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Working with Cancer: Health Disparities Among Working Cancer Survivors

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WORKING WITH CANCER: HEALTH DISPARITIES AMONG WORKING CANCER SURVIVORS

By
Tainya C. Clarke

A DISSERTATION

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WORKING WITH CANCER: HEALTH DISPARITIES AMONG WORKING CANCER SURVIVORS

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Cancer is the second leading cause of mortality in the United States, affecting more than 13 million individuals it has impacted the lives of a significant proportion of the population. With improvements in detection and treatment there have been more early diagnoses and improved prognosis for many survivors. These positive changes have led to an increase in the number of survivors that continue to work through diagnosis and treatment and or return to work.

There are an estimated 7.5 million working survivors in the US, though their proportions vary by occupational sectors. With occupational differences in workplace accommodations and perceived disparities in the motivation for re-entering the workforce, this dissertation examined health disparities among cancer survivors in the US workforce. Focusing on the under-explored associations among this special US worker population, we investigated disparities in health behaviors pertinent to health post diagnosis, such as cancer screening; and examined differences in indicators of health (such as; functional limitation, psychological distress, number of days in bed and reported health status). Most importantly differences were stratified by occupation and health insurance which are the main factors reinforcing health behaviors and return to work among survivors.
Using data from the 1997-2010 National Health Interview Survey (NHIS), we found that approximately 91.0% of working survivors reported having health insurance. This is higher than the 86.0% of insured persons without a history of cancer. We also found that while a large proportion of persons without a history of cancer reported having private insurance (71.1%) compared to working survivors (62.6%), adjustments for increased age associated with diagnosis decreased the difference between both working groups.

Health insurance appears to partially mediate the relationship between cancer status and employment, as such, understanding the distribution of the type of insurance available to workers within occupational sectors is important to wellness-programs targeting this special group of workers. The Patient Protection and Affordable Care Act (H.R. 3590), passed by the 111th US Congress under President Barack Obama in December 2009 has shown promise of being beneficial to cancer survivors. With exclusions for preexisting conditions such as cancer and insurance rates based accordingly, this bill will allow working cancer survivors to secure health insurance in new jobs that are more amenable to their physical and mental capabilities post diagnosis.

With a multitude of studies on working survivors concentrated on European populations, this dissertation sought to fill a research gap in exploring the existing health disparities among working cancer survivors within the US. Recognizing the diverse population of working survivors in the US and cognizant of the health disparities that exist among occupational sectors the findings from this research can further inform public policy aimed at the this worker population.
DEDICATION

This dissertation is dedicated to my mother and father, Maxine and Lynwall Clarke, who have always encouraged my quest for new discoveries and supported me wholeheartedly in whatever I chose to do. To my sisters whose own accomplishments further fueled my desire to succeed. To Dolce, a faithful companion who stayed by my side as I wrote research papers late at night and who helped keep my sanity through three graduate degrees.
ACKNOWLEDGEMENTS

There are so many metaphors that come to mind as I try to describe my dissertation experience, and though the cover bears a sole name, the journey would not be possible without the guidance, dedication, support and friendship of several persons.

I compare my doctoral experience to a fascinating train ride; one filled with adventures and knowledge gained at every stop. Before embarking, though, the journey began at home. I am grateful to my parents Lynwall and Maxine Clarke for instilling in me the thirst for knowledge at a very young age, never telling me my dreams were too big or that my outreach and charities too far. I thank my sisters for encouragement, for fun cards, shopping trips and brief visits to remind me that little sisters could be supportive too.

The first stop of the fantastic voyage led me to Dr William (Bill) Abraham and Dr Juan Sabater at the Mt Sinai Medical Center. I would not have embarked on a career in epidemiology without their influence. I thank Bill and Juan for always encouraging me to follow my dreams, and helping me grow as a clinical researcher in all aspects - from conducting and planning studies to learning to write my own protocols and serving as a member of the IRB.

Bill escorted me to the next leg of my trip, handing me off to “the engineer” who said she would make sure that I arrived at my destination. I am most grateful to Dr. Lora Fleming for her encouragement and practical advice, for adding coal to my passion for knowledge and research. Thank you for always pushing me to maximize my potential, for keeping me on the dissertation train even when I felt like jumping off, and making sure I was exposed to as many aspects of cancer research as possible.
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I can only go forward and do great things, because the examples I have to follow were phenomenal.

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Chapter I– Introduction

I. Overview

Cancer is the second leading cause of death among Americans, exceeded only by heart disease. In 2009, cancer was responsible for 562,875 deaths in the United States (US) (Kochanek 2011). According to a report by several health organizations including the National Cancer Institute (NCI), the number of people diagnosed with cancer annually will double from 1.3 million in 2000 to 2.6 million in 2050 (Reuben 2004). In addition, the 2006 Surveillance, Epidemiology and End Results (SEER) data indicated that about 40% of the more than 1 million Americans diagnosed with cancer each year were working-age adults, and more than 11 million people in the U.S. are cancer survivors (Hoving et al. 2009). This proportion is rapidly increasing. For the purpose of this dissertation, we have defined a cancer survivor as anyone who has had a cancer diagnosis, and is continuing to live out the balance of his or her life after undergoing treatment for the disease (NCCS 1986). Today, cancer survivors account for approximately 4% of the population; this is more than double the proportion of the population affected by the disease when SEER began recording morbidity and mortality data in 1973 (Howlader 2011).

With significant advances in early detection and treatment, and consequently greater cancer survival, a diagnosis of cancer is no longer viewed as terminal (Coups 2004). Many persons living with cancer (from diagnosis on) continue to lead full and productive lives at both home and at work (Arndt 2001).

Historically, most studies on survivorship have focused on the health disparities due to functional limitations between cancer survivors and persons without a cancer
history. However, with a growing number of survivors returning to work, it is important to characterize the differences in reported health status, cancer- and health-related behaviors, as well as the differences in pre-disposing and enabling factors by occupation.

Workplace accommodations (such as the Family Medical Leave Act (FMLA), sick-leave, and/or flexible work schedules) increasingly make it possible for many people living with cancer to continue to be valuable contributors in the workplace throughout the course of their illness, treatment, recovery and subsequent lives. Persons who have been diagnosed with cancer continue to work for several reasons besides income; some cope better with their illness when they are in a busy but familiar environment (Austoker 1994); while others continue to work because their health insurance is provided through their employers, and this is the most affordable way to manage treatment and subsequent ongoing screening costs. Given that health insurance and other benefits provided through employment have been shown to vary by type of occupation (Bradley et al. 2002), there may be a difference in cancer-related health behaviors (e.g. screening or quitting smoking) and consequently cancer survivorship by employment status (Kennedy 2007; NCI 2007).

The main objective of this dissertation was to describe the disparities in reported health status and disabilities of working cancer survivors in the US. A secondary aim was to identify differences in health and risk behaviors that affect reported health status by occupation. Thirdly, we investigated enabling (such as health insurance and income) and predisposing determinants of health changes (such as age, gender, race/ethnicity,
etc.) that are nested within, amplified by, or diminished by occupational sectors among cancer survivors.

In order to achieve these objectives, this dissertation has been organized into six chapters. The objective of chapter 1 is to provide a précis of the current scientific literature on adult cancer survivors in the U.S.; their cancer related health and risk behaviors, employment, and occupational disparities. This chapter also introduces the specific aims and hypotheses for each of the three papers/studies. Chapter 2 describes the data sources, the methodology and the analytic approach used to construct the study databases, study measures and algorithms used in analytical models to test each of the study hypotheses. Chapters 3 through 5 present the introduction, methods, results and conclusions for each of the three papers guided by the specific aims addressed in this dissertation. Finally, chapter 6 is a comprehensive summary of the results of this dissertation. Marrying the various relationships described in each dissertation chapter, it is an overview of the scientific evidence derived from this research and the current literature regarding health disparities among cancer survivors of working age in the U.S.

II. Cancer Survivors in the United States

According to the American Society of Clinical Oncologists (ASCO), surviving cancer or “survivorship” can be defined in several ways. The most common definitions include: Having no disease after the completion of treatment, and the process of living with, throughout, and beyond cancer. With the latter, cancer survivorship begins at diagnosis. It includes people who continue to have treatment to either reduce risk of recurrence or to manage chronic disease. In clinical settings, doctors use different terms
to describe the specific period a survivor is experiencing. These can include: acute survivorship which describes the period during diagnosis and/or in treatment for cancer, extended survivorship: which describes the time immediately after treatment has been completed, and permanent survivorship: which describes a more long-term period, usually the time since treatment measured in years (ASCO 2011). The definition used throughout this dissertation incorporates all of the above.

The 5-year anniversary of survivorship is a significant milestone; further, one of the national health objectives for 2020 is for 72.8% of persons with a cancer diagnosis to live 5-years and beyond (USDHHS 2010). In the mid-1970s, the 5-year survival for all cancers was approximately 50%; today, approximately 66.2% of persons survive cancer for 5 years after diagnosis in the absence of other causes of death (MMWR 2011).

Breast cancer survivors account for 9.8% of all survivors (male and female). Survivors of other common cancers include gynecologic cancers (including the ovarian, uterine and cervix- 17.0%) prostate cancer survivors (13.4% of all survivors), and colorectal cancer survivors (8.0%) (Figure 1.1). Among all current survivors, more than 4.7 million received their diagnosis 10 or more years ago. Five-year survival rates are highest among White females (Hispanics included), followed closely by White males. Both are greater than 65%, with their relative survival beyond the 5-year mark almost equal. The 5-year survival rates of American Blacks are however much lower, with male and female rates reported in the mid-fifties. For all cancers combined, the number of survivors in the US has increased steadily during the last four decades, and is
expected to continue and meet the 2020 goal of 72.8% of persons living 5 years or longer post diagnosis (Howlader 2011; USDHHS 2010).

The increases in the number of persons reaching the 5 year survival point and beyond are a result of a combination of several factors, including: earlier cancer detection due to increased screening, more effective treatments, lower rates of cancer recurrences and of treatment-related morbidities, and reduction in mortality from other causes (Green et al. 2010). Improved treatment and higher life expectancy have led to a change in the demographics of cancer survivors. Approximately 30% of survivors are actively employed (Clarke et al. 2011), and more than 60% are over 65 years of age (Howlader 2011).

