** compared the dietary practices of men with healthier diets to those of men with poor diets. Men with healthier diets ate more frequently throughout the day, had a regular eating schedule, and ate more foods that were inline with current dietary recommendations (e.g., lean proteins, whole grains, fruits and vegetables, and nuts); whereas men with poor diets had scattered eating schedules, ate less frequently, and ate more foods that were inconsistent with dietary recommendations (e.g., foods high in saturated fats, foods with empty calories, refined grains). Interestingly, both men with healthier diets and poor diets presented a taste versus health conundrum in which these two categories of foods were considered to be incompatible and mutually exclusive. Men with healthier diets described a higher level of motivation to make healthy food choices, often in an effort to lose weight and/or address other diet-related health concerns, and fewer barriers to health eating. In contrast, men with poor diets described a lack of willpower to make healthier choices and presented more barriers to healthy eating, specifically lack of time and the negative influence of their wives/partners (i.e., the primary food preparer). Only a few men mentioned making healthy dietary changes in

response to their cancer. Most men questioned the association between diet and cancer recurrence.

**Paper 3** was an in-depth exploration of relational influences on health, which was a key factor differentiating men with healthier diets from those with poor diets. Most men in our study were not the primary food purchasers or preparers in their household; therefore, their wives/partners played an important role in shaping their diets. Men with healthier diets portrayed their wives/partners as being a positive influence, while men with poor diets tended to depict their wives/partners as being a negative influence. There were different ways in which wives/partners influenced the diets of prostate cancer survivors: by regulating the types of food purchased, by determining how food was prepared, by encouraging healthy eating, and through behavioral role modeling. For a subset of men, wives/partners were interviewed, and for the most part, the prostate cancer experience did not alter couples' existing arrangements around food-related household tasks. Wives/partners remained primarily in charge of grocery shopping and cooking. Couples that made changes voiced a belief that there was a relationship between diet and cancer. In all cases where changes were reported, the prostate cancer survivor was credited with initiating the change by suggesting foods to incorporate or eliminate from their diet, and the wife incorporated these suggestions into her existing practices.

Together these three papers denote that for many men, non-cancer related motivators, facilitators, and barriers were more influential in their eating practices than a desire to reduce risk of recurrence or other cancer-related outcomes. In fact, many prostate cancer survivors did not perceive a connection between diet and recurrence, and therefore their diagnosis did not prompt them to reassess their eating habits. Table 6-1

summarizes factors that emerged as impacting the healthfulness of prostate cancer survivors' diets. A social ecological model was deemed appropriate to organize these factors because it exemplifies the multitude of factors that impact one's health behaviors and illustrates the reciprocal determinism between a person and their social and physical environment (McLeroy, Bibeau, Steckler, & Glanz, 1988). Because I did not probe specifically on each level of influence (intrapersonal, interpersonal, institutional, community, and public policy), and a large focus of this dissertation was on intrapersonal and interpersonal influences, I subsumed the three top levels into a single level labeled "environment."

**Table 6-1. Barriers and facilitators to healthy eating among prostate cancer survivors**

	<b>FACILITATOR</b>	<b>BARRIER</b>
<b>Intrapersonal</b>		
Taste	<i>“I just prefer – what I like is coincidentally healthy.”</i>	<i>“The unhealthy food is a lot more attractive. The unhealthy stuff is generally the better stuff that you like.”</i>
Perceived benefits of healthy eating	<p><b>Cancer recurrence</b>  <i>I wanna change my lifestyle a little bit, start eating better and being a bit more healthy and avoid any reoccurrence of any cancer. That’s for sure. If I can, so that’s what motivates me now.”</i></p> <p><b>Weight loss</b>  <i>“I really want to lose weight and I have lost and I’m continuing to lose weight. And I know that eating the right foods can help me do that.</i></p> <p><b>Longevity</b>  <i>“Healthy eating if you want to live longer. Stuff is killing you, so if you want to live long, you need to eat right.”</i></p>	<p><i>“I do not believe there’s any relationship [between diet and recurrence] whatsoever.”</i></p> <p><i>“My doctor me that there were...studies and so forth that link cancer and read meat, but once you’ve got it it’s kind of an academic consideration...and so no, I’ve made virtually no changes.”</i></p>
Time		<i>“The inconvenience is preparation [time]...and the inconvenience is what makes it hard to stick to a diet.”</i>