There is significant occupation, race-ethnic, and socioeconomic disparities among the population of cancer survivors. Although the disease itself does not “discriminate,” there are many factors that make some groups more likely to develop cancer when compared to others. These factors include greater exposure to risks, and genetic and socio-cultural differences which dictate different occupational exposures, environments, nutrition, and physical activity. Other factors contribute to disparities in morbidity and mortality such as differences in education, perceptions of cancer, associated prognostic factors (e.g. age, race/ethnicity, capacity to tolerate treatment, etc.), health insurance and socioeconomic status leading to poorer access to preventative measures including cancer screening (Soler-Vilá et al. 2011; Tian et al. 2011; Yin et al. 2010). There is a higher prevalence of cancer among non-Hispanic Whites in the U.S., but African Americans and Hispanics experience greater morbidity and mortality from the disease. Differences in the prevalence of disease and associated mortality between
specific groups within the population suggest the need for a greater understanding of the complex interaction of social determinants that may influence survivorship and survival.

A growing number of studies are examining return to work among cancer survivors (de Boer et al. 2011; Taskila et al. 2011; Taskila-Abrandt et al. 2004), but most of this research is among various European populations. Recognizing the diverse population of working survivors in the US and cognizant of the health disparities that exist among occupational sectors regardless of cancer status (Christ et al. 2012; Lee et al. 2006a), this dissertation sought to fill a research gap in exploring the existing health disparities among working cancer survivors within the US.

III. Cancer-related Health Behavior and Cancer Screening

Family history plays an important role in one’s risk of developing cancer, but other cancer risk factors have been identified. These cancer risk factors include: age, tobacco use (Vineis et al. 2004), excessive alcohol consumption (Klygis 1992), lack of physical activity, obesity (Healy et al. 2010; Percik & Stumvoll 2009), poor diet, certain occupational exposures (IARC 1988; Lipsett & Campleman 1999), and excessive exposure to ultraviolet radiation (Elwood & Jopson 1997). In general persons engaging in negative modifiable health behaviors are less likely to engage in preventive behaviors such as screening.

Historically, noncompliance with cancer screening recommendations has led to late stage diagnoses and reduced survival rates (Smith et al. 2008). Recommended cancer screening tests often differ by age and gender, therefore analyses of cancer
screening, cancer risk and/or health behaviors must be evaluated within these specific groups. For example, elderly women, women in certain racial and ethnic groups, and those who live below the poverty level are less likely to have had a mammography or Papanicolaou test (than middle aged non-Hispanic White women with more than a high school education) (Doescher 2009; Goel 2003; Mandelblatt 1999; Vidal et al. 2009; Ward et al. 2004). Despite increased awareness and proven effectiveness of colorectal cancer screening tests, many persons 50 years and older are not regularly screened (CDC 2001), and though there have been significant progress in the right direction, the Center for Disease Control (CDC) Behavioral Risk Factor Surveillance System (BRFSS) data still indicate a need for improving screening rates which would lead to earlier detection and reduced deaths (Doescher 2009; Smith et al. 2008).

A healthy lifestyle and attitude have been demonstrated to be important components of long term cancer survival (Brenner et al. 2007; Soler-Vilá 2011). In particular, access to increased screening required as part of the follow-up of both treatment and long term cancer survival becomes essential to persons living with cancer (Chalaire 2006). Disparities in access to healthcare and to workplace accommodations among workers living with cancer are just starting to be explored (Clarke et al. 2011; Lindbohm & Viikari-Juntura 2010; Vidal et al. 2009), but increasingly these factors will determine which workers in the U.S. can continue to work while living with cancer.

IV. The Cost of Cancer

Identifying the persons affected, understanding the toll cancer places on them, their family and others are critical to the study of the population of cancer survivors because
of their large numbers and consequent economic and emotional impact on society. Cancer has physical, psychological and emotional costs, and its greatest impact is on the affected individual – the survivor– and close family. Cancer survivors are three times as likely to be depressed as compared to persons without a history of cancer (Waraich et al. 2004). Partners of survivors are 39% as likely to be treated for depression or other affective psychological disorders compared to peers with never diagnosed partners (Nakaya et al. 2010).

The psychological effects of the disease are exacerbated by its devastating economic impact (Rosenbaum et al. 2011). Cancer is one of the most costly of all chronic diseases in the U.S. because of the expensive treatment options, the high cost of drugs, and the duration of treatment. According to the American Cancer Society (ACS), 1 in 5 privately insured Americans with chronic conditions (including cancer) struggle to pay their medical bills due to, often substantial, out of pocket expenses. Health insurance is of major importance for persons with a cancer diagnosis. It is often the deciding factor as to which secondary and tertiary prevention options to choose, if any. When out-of-pocket spending for medical care exceeds 2.5%of income, the financial burden become substantial (Mariotto 2011). In 2010, the costs for cancer care exceeded $124 billion and are projected to reach $158 billion by 2020 (Mariotto 2011). As oncologists assume a role in “bending the cost curve” by helping patients select affordable treatments (Smith & Hillner 2011), many survivors continue to work in order to afford the financial cost of their cancer care or to maintain employer’s insurance coverage. However, there are still an approximate 17% of cancer patients who do not return to work due to the disease (Torp et al. 2011).
V. Working with Cancer

Cancer can be both physically and psychologically debilitating for a cancer survivor. In the past, workers diagnosed with cancer usually experienced reduced work ability, or retired early due to illnesses and disabilities arising from the disease (Taskila et al. 2011; Taskila et al. 2007). Now, with a significant number of survivors of working age, a large number of persons diagnosed with cancer return to work after treatment, or even maintain regular work schedules during their cancer treatment (Hoffman 2005; Hoving et al. 2009; Satariano & DeLorenze 1996; Short et al. 2005). As the number of persons diagnosed with cancer increases, the workplace and potentially the national economy will be negatively impacted if these persons choose not to return to work after diagnosis and treatment. According to the NCI, persons living with cancer who continue to work are as productive on the job as other workers; research indicates that these workers do not have more absentee days than employees without a cancer history (Nowrouzi et al. 2009), although not all evidence supports this (Clarke et al. 2011). Nevertheless, there are occupational differences in work load and stress (Brown et al. 2006a), and some job sectors may experience a higher rate of return to work by cancer survivors than others (Clarke et al. 2011).

Persons returning to work often need small changes or accommodations in their daily routine, and rely on the understanding of employers and fellow employees to perform their duties effectively (Nachreiner et al. 2012; Nowrouzi et al. 2009). Whether persons living with cancer are able to resume full time employment may be dependent on the health benefits associated with the job such as long term disability and
extended sick leave which allows for recuperation while securing job position. In particular, persons who retire before age 65 years are too young to qualify for Medicare, and currently may be at risk of becoming uninsured (Cohen & Martinez 2005; de Boer & Frings-Dresen 2009; Monheit et al. 2001).

VI. Cancer Health Disparities among Workers

Most relevant to this work is that some of risk factors for cancer are not evenly distributed among all US workers (Fleming et al. 2003; Lee et al. 2006a; Lee et al. 2006b).

There are cancer-related health disparities by employment status and occupation. For example, certain occupational exposures, such as asbestos exposures in construction and mining, increase the risk of cancer (Birdsey et al. 2007; Rushton et al. 2010). Workers who consume tobacco products and are in occupations with potential exposure to additional lung carcinogens (e.g. asbestos in construction) were not more likely to receive smoking cessation advice from their healthcare provider; similarly, workers with obvious increased ultraviolet exposure (e.g. farm workers) were not more likely to receive skin examinations (LeBlanc et al. 2008; Lee et al. 2007).

In addition, as mentioned above, occupational differences in cancer mortality may be related to differences in insurance status. There is evidence that the lack of health insurance is associated with delayed diagnosis and treatment and that insurance status varies by employment status and occupation (Chen et al. 2007; Gimeno-García 2012; Sabatino et al. 2012). Furthermore, although many employed Americans receive some sort of private insurance through their employer (Naessens et al. 2008), this does
not necessarily translate into true access to healthcare since high co-payments may hinder some persons from routine doctors’ visits and many small businesses do not provide subsidized insurance for employees.

Both prevention and treatment are intimately linked to health insurance and within the US population there is a large divide between those who are able to seek basic preventive services and those who do not or cannot due to their insured status and/or an inability to afford it.

Cancer screening and counseling for cancer risk prevention is usually done during routine visits with a primary care provider, and persons without health insurance or who have a high co-payment are less likely to attend these routine doctors-visits (Clarke et al. 2011; Edwards et al. 2005; Lee 2006b; Nachreiner et al. 2012). As such, uninsured US workers may not be receiving appropriate cancer prevention and control information, representing a significant cancer health disparity (Monheit et al. 2001). In 2010, an estimated 28% of Americans between the ages 18 and 34 years were uninsured for at least part of the year (ACS 2011).

VII. *Dissertation Objectives*

Previous research has focused on racial/ethnic and socioeconomic disparities regarding cancer prevention and control issues (prevention, detection, treatment, and survival) (Semrad et al. 2011; Smigal et al. 2006; White et al. 2011). However, there is scarce systematic research using national samples [or data] examining cancer control among workers living with a cancer diagnosis, and the disparities that may arise from their condition as cancer survivors across different occupational categories and employment
status (LeBlanc et al. 2008; Vidal et al. 2009). Ascertaining such disparities is of vital importance for the design, development, and evaluation of targeted interventions to improve primary, secondary, and tertiary prevention practices among workers living with a cancer diagnosis particularly in medically underserved demographic and/or occupational subgroups.

Using the nationally representative 1997-2010 National Health Interview Survey (NHIS) database, the issues mentioned above were explored through the following specific aims and hypotheses:

**Specific Aim 1** – To describe and evaluate measures of health disparities, functional limitations, and morbidity among adults with cancer. Descriptive analyses include stratification by sociodemographic variables, health insurance, employment variables, and cancer type. Cancer survivors will be compared to persons without a previous cancer diagnosis.

**Specific Aim 2** – To reveal complex relationships among sociodemographic indicators, cancer risk behavior, cancer screening behaviors, employment status, and occupation in persons living with cancer using structural equation modeling (SEM). It is expected that:

\[ H_{2.1} \]: Cancer-risk behaviors (e.g. smoking) will be higher in blue collar versus white collar workers living with cancer, even after adjustment for other socioeconomic indicators including insurance status.
**H2-2:** Report of functional limitations, morbidity and reported health status would be less favorable in blue collar versus white collar workers living with cancer, even after adjustment for other socioeconomic indicators including insurance status.

**Specific Aim 3**—To identify variations across time in cancer survivors’ cancer control behaviors and participation in the workforce. Using NHIS data, trend analysis of cancer survivors by employment status and occupation explore the following hypotheses:

**H3-1:** Cancer screening behavior in persons living with cancer increased over time only in those currently employed with health insurance, relative to the unemployed and to those employed but without health insurance.

**H3-2:** The proportion of employed persons of working age living with cancer increased over time; in particular, growth of employment trajectories was highest in the white collar sector.

**VIII. Summary**

US workers living with a previous cancer diagnosis represent an important and understudied group for cancer education and screening with great potential for targeted interventions. The difficulty of recruiting a large enough sample of cancer survivors of working age has hindered data collection on this understudied population. Although the NHIS database has been analyzed to study cancer risk and cancer screening behavior patterns at the national level, (Klabunde et al. 2012; Rostron 2012) there has been very limited research exploring survivorship issues affecting persons who have returned to work after cancer diagnosis.
The results of these analyses tell a story of working cancer survivors in the US. As the population ages and the number of persons in the workplace with cancer increases, there will be a need for healthcare providers, employers, and policy makers attuned to the needs of this growing population. This study can serve as a window into the future of working employment paths and health behaviors of working survivors, and help in directing the necessary changes in the field of oncology practice. Information from this study will also help to highlight the importance of needed changes in health insurance policies, as well as promote awareness about working during or after cancer diagnosis at a more public level (Fowler 1996; Hiatt et al. 2002; Honda 2003; Honda et al. 2005).

Addressing health-related disparities in access to adequate care and timely diagnosis and treatment among cancer survivors would have a significant social and economic impact on our society. This is one of the objectives of the federal government's pre-existing condition insurance plan under the Patient Protection and Affordable Care Act (H.R. 3590), passed by the 111th US Congress under President Barack Obama in December 2009 (111th Congress 2010). With reforms focused on elimination of annual dollar limits, exclusions for preexisting conditions such as cancer and insurance rates based accordingly, as well as differences in rates based on gender and occupation, this bill will have a tremendous effect of working cancer survivors across all occupational sectors.
Chapter II – Methodology

I. Overview
This methodological chapter serves to: 1) describe the population and study sample; 2) provide details on data preparation, variable selection and measurement (including predictor and outcome measures of interest defined and measured); and 3) describe the analytical approaches and modeling used, while delineating which analyses included the entire sample of NHIS individuals and which included only the cohort of cancer survivors. This methodological section also includes detail on the cancer screening recommendations from the ACS used to guide analyses on cancer screening.

II. The National Health Interview Survey (NHIS)
The NHIS is a continuous multipurpose and multistage area probability survey of the U.S. civilian non-institutionalized population living at addressed dwellings. The Survey was authorized by Congress in order to obtain national estimates on disease, injury, impairment, disability, and related issues on a uniform basis for the entire U.S. population (Fowler 1996). In the Core interviews, basic demographic (e.g., age, gender, race-ethnicity) and socio-economic (e.g., income, education, occupation, industry) information is collected, as well as health information (e.g., insurance, health service utilization, and health conditions). Since 1997, a range of data are collected from one randomly selected adult ≥18 years per household, including: occupation, cancer and other health diagnoses, functional capacity, activity limitations, and a range of health behaviors (including cancer screening, tobacco and ethanol use)(NCHS 2011).
i. **Sample Survey and Design** – The NHIS uses a cross-sectional household interview survey, where sampling and interviewing of participants are continuous throughout each year. It employs a multistage area probability design that permits the representative sampling of households and non-institutional organizations (e.g., prisons, and college dormitories) in the U.S.

The sampling plan is redesigned after every decennial census. Using data from 1997 to 2010, this dissertation spans two separate sampling plans.

a. The 1995-2005 sampling plan, state-level stratification includes 358 primary sampling units (PSUs). In addition, both the Black and Hispanic populations were oversampled to allow for more precise estimation of health in these growing minority populations. The current sampling plan implemented since 2006, consists of 428 PSUs drawn from approximately 1,900 geographically defined PSUs that incorporate the 50 states and the District of Columbia. A PSU may be a county, a group of contiguous counties, or a metropolitan area. Within each PSU, two types of second-stage sampling units are employed: 1) area segments and 2) permit segments. Area segments are defined geographically and contain an expected eight, twelve, or sixteen addresses while permit segments cover housing units which were constructed after the administration of the 2000 census. The 2006 sample design reduced the NHIS sample size by approximately 13%. Similar to the previous design, Black and Hispanic populations are oversampled.

Additionally, the new sample design also oversamples the Asian population and
individuals from all three race-ethnic backgrounds have an increased probability of being selected in the adult sample core if they are ≥ 65 years (NCHS 2011).

b. The 1997-2010 NHIS data used for this dissertation consisted of a basic module as well as variable supplements, which included the 2000, 2005 and 2010 cancer supplements. The basic module has remained mostly unchanged from year to year and consists of several components: the family core, the person core, the sample adult core, and the sample child core. With a specific focus on adult cancer survivors, the sample population for this dissertation is drawn from the adult core (≥ 18 years), with additional variables of interest added from the family and persons’ core. While the family core includes household composition and some socio-demographic characteristics, the persons and adult core contains information on the basic indicators of health status, health and risk behaviors, activity limitations, chronic conditions including cancer, health insurance coverage, and access to and utilization of health care services.

The annual sample size of the NHIS has varied over the past 14 years (see Table 2.1). In 1997, the sample adult population included more than 36,000 participants, but from 1998 to 2001, the sample adult population averaged approximately 30,000 individuals. In 2002-2005 the NHIS sample size was reduced due to budget shortfalls, further reductions were made in and again in 2006-2008. The 2009 NHIS sample was reduced by approximately 50% during January-March 2009; newly available funding permitted an expansion during October-December, thus increasing that quarter’s normal sample size by approximately 50%. The net effect of the January-March cut and the October-
December expansion was that the 2009 NHIS sample size was approximately the same as it would be if the sample had been maintained at a normal level during the entire calendar year. In 2010, the NHIS sample was augmented during January-March by approximately 25% and there were no augmentations or reductions in the remaining months. The 2010 NHIS survey had a slightly larger household sample than the 2009 sample but the 2009 survey year yielded a larger sample of adult participants.

The final response rate for the sample adult component was calculated by (Overall Family Response Rate) (Sample Adult Response Rate), the sample adult response rate ranged from 60.8% to 80.4% from 1997 to 2010 (NCHS 2011).

ii. **Data Collection Procedures** - Data used for this study were collected through personal household interviews conducted by interviewers employed and trained by the U.S. Census Bureau according to procedures specified by the NCHS (NCHS 1999b). The NHIS is conducted using computer-assisted personal interviewing (CAPI). The CAPI data collection method employs computer software that presents the questionnaire on computer screens to each interviewer. Interviewers enter responses directly into the computer during the interview, this data collection technology reduces the time required for transferring, processing, and releasing data, and it ensures the accurate flow of the questionnaire. Generally, all recorded responses to questions in this section were self-reported.
Table 2.1. Dissertation sampling frame: Showing total number of adult participants (n=414,044) and number of cancer survivors (n=30,239) - [Pooled NHIS 1997-2010 data]

<table>
<thead>
<tr>
<th>Year</th>
<th>Sampling domains</th>
<th>Persons</th>
<th>Adults</th>
<th>Response rate (%)</th>
<th>Ever had Cancer?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Household Families Persons Adults</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>2010</td>
<td>34,329 35,177 89,976 27,157</td>
<td>60.8</td>
<td>2,333 24,804</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>33,856 34,640 88,446 27,731</td>
<td>65.4</td>
<td>2,304 25,411</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>28,790 29,421 74,236 21,781</td>
<td>62.6</td>
<td>1,851 19,916</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>29,266 29,915 75,764 23,393</td>
<td>67.8</td>
<td>1,785 21,585</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>29,204 29,868 75,716 24,275</td>
<td>70.8</td>
<td>1,739 22,505</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>38,509 39,284 98,649 31,428</td>
<td>69.0</td>
<td>2,428 28,969</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>36,579 37,466 94,460 31,326</td>
<td>72.5</td>
<td>2,339 28,944</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>35,921 36,573 92,148 30,852</td>
<td>74.2</td>
<td>2,142 28,674</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>36,161 36,831 93,386 31,044</td>
<td>74.3</td>
<td>2,262 28,734</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>38,932 39,633 100,761 33,326</td>
<td>73.8</td>
<td>2,327 30,954</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>38,633 39,264 100,618 32,374</td>
<td>72.1</td>
<td>2,151 30,195</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>37,573 38,171 97,059 30,801</td>
<td>69.6</td>
<td>2,085 28,688</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>38,209 38,773 98,785 32,440</td>
<td>73.9</td>
<td>2,109 30,270</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>39,832 40,623 103,477 36,116</td>
<td>80.4</td>
<td>2,384 33,650</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>495,794 505,639 1,283,481</td>
<td>414,044</td>
<td>30,239 383,299</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Summary statistic is an average.

iii. The Cancer supplement—The NHIS is the official federal monitoring instrument for the cancer screening objectives of the goals of the Healthy People 2010 and 2020 (Hiatt et al. 2002). In particular, since 1987, the National Cancer Institute (NCI) has supported a
series of periodic NHIS cancer control supplements which are designed to monitor trends in cancer behavioral risk factors and cancer screening (conducted most recently in 2000, 2005 and 2010). In 2000, the data contained in the adult cancer supplement were contained in the adult core questionnaire. The existence of three extra digits (.xxx) at the end of the question number helped to identify supplementary questions within the core questionnaire. In 2005 and 2010 data from the adult cancer control supplement were released in a separate file.

These Supplements are administered to one randomly selected adult (≥ 18 years) per household chosen to participate in the NHIS, and includes age/gender-specific cancer screening questions (for example, cervical cancer screening questions are administered to women ≥ 18 years). In 2010, a set of questions addressing issues of importance to cancer survivors also were added. Similar questions had not appeared in the NHIS since the 1992 survey. The inclusion of these questions provide much-needed data on how cancer survivors are doing in the U.S. Findings also inform public policies and the development of new programs for cancer survivors in the U.S.

A majority of the questions contained in the cancer supplements were asked in the 1999, 2003 and 2008 questionnaires; as such some analyses include data from these three years in addition to the three cancer supplements. The cancer control supplements are sponsored by the NCI and the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

The Appendix contains a matrix of questions administered as part of the 2000, 2005 and 2010 cancer control supplements, including questions on cancer treatment (year 2010 only), cancer screening, family history of cancer, diet and nutrition, physical
activity, and tobacco use. This study includes detailed analyses based on all sections. As can be seen in the matrix, in each major section of the interview, some questions were asked in an identical manner in years 2000, 2005 and 2010, some were asked in a similar fashion, and others were asked in one year only. Data from 2000, 2005 and 2010 will be combined in order to increase statistical power for selected analyses (see Table 1 for sample size estimates using pooled data). However, analyses will only be conducted if questions were asked in an identical or very similar manner.