	<b>FACILITATOR</b>	<b>BARRIER</b>
Willpower		<i>“If I see the food [I’m tempted]. If I can avoid bringing it into my house I’m best off.”</i>
<b>Interpersonal</b>		
Social support	<i>“Well, the first thing is, what [wife’s name] cooks and so she cooks very healthy. And I think that’s probably the primary thing...The food she buys at the store make a big difference in what’s around, and so I would say that’s the main thing. What you bring home.”</i>	<i>“I don’t want to blame her but she likes those things. She likes to eat, so I go along with it. I don’t want to cause a problem, but if I could just change some of the things that way I could eat healthier.”</i>
Social norms		<i>“Once in a while, when you want to feel belong you just [eat fast food]... For most part, I would rather see to prepare my own food and eat that too than going out to eat.”</i>
<b>Environmental</b>		
Costs/accessibility	<i>“Well, yeah. I mean I think access. We live in an area that is very easy to get fresh vegetables and things like that. And the grocery stores now are more attentive I think to providing things with less preservatives.”</i>	<i>“During the first of the month like when my money is pretty loose or whatever, I tend to, you know, pack up with the fresh stuff. But during the course of the month, I may well let me just get something, you know a little cheapest as opposed to paying good money for the fresh vegetables and I think that’s what the problem is the cost.”</i>

	<b>FACILITATOR</b>	<b>BARRIER</b>
Concordance of healthy eating with important social roles	<p><b><i>Cultural/religious identity</i></b></p> <p><i>“I tend to be more natural in terms of where my food is coming from so that kind of help me. And, I believe, my culture too has played a major role...For most part, I would rather see to prepare my own food and eat that too than going out to eat.”</i></p> <p><i>“Being kosher actually makes it easier. You can’t believe how much easier it is.”</i></p>	<p><b><i>Work identity</i></b></p> <p><i>“Work is a major thing. When I’m busy, I work as early from 8:00 til 4:00 or 5:00. Some days, I don’t really have time to eat. So, and I don’t junks. So, work is one major thing that prevent me from eating at regular time that I want to.”</i></p>

## LIMITATIONS

This exploratory study sought to better understand influences on prostate cancer survivors' diets to inform future efforts to promote healthy eating. In that vein, there may be some limitations to the transferability of these findings. The parent study of this dissertation included breast cancer survivors, and we found it to be more difficult and time-intensive to recruit prostate cancer survivors relative to breast cancer survivors. Eventually, we were able to enroll our goal of 20 prostate cancer survivors, but our participants likely reflect a 'motivated' group interested in issues related to survivorship and diet. Participants are regarded as being motivated because their participation required partaking in four separate study activities over a period of approximately a month, and all participants completed study activities. Consequently, they may have differed in some ways from men who declined to participate in the study. The resultant sample was comprised primarily of men of higher socioeconomic status (SES). There may be issues unique to lower SES men that were not captured in this study. However, we were successful in obtaining variation with respect to characteristics that have been posited to influence men's cancer experience, including treatment type, age at diagnosis, and race/ethnicity. We did not collect data on men's disease stage and grade, which are predictive of disease severity, and therefore may influence men's motivation to make healthy behavior changes.

Another limitation was that I was unable to recruit as many wives/partners and other significant others as I had anticipated. The goal was to identify a significant other for each of prostate cancer survivors participating in the study. Eighteen of the 20 prostate cancer survivors were approached about the significant other sub-study (two had enrolled prior to obtaining Institution Review Board approval for the sub-study). Of these, 12 identified a

potential person, of which nine agreed to participate and were interviewed. In two of these cases the prostate cancer survivor did not discuss the selected person during his interview, which hindered my ability to analyze these data as a dyadic unit. I was able to include one additional case in which both the husband and wife were cancer survivors and participated in the main study. Thus, the analysis of dyadic data was based on eight dyads.