Presented below are key definitions for health and screening behaviors (for item wording, see Matrix in Appendix). Whenever possible, definitions that have been published using the 2000, 2005 and 2010 NHIS Cancer Control Supplement data were used.

III. The Study Population

Using data from the pooled 1997 to 2010 NHIS, we selected from the sample of adults, i.e. all persons 18 years and older, (n=414,044), a subsample of persons who have had a previous diagnosis of cancer (n=30,239). The initial analyses compared the representative sample of the U.S. population with a self-reported history of cancer, to those without cancer (n=383,299).

We further investigated adherence to recommended screening behaviors among these cancer survivors. The information regarding this very valuable preventive health measure was available in the cancer control supplements for 2000, 2005 and 2010 as well as in 1999, 2003 and 2008. The sample size for this research question was 12,990 cancer survivors and 161,246 persons without a history of cancer. Some questions were only
fielded in the cancer supplements, as such, these subgroup analyses contained 6,912 cancer survivors and 83,968 persons with no prior diagnosis of the disease. Figure 2.1 provides an overview of the distribution of the study population used throughout the course of the analyses.

Figure 2.1. Overview of Study population

Specific Aim 1

Total Study Population

414,044

Cancer Survivors
Persons without a cancer diagnosis

Specific Aim 2

Pooled 1997-2010

30,239

383,299

Specific Aim 3

Survey years

12,990

161,246

Subgroup analyses

Survey years

6,912

83,968
IV. Key 1997-2010 NHIS Measures

Outcome measures for cancer survivors were compared across several sociodemographic determinants of health. Some variables were classified as defining variables as they allowed classification of cancer survivors and persons without a prior cancer diagnosis into specific subcategories/strata and others were predictors as they were used to predict the participants’ response to the outcome of interest. With regards to health conditions, self-rated health status, functional limitation, psychological distress, and activities of daily living, participants were assessed annually. Depending on the health condition, participants were asked to indicate if they had ever been diagnosed (and if yes, when), or had they been diagnosed within the previous 12 months; therefore, the diagnosis of cancer will be based on these questions, providing time period since cancer diagnosis as well as the type(s) of cancer diagnosed.

Some items were administered intermittently; however, they were not a major focus of this research since most study aims required the use of pooled data to enhance statistical power and to carry out the proposed trend analyses. A complete list of all variables used throughout the study has been presented in the Appendices of the document proper. The main outcomes and predictors in this dissertation are discussed below.

I. Outcome measures – The main outcomes of interest were employment status, i.e. whether study participants were employed/working in the one year prior to the interview, and reported health status, cancer screening and functional limitations.
**a. Employment / Work Status**—For the purposes of these analyses, employment included paid as well as unpaid work, and was only asked of adult participants. In some analyses, employment functioned as a predictor. Employment was categorized as a dichotomous variable; participants were categorized as working if their response to “Which of the following (was person) doing last week?” was ‘Working for pay at a job or business’, “With a job or business but not at work” and/ or “Working, but not for pay, at a family-owned job or business”. Persons who responded “Looking for work” and/ or “Not working at a job or business and not looking for work” were categorized as not working. All other responses were coded as missing.

Among workers, some analyses further assessed differences by occupational categories. The NHIS employs U.S. Census Occupational and Industrial Codes to classify workers. NCHS recoded the Census Occupational Codes into 13 broad categories, and also into 41 more specialized categories; depending upon sample size, the occupational definitions were evaluated by these codes or using 4 classes as discussed by Krieger et al (2005) such as “blue-collar, white-collar, farm and service workers”. We compared differences across the four major occupational categories as defined by the National Center for Health Statistics (NCHS)(NCHS 2003). Table 2.2 illustrates the jobs that are organized and grouped into these occupational groups as well as how the thirteen level occupational grouping collapses into the four categories of white-collar, blue-collar, service workers and farmers.
<table>
<thead>
<tr>
<th>Occupational categories</th>
<th>with 23 Occupations</th>
<th>Occ13</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>White-collar workers</strong></td>
<td>1 = Management</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2 = Business and Financial Operations</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>3 = Computer and Mathematical</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4 = Architecture and Engineering</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>5 = Life, Physical, and Social Science</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>6 = Community and Social Services</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>7 = Legal</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>8 = Education, Training, and Library</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>9 = Arts, Design, Entertainment, Sports, and Media</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>10 = Healthcare Practitioners and Technical</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>16 = Sales and Related</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>17 = Office and Administrative Support</td>
<td>3</td>
</tr>
<tr>
<td><strong>Service workers</strong></td>
<td>11 = Healthcare Support</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>12 = Protective Service</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>13 = Food Preparation and Serving Related</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>14 = Building and Grounds Cleaning and Maintenance</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>15 = Personal Care and Service</td>
<td>8</td>
</tr>
<tr>
<td><strong>Farm workers</strong></td>
<td>18 = Farming, Fishing, and Forestry</td>
<td>9</td>
</tr>
<tr>
<td><strong>Blue-collar workers</strong></td>
<td>19 = Construction and Extraction</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>20 = Installation, Maintenance, and Repair</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>21 = Production</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>22 = Transportation and Material Moving</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>23 = Military Occupations</td>
<td>11</td>
</tr>
</tbody>
</table>
Table 2.2.b Conversion of detailed (41 level) occupational standard codes (SOC) into the National Centers for Health Statistics (NCHS) four Occupational sectors.

<table>
<thead>
<tr>
<th>41 Occupations</th>
<th>Occ13</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>White-collar workers</strong></td>
<td></td>
</tr>
<tr>
<td>01 = Officials and administrators public admin</td>
<td>1</td>
</tr>
<tr>
<td>02 = Managers administrators, except public administration</td>
<td>1</td>
</tr>
<tr>
<td>03 = Management related</td>
<td>1</td>
</tr>
<tr>
<td>04 = Engineers</td>
<td>2</td>
</tr>
<tr>
<td>05 = Architects and surveyors</td>
<td>2</td>
</tr>
<tr>
<td>06 = Natural mathematical/computer scientists</td>
<td>2</td>
</tr>
<tr>
<td>07 = Health diagnosing</td>
<td>2</td>
</tr>
<tr>
<td>08 = Health assessment/treating</td>
<td>2</td>
</tr>
<tr>
<td>09 = Teachers, librarians, counselors</td>
<td>2</td>
</tr>
<tr>
<td>10 = Writers, artists, entertainers, athletes</td>
<td>2</td>
</tr>
<tr>
<td>11 = Other professional specialty</td>
<td>2</td>
</tr>
<tr>
<td>12 = Health technologists/technicians</td>
<td>3</td>
</tr>
<tr>
<td>13 = Technologists, technicians except health</td>
<td>3</td>
</tr>
<tr>
<td>14 = Supervisors and proprietors</td>
<td>4</td>
</tr>
<tr>
<td>15 = Sales representatives, commodities and finance</td>
<td>4</td>
</tr>
<tr>
<td>16 = Other sales</td>
<td>4</td>
</tr>
<tr>
<td>17 = Computer equipment operators</td>
<td>5</td>
</tr>
<tr>
<td>18 = Secretaries, stenographers and typists</td>
<td>5</td>
</tr>
<tr>
<td>19 = Financial records processing</td>
<td>5</td>
</tr>
<tr>
<td>20 = Mail and message distributing</td>
<td>5</td>
</tr>
<tr>
<td>21 = Other administrative support</td>
<td>5</td>
</tr>
<tr>
<td><strong>Service workers</strong></td>
<td></td>
</tr>
<tr>
<td>22 = Private household</td>
<td>6</td>
</tr>
<tr>
<td>23 = Police and firefighters</td>
<td>7</td>
</tr>
<tr>
<td>24 = Other protective service</td>
<td>7</td>
</tr>
<tr>
<td>25 = Food service</td>
<td>8</td>
</tr>
<tr>
<td>26 = Health service</td>
<td>8</td>
</tr>
<tr>
<td>27 = Cleaning and building service</td>
<td>8</td>
</tr>
<tr>
<td>28 = Personal service</td>
<td>8</td>
</tr>
<tr>
<td><strong>Farm workers</strong></td>
<td></td>
</tr>
<tr>
<td>29 = Farm operators and managers</td>
<td>9</td>
</tr>
<tr>
<td>30 = Farm workers and other agricultural workers</td>
<td>9</td>
</tr>
<tr>
<td>31 = Forestry and fishing</td>
<td>9</td>
</tr>
<tr>
<td><strong>Blue-collar workers</strong></td>
<td></td>
</tr>
<tr>
<td>32 = Mechanics and repairers</td>
<td>10</td>
</tr>
<tr>
<td>33 = Construction and extractive trades</td>
<td>10</td>
</tr>
<tr>
<td>34 = Precision production</td>
<td>10</td>
</tr>
<tr>
<td>35 = Machine operators/tenderers, except precision</td>
<td>11</td>
</tr>
<tr>
<td>36 = Fabricators, assemblers, inspectors, samplers</td>
<td>11</td>
</tr>
<tr>
<td>37 = Motor vehicle operators</td>
<td>12</td>
</tr>
<tr>
<td>38 = Other transportation, except motor vehicles</td>
<td>12</td>
</tr>
<tr>
<td>39 = Material moving equipment operators</td>
<td>12</td>
</tr>
<tr>
<td>40 = Construction laborers</td>
<td>13</td>
</tr>
<tr>
<td>41 = Freight, stock, material handlers</td>
<td>13</td>
</tr>
</tbody>
</table>
b. Health Status – Participants were asked ‘Would you say your health in general is excellent, very good, good, fair, or poor?’ Response options were; poor, fair, good, very good, and excellent. Throughout this study, health status was used as a dichotomous variable coded as ‘poor-fair’ or ‘good-excellent’ health. Self-reported health status was an outcome variable when used as an indicator of health among employed and unemployed cancer survivors, but served as a predictor for health insurance and employment when evaluating return to work among survivors.

c. Functional and Activity limitations – Participants were asked about their level of difficulty in performing specific task related to daily functioning such as; walking, climbing, standing, sitting, stooping, carrying, pushing, grasping, and reaching (Milidonis & Greene 2005; Theis et al. 2007). Questions were stated in a similar fashion to the following; ‘By yourself, and without using any special equipment, how difficult is it for you to... [...Walk a quarter of a mile - about 3 city blocks?, ...Walk up 10 steps without resting?, ...Stand or be on your feet for about 2 hours?, etc]’. While questions differed according to the limitation, responses were all measured on a common 5-point Likert scale: 1=Not at all difficult; 2=Only a little difficult; 3=Somewhat difficult; 4=Very difficult; or 5=Can't do at all.

Functional limitation served as both predictor and outcome in separate analyses, and was treated with separate measures in each instance. For specific aim 1, functional limitation served as an indicator of health and was modeled as an outcome. In specific aim 3, it served as a predictor. For logistic regression analyses, we collapsed the responses into a dichotomous variable of two or more (>2) functional limitations and less than two (<2)
functional limitations. For studies using structural equation modeling, we first conducted a confirmatory factor analysis (CFA) to determine if each limitation loaded on a single latent factor. A latent factor is a theoretical factor that is inferred by several observed and measurable variables. Functional limitations served as a predictor in the in structural equation model (SEM) of return to work among cancer survivors.

**d. Cancer Screening** – NHIS participants were asked general screening questions each survey year, these questions asked if they had ever received screening for a specific cancer in their lifetime. This variable recoded as ‘ever_screened’ was treated as a dichotomous variable for all cancers amenable to screening that were fielded in the NHIS questionnaires. In 2000, 2003, 2005, 2008, and 2010, more specific cancer screening questions were asked; these questions were testing adherence to recommended screening and were therefore time-dependent, and dependent on participant age and gender (Clarke & Lee 2012). These included: pap test [women ≥ 18 years], mammography [women ≥ 30 years], prostate specific antigen (PSA) [men ≥ 40 years], sigmoidoscopy/colonoscopy/proctoscopy (i.e., endoscopy) [adults ≥ 40 years], and fecal occult blood test (FOBT) [adults ≥ 50 years]. We used definitions developed by Swan and colleagues at the NCI as well as the guidelines put forth by the American Cancer Society (ACS) to determine the percentage of workers meeting screening guidelines (ACS 2012a; Swan et al. 2003).

Throughout the survey period used in this study, the NHIS employed different formats for response to cancer screening questions in order to maximize the precision of information gathered across years. To facilitate the use of the same computational procedures across all years, we used one common method of variable
response coding for all data years. The NCHS uses three different formats for recording information related to reported cancer screening behavior in order to maximize the precision of information obtained as well as the completeness of the data files.

The general questioning across the years included in these analyses was as follows: ‘‘When did you have your MOST RECENT (screening exam)?’’ We examined each format, and used complementary but mutually exclusive categories to report adherence to screening guidelines for each year. In format 1, survey participants responded with the “date” (i.e., month and year) of their last screening examination. If the year was provided, then this sequence of questions was terminated regardless of whether or not the month was provided. If the year was not provided, then participants were questioned further and responses were recorded using format3. Also, if the year but not the month of the last screening was provided using format 1, the method of imputation used July as the month. In format 2, participants were asked to provide the “number of time units” since their last screening (in days, weeks, months, or years ago). If the number of time units was not provided, participants were then interviewed further and responses recorded using format3. In format 3, participants were asked to identify the “time interval” since their last mammogram (i.e.; ≤1 year ago, >1 year but ≤2 years ago, >2 years but ≤3 years ago, >3 years but ≤5 years ago, or >5 years ago).
II. Predictive Measures— The main predictive measure of interest was cancer survivor status which was used throughout the entire study. The other major predictor which also served as an outcome variable was mentioned above (functional limitation). Predisposing variables (such as age, race/ethnicity and marital status) which exert their effects prior to an individual’s decision to adopt a specific cancer health or risk behavior, as well as enabling variables (such as insured status (health insurance)) which facilitate these behaviors, were also modeled as controls. In some analyses health insurance and psychological distress functioned as predictors of health status and employment.

a. Cancer Survivors— Study participants were defined as cancer survivors or persons without a prior cancer diagnosis depending on their response to the question ‘Have you EVER been told by a doctor or other health professional that you had...Cancer or a malignancy of any kind?’ Respondents who answered ‘yes’ were defined as “cancer survivors” for the purposes of these studies; those who answered ‘no’ were defined as persons without a prior cancer diagnosis. Persons with multiple tumors were categorized according to their first/primary tumor; for example, a person with melanoma, and later colon cancer was counted as a survivor from melanoma but not from colon cancer. Estimators of the number of persons with cancer using different methods of counting multiple tumors are available (Reis 2003). Cancer survivor serves as both a defining and a predictor variable.

Participants were also asked about the time since diagnosis. The study years 1997 to 2010 yielded 30,239 cancer survivors and 383,299 persons without a prior cancer
diagnosis. There were 506 participants who did not respond to the question during the 14 years surveyed (figure 1.2).

**b. Psychological Distress** - The Kessler 6 (K-6) scale of psychological distress was used to quantify participant responses to six questions (Kessler 1998; Rehm 1999b). The questions which included “How often did you feel .... (nervous, sad, restless, hopeless, worthless and ‘that everything was an effort’)?” were loaded onto a single latent factor (Psych_d) for the purpose of these analyses. The K-6 scale, derived from Item Response Theory (IRT), was scored using the un-weighted sum of answer responses; these response options were “none of the time” “a little of the time”, “some of the time”, “most of the time” to “all of the time being,” and yielded a score between 6 and 30 (QCMHR. 2004).

c. **Health Insurance** – Health insurance was recoded from multiple NHIS categories into full-year privately insured, full-year publicly insured, part-year insured and uninsured. In some analyses insurance was treated dichotomously.

d. **Age** – In each survey year, participants were asked to report their chronological age at time of interview. For the purposes of our analyses, age was sometimes treated as a continuous variable and at other times it was categorized. Categories were based on the objectives/ questions being answered. Details of the categories are further explained in the methodological subsections of the associated analyses in chapters 3, 4 and 5.
e. **Gender** - In each survey year, participants were asked to report their sex at time of interview. Variable Name: SEX. We included both males and females in all analyses; however since some cancers are gender specific, there were some instances where a gender specific referent group was unavailable.

f. **Race/Ethnicity** – Each survey year, participants were asked to self-report their race and ethnicity. Using the variables MRACBPI2 and HISPAN_I, we were able to identify the primary or main race reported by the respondent. This study categorized participants as: White, Black, or Other race; and as Hispanic or Non-Hispanic. These options were present throughout all 14 years. In most analyses, a race-ethnicity variable was created with four categories namely, non-Hispanic White, non-Hispanic Black, Black and Other.

g. **Marital Status** – Survey respondents were asked to report their current marital status. Using the variable R_MARITL, we recoded survey responses as:
Married/Living with partner; or Single (including widowed, divorced or separated).

h. **Education** – Survey respondents were asked ‘What is the HIGHEST level of school (person has) completed or the highest degree (person has) received?’ They were given a card with a list of educational grade levels ranging from never to professional degrees. Responses were recorded in the NHIS survey as individual grade levels. For the purpose of our analyses, we recoded responses into ‘less than
High School’ (≤12 years), ‘High School Diploma/GED’ (12 years), and ‘Some College or Higher’ (≥12 years). The NHIS survey variable used was: EDUC.

V. Analytic Methods and Models

i. **Statistical Packages and Data Management** – Several statistical packages were used for the management (e.g. cleaning, coding, concatenating, merging) and analyses of datasets used throughout this study. We used the Statistical Analysis System (SAS) version 9.3 for most statistical analyses and data management, and MPlus version 6.0 to analyze data and Amos 17.0.2 to construct Structural Equation Models. All analytical packages accounted for the complex nature of the data, i.e. survey weights, strata, and PSUs.

ii. **Analysis of Variables** – Following the analyses for descriptive statistics of cancer related health and risk behaviors, occupation and employment. Structural Equation Modeling (SEM) and logistic regression models were be used for more complex variable relationships.

iii. **General Considerations** – The following detail specific statistical issues are relevant to the use of very large weighted data bases with cross-sectional data, all relative to the analyses conducted in this study using the NHIS database:

   a. **Data Aggregation and Trend Analyses** – As described previously, data was aggregated only when variables remained largely unchanged across survey years (Lucas 2004). In the case of substantive changes, only limited aggregation and trend analyses will be performed.
b. **Complex Sample Design Weights** – Original sampling weights are usually inappropriate for data aggregated across survey years. For example, for NHIS data aggregated across survey years, we will adjust the weights in accordance with the work of Botman et al. (Botman & Jack 1995a).

The data analysis plan sample weights were adjusted to account for the aggregation of data over multiple survey years by dividing the original weight by 14 (the number of years combined in NHIS years 1997 through 2010). PSUs and Cluster variables were also used in conducting these complex analyses.

c. **Trend Effects** – When analyzing data that is aggregated over years, there may be a trend in the outcome that is dependent on time. We therefore, included terms in the analysis model to check for trends.

d. **Count Data** – Data for counts of morbidities, health conditions, and health behaviors were tested to determine which analysis was appropriate since count data had a normal or a Poisson distribution. We used multivariable regression for normally distributed data or multivariable Poisson regression for data with a Poisson distribution. In the analysis plans of the methodology subsections in chapters 3, 4 and 5, the term “multivariable regression” means either type of regression.

e. **Statistical Software** – SAS® 9.3. Cary, NC: SAS Institute. Inc. was the main statistical software used for data management. Mplus, version 6.1 (Muthén & Muthén, Los
Angeles, California) was used for SEM. SAS, and Mplus were used for analyses because these packages are able to apply the appropriate weight, adjust variances as well as adjust for the other design effects of the complex multi-stage sampling technique used in the NHIS. (Blackwell 2002; Checkoway 2004; Lethbridge-Cejku 2005; Lucas 2004; NCHS 1999a; Pleis 2003b, 2006; Swan et al. 2003).

**f. Application of SEM to Modeling Risk, Health Status and Employment, post Diagnosis**— SEM is a modeling framework that incorporates several statistical methods including regression, ANOVA, confirmatory factor analyses, and simultaneous equations (Bollen 1989). Offering several advantages over traditional analytic methodology; SEM allows for the estimation of multiple equations simultaneously, thus associations between multiple predictor and outcome variables can be assessed in the same model. In our model, SEM facilitated the assessment of mediation and/or moderation of several factors. Mediation and moderation analyses are a key part of what has been called process analysis (Kenny 2012), as they help to explain the complex relationships occurring between multiple variables simultaneously. In SEM, mediation refers to a situation which includes a causal process between several variables. A mediator interacts with a predictor to change the effect of an outcome.