## **STRENGTHS**

A primary strength of this study was the multiple data sources. Each prostate cancer survivor completed a structured questionnaire on demographic characteristics, health status and health behaviors; two in-depth interviews – one about cancer and one about diet; and three 24-hour dietary recalls. The 24-hour dietary recall is considered to be the gold standard for collecting dietary data, and permitted estimation of usual intake and calculation of diet quality (Moshfegh et al., 2008). The design of the study participants allowed participants to engage with their own data (e.g., identity exercise and summary feedback from the three 24-hour dietary recalls) and participants' interpretations during the in-depth interviews added to the richness of the data.

Furthermore, including wives/partners in the study enriched the exploration of the importance of the couple as an entity in shaping the diets of partnered prostate cancer survivors. Although wives have often been included in studies examining the influences of prostate cancer on couples during the treatment phase, their perspective has been less visible in survivorship studies.

## IMPLICATIONS AND RECOMMENDATIONS

Although it is recommended that prostate cancer survivors adhere to specific dietary guidelines to improve their health and quality of life, many do not. This study sheds light on factors that may influence men's ability and motivation to follow healthy eating guidelines. The following are implications/recommendations for public health programs seeking to promote healthy eating among prostate cancer survivors.

1. **Many men with a history of prostate cancer do not espouse a 'cancer survivor' identity, so public health programs for 'cancer survivors' may miss a substantial portion of their intended population.** While there are some men who identify as cancer survivors and may be interested in 'cancer survivor' focused health promotion programs, other men reject 'cancer survivor' as a defining identity and programs need to identify strategies for reaching these men. One possibility is designing programs around other salient identities that may prompt behavior change (e.g., staying healthy so they can fulfill their provider role, or staying healthy so they can be around to see their grandchildren grow up).
2. **Given that many men did not perceive a relationship between diet and risk of recurrence, public health interventions to promote healthy eating among prostate cancer survivors may benefit from framing interventions in more holistic ways.** For many men, cancer was not mentioned as a primary motivation for healthy eating. Currently, the evidence linking diet to cancer recurrence and mortality is inconclusive, and men's beliefs reflect this. The strongest evidence links weight/obesity to prostate cancer recurrence and mortality (Joshu et al., 2011; Neugut, Chen, & Petrylak, 2004). Several men expressed an interest in healthy eating

for weight loss (unrelated to cancer), which suggests that framing healthy eating as a strategy for weight loss may appeal to some men. Also, men often had other comorbidities (e.g., hypertension, diabetes) that could benefit from dietary changes. Rather than designing disease-specific programs that may overlap, health promotion programs could be designed for sub-populations (e.g., older men) and potentially impact multiple health outcomes. Given that cancer was not reported as having a major impact on most men's diets, the factors that impact prostate cancer survivors' capacity to eat healthy may be similar to those of older men in general.

- 3. To be effective, health promotion programs need to adequately address men's barriers to healthy eating.** Taste and time emerged as two substantial barriers to healthy eating that would likely impact behavior change attempts. Men did not want to eat foods that were bland and flavorless, and wanted to include their favorite (unhealthy) foods into their diets in moderation. Therefore, programs need to emphasize that healthy eating can be flavorful and the ways in which favorite foods can be incorporated into a healthy diet. Many men, particularly those who were still working, cited time as a barrier to healthy eating. For healthy eating to appear feasible, men need guidance on how to fit healthy eating into their busy schedule, including strategies for eating healthy when eating out.
- 4. Wives/partners should be included in efforts to promote healthy eating among prostate cancer survivors.** Often men are not the primary food purchasers or preparers in their household. Wives/partners can either facilitate or derail prostate cancer survivors' efforts to eat healthy. Programs need to consider how to best integrate wives/partners of prostate cancer survivors for optimal outcomes.

## **FUTURE RESEARCH**

Although cancer was not a primary motivator for healthy eating, many of the men in our study expressed an interest in healthy eating for other reasons (e.g., weight loss, diet-related co-morbidities). Older men may be receptive to health promotion efforts because it is viewed as pertinent at this stage of their life (Tannenbaum & Frank, 2011). Some men conceptualized retirement as a phase when there would be more time to dedicate to healthy lifestyle. The following of areas of research that can build off or supplement the findings from this study:

- Development and evaluation of gender-based (masculinity informed) weight-loss interventions for older men
- Development and evaluation of couples-based health promotion interventions utilizing relational approaches guided by interdependence theory
  - Theory building on the intersection between aging and gender on health
  - Exploratory studies of dietary influences for unpartnered prostate cancer survivors to inform the development of healthy survivorship programs

Additionally, there is a continued need for epidemiologic studies that strengthen the evidence-base around lifestyle and health outcomes in prostate cancer survivors, so that evidence-based messages about the benefits of lifestyle change can be effectively communicated to survivors.

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## CURRICULUM VITAE

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### PERSONAL DATA

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### EDUCATION AND TRAINING

- 2014 (expected) Ph.D. Candidate, Health, Behavior, & Society  
Johns Hopkins Bloomberg School of Public Health  
Baltimore, Maryland  
Advisor: Katherine Clegg Smith, PhD  
*Dissertation Topic:* The salience of cancer in the dietary behaviors of prostate cancer survivors
- 2004 M.P.H, Health Behavior and Health Education  
University of North Carolina School of Public Health  
Chapel Hill, North Carolina  
Advisor: Allan Steckler, PhD
- 2002 B.A., Sociology (summa cum laude)  
University of Pittsburgh  
Pittsburgh, Pennsylvania

*Proficient:* STATA, ATLAS.ti, NVivo

### PROFESSIONAL EXPERIENCE

- January 2012 - **Consultant**  
Bruce and Marsha Moskowitz Foundation
- Conducting an analysis of a cross-sectional study of 1,199 cancer patients undergoing cancer treatment at 7 cancer centers to assess the impact of cancer treatment on diet and associations with quality of life

October 2010 -

**Graduate Research Assistant**

Department of Health, Behavior & Society  
Johns Hopkins Bloomberg School of Public Health  
*Supervisor:* Katherine Clegg Smith, PhD

- Managing a mixed-methods study exploring the dietary behaviors of long-term cancer survivors to characterize the saliency of cancer in their dietary practices and potential opportunities for intervention. Responsibilities include day-to-day management of study activities, instrument development, securing human subjects approvals, conducting in-depth interviews with health care providers and cancer survivors, quantitative and qualitative data analysis, and manuscript preparation.
- Conducted an analysis to describe the experiences of nutrition researchers who have worked extensively with the news media, including their primary objectives in working with the news media and perceptions of their role in the news making process.

2005-2010

**Research Associate**

Westat

*Supervisor:* William Frey, PhD

- Managed a Centers for Disease Control and Prevention contract (CDC) to develop and evaluate a patient navigation program to increase colorectal cancer screening rates for low-income medically underserved populations aged 50-64. Responsibilities included conducting a literature review and environmental scan, developing intervention and study design plans, and securing human subjects review approvals.
- Member of the Instrument Design, Evaluation and Analysis (IDEA) Unit, an internal Westat group that provides projects throughout the company with assistance in designing/redesigning and evaluating instruments administered in various modes, developing study materials, evaluating the usability of instruments, and planning analyses. Responsibilities included conducting and analyzing cognitive interviews and focus groups for numerous projects.
- Managed tasks for a scientific support contract with the National Cancer Institute's Behavioral Research Program. Responsibilities included qualitative data collection, coding, and analysis in areas such as smoking cessation, informed-decision making, patient-provider communication, and acceptance of the HPV vaccine; developing a shared measures database for behavioral researchers; and

coordinating the national activities for the Centers of Excellence in Cancer Communication Research and the Transdisciplinary Tobacco Use Research Centers.

- Managed the instrument development for the third iteration of the Health Information National Trends Survey (HINTS 2007). Responsibilities included assisting in the design and pretesting of the telephone and mail questionnaires and overseeing the conversion of the telephone instrument to computer assisted telephone interview (CATI) format.
- Managed a National Cancer Institute contract to evaluate the effectiveness of 8 public-private state-level partnerships in increasing breast and cervical cancer screening rates. Responsibilities included instrument development, semi-structured interviewing, data analysis, and report writing.