Moderation also includes three or more variables, such that the presence of at least one of those variables changes the relationship between the others. Moderation exists when the association between two variables differs at all levels of a third variable/ moderator (SAS 2000). Morbidity constructs and cancer health
behaviors were estimated adjusting for measurement error, facilitating an unbiased estimation of the associations between latent variables (constructs).

We performed independent confirmatory factor analyses (CFAs) to test whether measures of the ADL, functional limitation and psychological distress constructs were consistent with our understanding of the nature each construct in the context of this research. We then performed a 3 factor CFA fitting all three latent factors on one model. Multiple group analyses in SEM were used to test if the model provided a good fit to the data in subgroups of interest such as occupation, type of cancer, gender, and race-ethnicity groups (Pentz & Chou 1994). Multiple group analysis is a streamlined method of assessing moderation of grouping variables for one or more model effects. Using, the most recent version of Mplus (6.1) provides the ability to specify survey design, account for missing data, and incorporate sample weights and subpopulation analyses into SEM analyses (Allison 2003; Asparouhov, 2005). Mplus uses all data that is available to estimate the model using full information maximum likelihood (FIML). Each parameter is estimated directly without first filling in missing data values for each individual. FIML has come to mean Maximum Likelihood (ML) under the Missing at Random (MAR) assumption of missing data. For CFAs we used listwise deletion with the option “LISTWISE=ON”. For path analyses we used “MISSING are 99” and “ANALYSIS= TYPE COMPLEX MISSING” to account for missing individual data points associated with categorical outcomes.

Since NHIS data were collected in a cross-sectional fashion, the models proposed cannot incorporate a strong life course perspective in which health and cancer screening
behaviors of workers is a function of accumulation of exposures and other biological, social, and environmental factors occurring over time.

g. **Statistical Power and Sample Size Considerations**—The formulae for SEM power calculations which take into account the complex sample survey design of surveys such as the NHIS have yet to be developed. However, analyses were well powered given the large sample size of the 2000, 2005 and the 2010 NHIS Cancer Control Supplements and the added participants from the 1999, 2003 and 2008 survey years. Presented in this section are a few examples of calculations for adequate statistical power for analyses conducted. In Specific Aim 3, H3-2, a comparison of employment status and cancer screening behavior among persons diagnosed with cancer for two of the most commonly screened cancers, had a statistical power of 0.97 at the 0.05 level for detecting a significant difference in colorectal screening, and 0.89 at the 0.05 level for detecting a significant difference in mammography.

Power was lower for subset analyses (e.g. occupational groups or insured status); although for analyses comparing working cancer survivors with non-working cancer survivors, the power will be higher due to larger numbers.

VI. **Analytic Approach to the Specific Aims**

The analytic approach and measures selected for each analysis varied according to the objective of each specific aim. The following is a summary description of the analytic
approach used for each specific aim and associated testable hypotheses. More details can be found in the specific substantive chapters.

The results of specific aim 1 are presented in chapter 3; we performed comprehensive descriptive analyses of the prevalence of all adults (with and without a previous cancer diagnosis) to evaluate measures of health disparities, functional limitations, and morbidity using nationally representative NHIS data pooled from 1997-2010 (n=414,044). Descriptive statistics including means and 95% confidence intervals for continuous data, and percent and 95% confidence intervals for discrete data, were presented for each variable of interest for the overall sample. These descriptive analyses included stratification by age, gender, race/ethnicity status, education, health insurance, employment status and occupational/industry categories, and cancer type. We used multivariable logistic regression with contrasts to compare the subgroup of cancer survivors to persons without a previous cancer diagnosis as well as compare persons by employed status within each group.

Using multivariable logistic regression with contrasts, we evaluated self-reported health status, reports of functional limitation, chronic conditions, and >1week spent in bed among subgroups separated by employed status and/or cancer diagnosis while controlling for sociodemographic factors such as race/ethnicity, gender, etc. Further methodological description for this aim is described in chapter three.

The results of specific aim 2 are presented in chapter 4; Using Structural equation modeling (SEM), we examined the relationship between sociodemographic indicators, predictors of health (functional limitation, psychological distress, etc.) on employment status and occupation among persons living with cancer utilizing pooled 1997-2010 NHIS data (n=30,239). Two hypotheses were tested:
- **H2.1**: Report of functional limitations, morbidity and reported health status will be higher in blue collar versus white collar workers living with cancer, even after adjustment for other socioeconomic indicators including insurance status (using the 1997-2010 NHIS data).

Figure 2.2. Path model illustrating the relationship between employment, health status and determinants of health (psychological distress, functional limitations and activities of daily living) in the structural equation model.

N.B. All paths are controlled for covariates with the exception of the paths from psychological distress, functional limitations, and activities of daily living to their indicators, (but these paths are not presented in the figure).
SEM was used to estimate models based on the conceptual model in Figure 2.2. For concepts that were measured with multiple observed items (functional limitations, activities of daily living, and psychological distress), latent variable models were used to measure constructs. For example, multiple specific/individual functional limitations were combined to provide a global estimate of functional limitation. Latent variables combine items while removing random measurement error. Model fit statistics were used to assess the operational definitions of the constructs. Using the latent variables along with observed variables, the relationships in the models were simultaneously estimated.

Models were assessed using model fit statistics that indicated whether or not the models reproduced the data well. Mediated pathways were estimated and tested using a product of coefficients method. Moderation of pathways was tested using standard interactions of observed variables. This was done by creating a new variable which is the cross-product between the predictor and the moderator. This “interaction term” was included directly into the path model. Estimates from different pathways varied based on the functional form of the outcomes. For example, some pathways were estimated using ordinary linear regression parameters, while other pathways with non-continuous outcomes were estimated using probit, or logit parameters.

The conceptual model presented was based, in part, on a more complex model about causal relationships between demographic variables and environmental/occupational exposures proposed by Murray et al. (2003). The outcomes modeled were health and functional status. Correlates posited to be associated with these outcomes included sociodemographic indicators such as; cancer history, occupation, and insured status.
The indirect and direct pathways between socio-demographic factors, occupation, cancer-related health behaviors, and cancer screening behaviors were examined as outlined in the models above.

Due to the large sample size, $\chi^2$ was always statistically significant; as such for CFAs we used alternative measures to determine model fit. The fit of the model was evaluated in terms of (a) the comparative fit index (CFI), which compares the hypothesized model to a null model with no paths or latent variables; and (b) the root mean square error of approximation (RMSEA), which estimates the extent to which the covariance matrix specified in the model deviates from the covariance matrix observed in the data. CFI values of 0.95 or greater and RMSEA values of 0.05 or less were used as indicators of good model fit (Kenny 2010).

The results of specific aim 3 are presented in chapter 5-Continued screening post diagnosis is integral to detection of secondary tumors and consequent limitations. The US population met the Healthy people 2010 goal for mammography and colorectal cancer screening, with cancer survivors exceeding them since 1999. First we investigated the employment trajectories (trends over time) among working survivors, then we investigated a decade of screening trends among all cancer survivors and among working cancer survivors compared to the general population. Trends in adherence to recommended screening were analyzed by site-specific cancer for working and non-working cancer survivors. We selected participants $\geq$ 18 years from 1997 to 2010 National Health Interview Survey (NHIS) for survey years where detailed cancer screening information was available.
- **H3.1**: Over time, there will be an increasing proportion of working age persons living with cancer who are employed; in particular, growth of employment trajectories will be highest in the white collar sector (n = 30,239);

- **H3.2**: Cancer screening behavior in persons with cancer will increase over time only in those currently employed with health insurance, relative to the unemployed and to those employed but without health insurance (n = 10,905);

We used a subset of the pooled 1997-2010 NHIS data, i.e. the 2000, 2005 and 2010 NHIS Cancer Supplements as well as the 2003 and 2008 survey years, to perform the trend analysis of cancer screening behavior, employment status and occupation among cancer survivors for H3.2 (n = 10,905). Logistic regression was used to test for a significant linear association of year with employment for H3.1 and screening behavior in H3.2. The model for H3.2 included year as a continuous variable nested within employment/insurance status as a three-level categorical variable in order to fit a separate slopes model that enabled comparisons of the three slopes. For H3.1 a similar model was fitted using a four-level categorical variable for occupation (Krieger et al. 2005). The models were expanded by adding sociodemographic variables to control for possible confounding effects.

Each cancer screening behavior was analyzed separately for the appropriate gender and age group using the guidelines put forth by the ACS and the NCI (ACS 2012b; NCI 2012) (Appendix I).
I. **Statistical Strengths and Weaknesses of this Study**

The issues of probability sampling and linkage, as well as the pooling of data from multiple surveys, inherent in the use of the NHIS survey data, have been discussed at length above, and are dealt with extensively in published literature.\(^{78,96-97}\) Despite its official designation as the federal monitoring instrument for the cancer screening objectives of Healthy People 2000, 2010 and 2020,\(^74\) it is essential to acknowledge that the major limitation of the NHIS survey is the self-reporting of data without objective confirmation. Self-report survey items always involve some level of measurement error which can lead to biased prevalence and parameter estimates. Of note, constructs such as cancer health behaviors and cancer screening behaviors can be estimated net of measurement error using SEM. Thus, the proposed Specific Aim 2 analyses using SEM partially addressed the self-report limitation of the NHIS.

The strengths of the study included the use of 14 years of pooled data which provides a very large sample size, and the NHIS survey is a true representation of the U.S. civilian population. The NHIS data also presents opportunities for theory-based and alternative modeling approaches to guide studies of the many complex risk factors, their interrelationships, and their impacts on cancer screening behaviors and employment after cancer diagnosis. Ultimately, this proposed research identified specific occupational groups which need targeted cancer education and screening, while the proposed modeling informed the design of appropriate programs and interventions. Although little prior research has been completed in this area, it was the goal of this research proposal to examine these associations that inform workplace strategies to meet the unique needs of the increasing population of persons in the U.S. and elsewhere who continue to work post-cancer diagnosis.
Chapter III – Specific Aim / Paper #1

Working with Cancer: Health and Disability Disparities among Employed Cancer Survivors in the U.S.

I. Summary

Approximately 40% of Americans diagnosed with cancer each year are working-age adults. We characterized differences in health status by occupation of working cancer survivors and persons without cancer.

Cross-sectional data from the US National Health Interview Survey (1997-2009) for adults with self-reported physician-diagnosed cancer (n=22,952) and without a cancer diagnosis (n=358,495) were analyzed. Multivariable logistic regression was used to compare the health and disability status of employed cancer survivors across occupational categories relative to workers without a cancer history and unemployed cancer survivors.

Adult cancer survivors were more likely to have white-collar jobs and less likely to have service-jobs compared to workers with no cancer history. Among survivors, workers were significantly less likely to report poor health and multiple disabilities compared to the unemployed. Employed survivors were significantly more likely to report poor health, multiple disabilities and more illness related bed-days than workers without a cancer history. Among employed cancer survivors, blue-collar workers reported worse health outcomes but still reported fewer workdays missed than white-collar workers.

Blue-collar cancer survivors are working with the highest levels of poor health and disability. Workplace health promotion programs and flexible accommodations are necessary for working cancer survivors, especially blue-collar workers.
II. **Background**

It is estimated that more than 11 million people in the United States (U.S.) are cancer survivors. Of the more than 1 million Americans newly diagnosed with cancer each year, about 40% are working-age adults (Horner 2006). Significant advances in cancer control and treatment have translated into greater cancer survival and quality of life. Consequently, many survivors continue to lead full and productive lives (Hubbard 2010). In the past, workers diagnosed with cancer usually experienced reduced ability to work or retired early due to disease-related disability, or treatment-related sequelae (Taskila et al. 2007). Today, with almost 50% of all cancer survivors under 65 years of age (adult survivors), a large number continue working during treatment or return to work shortly after treatment (Hoffman 2005; Short, et al. 2005).

The underemployment of adult survivors has a negative socio-economic effect on survivors and employers in particular and on society in general. In addition to economic considerations, adult survivors may continue to work in an effort to regain some level of “normalcy,” which may have a positive impact in the form of greater social support (Tamminga et al. 2010). Employed cancer survivors tend to be as productive and to have a comparable number of absentee days as employees without a cancer history. Nevertheless, due to differences in work load, stress and accommodation (Brown et al. 2006b), certain job sectors may experience a higher rate of return of cancer patients than others.

Though some studies have investigated the functional limitations of adult survivors (Dellapasqua et al. 2006; Sehl et al. 2009; Sweeney et al. 2006), few have compared cancer survivors who continue to work and workers with no cancer history.
Even fewer studies have investigated this topic across occupational sectors in the United States (Frazier et al. 2009b; Park et al. 2008). Utilizing nationally representative U.S. data; we compared the socio-demographic characteristics, health status, and occupational sectors of cancer survivors versus those of individuals with no cancer history in order to inform future return-to-work interventions.

III. Methods

We analyzed pooled cross-sectional data from the 1997 to 2009 U.S. National Health Interview Survey (NHIS) (Botman & Jack 1995b). The NHIS collects demographic and health information from a representative sample of the non-institutionalized U.S. civilian population annually. Information is collected by household; one adult per family is randomly selected and administered questions related to health, including questions about cancer history and cancer-related health behaviors such as smoking. Annual response rates to the 1997-2009 adult core averaged 71.3% (range: 69%-80%) (NCHS 2005, 2011). The study sample included all persons 18 years and older (n=381,447).

Definitions of Cancer Survivor, Employment Status and Occupational Sector

Cancer survivors were individuals who reported being diagnosed with cancers other than non-melanoma skin cancers. Employment status was determined by whether or not respondents were working during the week prior to the NHIS interview. Employed participants were stratified by occupational sector. For occupational sector,
we used a four-category variable commonly used by the National Center for Health Statistics, which was based on the 2000 U.S. Census and included the categories of white-collar workers (e.g. banker), service workers (e.g. police officer), farm (including fishing and forestry) workers, and blue-collar workers (e.g. construction worker).

**Health Outcomes Ascertainment**

Participants self-reported their health status. The five-item Likert-type scale used in the NHIS dataset to measure health status was re-coded and collapsed into two categories (“poor to fair” and “good-excellent” health). Information on the presence or absence of several chronic conditions (e.g., asthma, joint or neck injury, heart problem) was dichotomously re-coded into presence or absence of ≥2 chronic conditions. Cancer was not included in this list since its presence defines the population of study. We assessed functional limitations by summing responses to 12 indicators of activities of daily living (ADLs) (e.g., walking, stooping) and instrumental activities of daily living (IADLs) (e.g., shopping, other social activities). If respondents reported the activity being “only a little difficult” to “very difficult” it was coded as a functional limitation. We dichotomized the variable into presence or absence of ≥2 functional limitations. Finally, we assessed whether or not respondents spent more than seven days in bed due to illness or injury in the last 12 months.

**Covariates/Socio-demographic Characteristics**

We examined social and demographic characteristics of the sample population to identify any correlations with the predictive variables listed below. Socio-
demographic characteristics included age, gender, race, ethnicity, as well as education, employment and insurance status at time of interview. Age was divided into three categories (18-39 years, 40-64 years and ≥ 65 years) to account for the number of persons in the work force below and above the average retirement age of 65 years (SSA 2009). Race was categorized into “White, Black or other race” and ethnicity into “Hispanic or non-Hispanic.” Education was divided into <12 years (did not complete high school), 12 years (high school diploma or GED equivalent) and >12 years (some college, college graduate or professional degree).

**Statistical Analyses**

Data management and analyses were conducted using SAS statistical software package version 9.2 which allows the analysis of weighted, complex survey data (SAS 2008). Due to the complex sample survey design, analyses were completed with adjustments for sample weights and design effects using SAS survey procedures (SAS 2008). Records from each survey year were weighted according to person-level weights provided in annual NHIS data files. Weights were adjusted according to the number of representative years used in analyses (Botman & Jack 1995b). We used SAS SURVEYLOGISTIC to perform a multivariable logistic regression with contrasts between occupational sectors and employment status of persons with and without cancer for each health indicator. Analyses were adjusted for socio-demographic variables including age, gender, race, ethnicity, education and health insurance status.
IV. Results

Characteristics of Study Participants

There are 22,952 persons who reported having been diagnosed with cancer. Approximately one third of these persons (n=7,424) were employed in the week prior to the NHIS survey and the remaining persons were retired or not employed. In contrast, of the 358,495 individuals without a cancer diagnosis, two thirds (n=218,237) were working in the week prior to the NHIS interview. Approximately 30% of cancer survivors reported poor-fair health, the majority of these individuals was unemployed.

Participants with a Cancer Diagnosis

Forty percent of persons diagnosed with cancer are under 65 years. Men account for 35% and the majority are white. Over 90% reported having health insurance and approximately 70% reported good-excellent health. The majority of cancer survivors were employed in the white-collar occupational sector (67.9%), a similar percentage in blue-collar (15.7%) and service (15.0%) and less than 2% in the farm sector. Among adult cancer survivors, workers were significantly less likely to report poor health and multiple disabilities when compared to the unemployed.

Employed Participants

The vast majority (84.4%) of workers with cancer was 18–65 years of age. Compared to those without a cancer history, a larger percentage of workers with a cancer history reported having health insurance (89.3% versus 78.2%). Occupational distribution of persons without a history of cancer (white-collar 58.5% and service
23.4%) differed from working survivors (white-collar 67.9% and service 15.0%). The percentage of employed cancer survivors reporting “poor to fair” health was more than twice that of employed persons without cancer (14.6% versus 6.0%). More than a quarter (28.1%) of working persons with a cancer history reported having two or more functional limitations, which is more than double the proportion of those with no cancer history (12.5%). Employed cancer survivors were more than twice as likely to report having two or more chronic conditions when compared to working persons without a cancer history (5.9% and 2.2%, respectively). A larger percentage of employed cancer survivors (11.7%) reported spending more than 1 week in bed due to related illness in the past year when compared to employed persons without a diagnosis (4.6%).

In Table II, we report the multivariable logistic regression results comparing workers with cancer by occupational sector to, first, unemployed persons with a cancer history and then, second, to employed persons without a cancer history. Finally, we compared cancer survivors between occupational sectors.

**Health Status**

Adjusting for socio-demographic characteristics and health insurance, we find that, irrespective of work sector, workers with a cancer history were significantly less likely to report “poor to fair” health status when compared to unemployed persons with cancer: all workers [Odds Ratio (OR)= 0.12 – 0.35]. When comparing workers with cancer to employees without a cancer history, all workers (OR= 2.06 – 4.44) were significantly more likely to report “poor to fair” health status. Finally, between occupational group comparisons of cancer survivors showed that blue-collar workers
were significantly more likely than white-collar workers (OR= 1.98; 95% Confidence Interval (95% CI) =1.53-2.56) to report poor to fair health status. Farm workers were less likely than blue-collar workers (OR=0.21; 95% CI=0.09-0.52) to report a poor to fair health status. Service workers were less likely than blue-collar (OR=0.60; 95% CI=0.43-0.83) but more likely than farm workers (OR=2.82; 95% CI=1.16-6.86) to report a “poor to fair” health status.

Functional Limitations

Workers with cancer were significantly less likely to report two or more functional limitations when compared to unemployed persons with cancer (OR= 0.34 – 0.48). When compared to employed persons without a history of cancer, all workers with cancer (OR= 1.72 – 2.29) were significantly more likely to report two or more functional limitations. Between occupational group comparisons among employed survivors revealed that blue-collar workers were significantly more likely (OR=1.28; 95% CI=1.04-1.59) to report having two or more functional limitations in comparison to white-collar workers.

Chronic Conditions

When compared to unemployed persons with cancer, working survivors were less likely to report two or more chronic conditions (OR= 0.30 – 0.47). When compared to employed persons without a history of cancer, workers with cancer were more likely to report having two or more chronic conditions (OR= 1.31 – 3.16). Finally, among working persons with a history of cancer, blue-collar workers are twice as likely (OR=
2.03; 95% CI=1.35-3.05) as white-collar workers to report having two or more chronic conditions.

**Number of Days Spent in Bed per Year Due to Illness or Injury**

Workers with cancer were significantly less likely to report more than 7 bed days per year when compared to unemployed persons with cancer (OR=0.28 – 0.47). However, when compared to working persons without cancer, employed survivors were significantly more likely to report more than 7 bed days per year (OR=1.89 – 3.13). Finally, there were no significant differences in bed days observed between occupational sectors; though the comparison between blue-collar and white-collar survivors approached significance suggesting that the former may have a higher likelihood of spending more than 7 bed days per year than the latter.