2004-2005

**ASPH/HRSA Public Health Fellow**

Evaluation and Analysis Branch

Health Resources and Services Administration

*Supervisor:* Sarah Richards

- Managed a congressional mandate to evaluate the adequacy of the pediatric rheumatology workforce.
- Assisted on several health workforce contracts, including a national study of community health workers and a study to evaluate the success of college/university based mentoring and other health professions development programs in recruiting minorities into health professions.

2003-2004

**Research Assistant**

Division of Infectious Diseases

University of North Carolina Department of Medicine

*Supervisor:* Andrew Kaplan, MD

- Enrolled patients in a study comparing directly observed to self-administered antiretroviral therapy for incarcerated HIV-infected persons.
- Followed up with study participants, including administering surveys, abstracting medical information from charts, and conducting motivational interviews.
- Participated in weekly meetings to discuss the research study protocol and other relevant issues.

2003

**Project Assistant**

North Carolina Pediatric Assistant

*Supervisor:* Patricia Garrett, PhD

- Conducted a case study to assess different outreach strategies counties employed to identify and enroll eligible children in

Health Check/Health Choice (Medicaid/Children's Health Insurance Program).

## PROFESSIONAL ACTIVITIES

Member, American Society of Preventive Oncology, 2012-present  
Member, American Association of Cancer Research, 2011-present  
Member, Maryland Cancer Collaborative, 2011-2013  
Member, Society of Behavioral Medicine, 2010-present  
Member, American Public Health Association, 2003-present  
Member, American Association of Public Opinion Research, 2007-2009

## HONORS AND AWARDS

2012-2014	JHSPH Department of Health, Behavior and Society Doctoral Distinguished Research Award
2010-	NIH Cancer Epidemiology, Prevention and Control Training Fellowship, Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health
September 2011	AACR Minority Scholar in Cancer Research Award American Association of Cancer Research
July 2011	Health Communication Pre-Doctoral Fellowship Cancer Research Network (CRN) Cancer Communication Research Center
2002-2004	Scholars for Tomorrow Fellowship University of North Carolina at Chapel Hill
2002	Phi Beta Kappa
2002	Robert Avery Award for Excellence in Undergraduate Sociology Department of Sociology, University of Pittsburgh
1998-2002	Helen Faison Scholarship University of Pittsburgh

## PUBLICATIONS

DeGroff, A., Coa, K., Morrissey, K.G., Rohan, E., & Slotman, B. (2013). Key considerations in designing a patient navigation program for colorectal cancer. *Health Promotion Practice*, [online ahead of print].

Thorpe Jr., R.J., Wilson-Frederick, S., Bowie, J.V., **Coa, K.**, Clay, O., LaVeist, T.A., & Whitfield, K.E. (2013). Health behaviors and all-cause mortality in African American men” *American Journal of Men’s Health*, 7(4 Suppl), 8S-18S.

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Chou, W.S., Han, P., Pilsner, A., **Coa, K.**, Greenberg, L., & Blatt, B. (2011). Interdisciplinary research on patient-provider communication: a cross-method comparison. *Communication & Medicine*, 8(1): 29-40.

Moser, R. P., Hesse, B. W., Shaikh, A. R., Courtney, P., Morgan, G., Augustson, E., Kobrin, S., Levin, K.Y., Helba, C. Garner, D., Dunn, M., **Coa, K. I.** (2011). Grid-enabled measures: using Science 2.0 to standardize measures and share data. *American Journal of Preventive Medicine*, 40(5), S134-S143.

## TEACHING

- 2<sup>nd</sup> Term 2013    Teaching Assistant, Johns Hopkins Bloomberg School of Public Health, Department of Health, Behavior and Society  
*410.710.01* Concepts in Qualitative Research for Social and Behavioral Sciences (Professor: Dr. Katherine Clegg Smith)
- Spring 2012    Teaching Assistant, Johns Hopkins University Krieger School of Arts and Sciences, Department of Sociology  
*230.341* Medical Sociology (Professor: Dr. Katherine Clegg Smith)
- Led 2 weekly sections of 15 students to review main concepts and apply them in group and individual activities
  - Graded quizzes and papers
  - Held weekly office hours

## ACADEMIC SERVICE

- 2012-2013    Student Representative, Johns Hopkins Bloomberg School of Public Health, Department of Health, Behavior, and Society Curriculum Committee
- 2011-2012    Co-Coordinator, Cancer Epidemiology, Prevention and Control Research in Progress Seminar Series

## COMMUNITY SERVICE

2012 – 2013

### **SOURCE Service Scholar**

American Heart Association's Recess Baltimore

*Supervisors:* Sarah Kramm and Angela Wheeler

- Conducted in-depth interviews with center directors to inform the curriculum development and program implementation for Recess Baltimore, an eight-month program seeking to promote physical activity and nutrition among Baltimore children ages 5 to 14 attending after school programs at participating recreation centers
- Designed curriculum lessons on physical activity and nutrition
- Evaluated program implementation and outcomes
- Trained and managed site-visit interns delivering curriculum lessons

## PRESENTATIONS

### Scientific Meetings

**Coa, K.I.,** & Smith, K.C. (2014). Mixed methods exploration of diet among prostate cancer survivors. Oral presentation at the American Society of Preventive Oncology Annual meeting, Arlington, VA.

**Coa, K.I.,** Bell, S., Epstein, J.B., Ettinger, D., Jatoi, A., Langbaum, T., McManus, K., Platek, M., Price, W., Steward, M., Teknos, T.N., & Moskowitz, B. (2013). The impact of treatment on the diets of cancer patients and associations with quality of life. Poster presentation at the American Institute for Cancer Research 2013 Annual Research Conference, Bethesda, MD.

DeGroff, A., Rohan, E., **Coa, K.,** Slotman, B., & Morrissey, K.G. (2013). Key considerations in designing a patient navigation program for colorectal cancer screening. Oral presentation at the 141<sup>st</sup> American Public Health Association Annual Meeting and Expo, Boston, MA.

Smith, K.C., **Coa, K.,** Klassen, A.C., Caulfield, L., Shockney, L., Helzlsouer, K., & Baker, A. (2013). Capitalizing on the 'teachable moment' to promote healthy behavior

changes among cancer survivors. Oral presentation at the 141<sup>st</sup> American Public Health Association Annual Meeting and Expo, Boston, MA.

Smith, K.C., **Coa, K.**, Klassen, A.C., Caulfield, L.E., Shockney, L., Helzlsouer, & Baker, A.M. (2013). Promoting Dietary Change in the Care of Long Term Cancer Survivors: What are the Perspectives of the Clinical Care Team? Poster presented at the 2013 American Association for Cancer Research, Washington, D.C.

Smith, K.C., **Coa, K.**, Klassen, A.C., Caulfield, L.E., Shockney, L., Helzlsouer, & Baker, A.M. (2013). Identifying a potential ‘teachable moment’ around lifestyle behaviors for long term cancer survivors: Perspectives of the clinical care team. Poster presented at the 2013 American Society for Preventive Oncology, Memphis, TN.

**Coa, K.I.**, Phelan, D.F., Pollack, C.E., Garza, M.A., Bone, L., Wenzel, J., Shapiro, G.R., Johnson, L., & Ford, J.G. (2012). Are knowledge and trust in the healthcare system associated with cervical cancer screening behaviors among older, urban black women? Poster presented at the 2012 American Society of Preventive Oncology Annual Meeting, Washington, DC.

**Coa, K.I.**, Clark, M., Farrell, S., Palan, M., Deaton, C., Hagood, H., & Augustson, E. (2010). LiveHelp: Using instant messaging to communicate with smokers about cessation. Poster presented at the 2010 Society for Research on Nicotine and Tobacco Annual Meeting, Baltimore, MD.

**Coa, K.I.**, & Kerwin, J.J. (2009). The use of cognitive interviewing to improve questionnaire design: Health Information National Trends Survey (HINTS) 2007. Poster presented at the HINTS Data Users Conference, Silver Spring, MD.

## **ADDITIONAL INFORMATION**

### Research Interests

- Obesity prevention
- Cancer control and prevention
- Men’s health
- Aging