V. **Discussion**

In this nationally representative sample, the typical employee who continues to work post cancer diagnosis is a middle aged individual in the white-collar job sector, who has very few if any functional limitations and reports good-excellent health. Our data also reflect a comparatively smaller, but significant proportion of blue-collar cancer survivors who report poor-fair health, ≥ 2 functional limitations and ≥2 chronic conditions, yet continue to work. One would expect that those with poorer health outcomes would be more likely to become or to remain unemployed. However, it is also possible that for a portion of the survivors, being unemployed had a negative impact on their well-being due to lower income, loss of vital health insurance coverage, worse
lifestyle behaviors, and/or a reduction of social support; though the evidence is inconclusive (Kasl & Jones 2000). Due to the cross-sectional nature of the data, we cannot characterize the direction of this association. There was very little difference in socio-demographic characteristics between working cancer survivors and other persons in the workforce.

Also, given that our sample may include individuals who are recently diagnosed, undergoing treatment, or still suffering treatment-related comorbidities, our data indicate that survivors are more likely to report poor health, more chronic conditions and functional limitations than workers without a history of cancer; which supports previous findings (Bradley & Bednarek 2002; Spelten et al. 2002).

Whereas the type of cancer treatment and its sequelae, and the individual’s health status and functional limitations may determine whether or not a survivor returns to work (Ahn et al. 2007; Ganz 2001; Gurney et al. 2003; Taskila et al. 2007), the job type, job-related social support and the work environment may influence their perceived health and desire to continue working post diagnosis (Bouknight et al. 2006; Grunfeld et al. 2010; Grunfeld et al. 2008; Yarker et al. 2010). Persons with a history of cancer may return to work for financial reasons and may be motivated by the cost of continued care and health insurance (Pransky 2010). Our results indicate that a larger percentage of employed persons with cancer (89.3%) have health insurance when compared to employed persons without cancer (78.2%). This finding is favorable since we know that a person with cancer as a pre-existing condition will find it difficult to qualify for, or afford new insurance coverage; whether through a new job or as an individual (Cohen & Martinez 2005; Thorpe & Howard 2003). Having access to health insurance is
instrumental in obtaining continued care post diagnosis. With working cancer survivors significantly more likely to report poorer health conditions when compared to employed persons without cancer, a greater understanding of what aspects of these jobs aid in eliciting poor health during and after treatment is pertinent to helping this group.

We investigated differences in health profiles among occupational sectors. Sectors with jobs that require more manual labor are understandably less conducive to persons who recently underwent or are undergoing cancer treatment. These sectors often require less education than the less physically demanding jobs in the white-collar sector, making it difficult for cancer survivors within blue-collar and service sectors to transition into white-collar jobs. When compared to white-collar workers, blue-collar workers with a history of cancer were twice as likely to report poor-fair health and having \( \geq 2 \) chronic conditions and 30% more likely to report \( \geq 2 \) functional limitations. This finding raises the question of why persons continue to work post cancer despite reporting functional limitations as well as hints at the possibility that many blue-collar workers continue to work post diagnosis out of necessity rather than desire (Berkley Assoc. 1982; Zwerling et al. 2003).

With more reports of poor-fair health and longer time before retirement, it is important to understand and attempt to alleviate some of the work related difficulties affecting the health of young working cancer survivors. It has been well documented that some job types are more apt to offer flexible work schedules, reduced work hours and job assistance while others are not (Rowland & Yancik 2006), as such there are still a significant number of persons who do not share their struggle with cancer because of fear of discrimination or forced resignation (Ferrell et al. 1996). Although there is
continued support through organizations such as the American Cancer Society and a myriad of non-profit organizations, there is still no official venue for cancer survivors returning to work to seek job related support here in the U.S. Our European counterparts have embarked on studies aimed at identifying priorities for the successful rehabilitation of employees who return to work after a cancer diagnosis (Mao et al. 2007). The new U.S. healthcare reform bill that supports workplace health promotion programs may assist employers in developing re-integration programs and reduce the extent of occupational health disparities among working cancer survivors. It encourages larger and eligible small business to apply for tax incentives for workplace wellness programs (111th Congress 2010). This strategy will go beyond the classical health promotion intervention and target specific worker groups within the work environment. The bill also stipulated additional funding to support more intensive health promotion research as well as the Senate Health, Education, Labor and Pensions (HELP) act. The effects of this bill will be most evident among working survivors when the current economic recession is ended.

The socio-epidemiological effects of cancer on survivors of working age is still underexplored and requires evidence-based research to further inform public health policy. The Senate bill provides for grants to state or local health departments to carry out 5-year pilot programs to provide public health community interventions, screenings, and the establishment of workplace wellness programs.

These findings should be interpreted in the context of the study’s limitations. NHIS data are self-reported and cross-sectional which precludes the differentiation between correlative associations from causal relationships when examining persons
with a history of cancer, their current occupation and reported health status. The job worked in the one week period prior to the survey may not represent long-term/ lifetime occupation or the occupation prior to cancer diagnosis, though we cross-checked the accuracy of the occupational data based on several questions addressing employment; but Gómez-Marín et al. (2005) demonstrated a moderate to high agreement between current job and longest job held using earlier NHIS data.

Clinical variables such as stage at diagnosis, type of treatment received or recurrences of cancer are not available in the public NHIS files. The authors wish to acknowledge the potential confounding introduced by including all cancers (except non-melanoma skin cancer) and all stages, as our health-related outcome variables and whether a person is employed or not will vary substantially by cancer characteristics, treatment and sequelae and the physical demands of the job (i.e., some cancers may render some jobs physically impossible while not limiting others).

Major strengths of this study include the large sample size (spanning 13 years) and the novel use of the NHIS data to examine occupational differences in health profiles among persons with a history of cancer. The data are representative of the US population and can be used as a guide to inform public health policies related to work related issues among cancer survivors. Our multivariable analyses controlled for common potential socio-demographic confounders in addition to health insurance, which was not usually controlled for in previous similar studies despite having a potentially substantial bearing on associations between employment, occupational sector, and health, especially among cancer survivors.
Among workers with a cancer history, blue-collar workers seem to be at the greatest disadvantage. A larger percentage of white-collar workers are >65 years and in addition to fewer reports of poor-fair health have the option of retiring, i.e. not working due to poor health status. This generates important questions beyond the scope of this study: how do survivors cope with returning to work, how do work policies accommodate survivors, and does the re-entry process vary by occupational sector?

<table>
<thead>
<tr>
<th>Socio-demographics</th>
<th>Persons with Cancer diagnosis (n=22,952)</th>
<th>Persons without cancer (n=358,495)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Employed (n=7,424)</td>
<td>Unemployed (n=15,528)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>1,549 [20.9%] 828 [5.3%]</td>
<td>108,834 [49.9%] 41,906 [29.9%]</td>
</tr>
<tr>
<td>40-64</td>
<td>4,720 [63.6%] 3,926 [25.3%]</td>
<td>102,150 [46.8%] 45,764 [32.6%]</td>
</tr>
<tr>
<td>≥ 65</td>
<td>1,155 [15.5%] 10,774 [69.4%]</td>
<td>7,253 [3.3%] 52,588 [37.5%]</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2,494 [33.6%] 5,722 [36.8%]</td>
<td>109,352 [50.1%] 48,714 [34.7%]</td>
</tr>
<tr>
<td>Female</td>
<td>4,930 [66.4%] 9,806 [63.2%]</td>
<td>108,885 [49.9%] 91,544 [65.3%]</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>6,542 [88.1%] 13,571 [87.4%]</td>
<td>171,908 [78.7%] 107,983 [77.0%]</td>
</tr>
<tr>
<td>Black</td>
<td>627 [8.5%] 1,535 [9.9%]</td>
<td>31,575 [14.5%] 23,233 [16.6%]</td>
</tr>
<tr>
<td>Other</td>
<td>255 [3.4%] 422 [2.7%]</td>
<td>14,754 [6.8%] 9,042 [6.4%]</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>6,879 [92.7%] 14,454 [93.1%]</td>
<td>179,121 [82.1%] 115,245 [82.2%]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>545 [7.3%] 1074 [6.9%]</td>
<td>39,116 [17.9%] 25,013 [17.8%]</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;12 years</td>
<td>4,620 [62.5%] 6,157 [40.0%]</td>
<td>128,475 [59.2%] 54,697 [39.7%]</td>
</tr>
<tr>
<td>12 years</td>
<td>2,063 [27.9%] 4,856 [31.6%]</td>
<td>59,402 [27.4%] 42,013 [30.5%]</td>
</tr>
<tr>
<td>&gt;12 years</td>
<td>714 [9.6%] 4,373 [28.4%]</td>
<td>29,019 [13.4%] 41119 [29.8%]</td>
</tr>
<tr>
<td><strong>Health Insurance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>795 [10.7%] 708 [4.6%]</td>
<td>39,680 [21.8%] 23,010 [16.5%]</td>
</tr>
<tr>
<td>Insured</td>
<td>6,623 [89.3%] 14,797 [95.4%]</td>
<td>178,018 [78.2%] 116,599 [83.5%]</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White collar</td>
<td>5,007 [67.9%] †</td>
<td>126,064 [58.5%] †</td>
</tr>
<tr>
<td>Blue collar</td>
<td>1,160 [15.7%] †</td>
<td>34,907 [16.2%] †</td>
</tr>
<tr>
<td>Farm</td>
<td>102 [1.4%] †</td>
<td>4,153 [1.9%] †</td>
</tr>
<tr>
<td>Service</td>
<td>1,107 [15.0%] †</td>
<td>50,435 [23.4%] †</td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good-excellent</td>
<td>6,327 [85.4%] 9,413 [60.8%]</td>
<td>205,899 [94.0%] 107,057 [76.4%]</td>
</tr>
<tr>
<td>Poor-fair</td>
<td>1,084 [14.6%] 6,081 [39.2%]</td>
<td>12,253 [6.0%] 33,013 [23.6%]</td>
</tr>
<tr>
<td>≥ 2 Function limitations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2,084 [28.1%] 9,555 [61.5%]</td>
<td>7,101 [3.3%] 35,337 [25.2%]</td>
</tr>
<tr>
<td>No</td>
<td>5,340 [71.9%] 5,973 [38.5%]</td>
<td>211,136 [96.7%] 104,921 [74.8%]</td>
</tr>
<tr>
<td>≥ 2 Chronic conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>435 [5.9%] 2,365 [15.2%]</td>
<td>4,861 [2.2%] 13,603 [9.7%]</td>
</tr>
<tr>
<td>No</td>
<td>6,989 [94.1%] 13,163 [84.8%]</td>
<td>213,376 [97.8%] 126,655 [90.3%]</td>
</tr>
<tr>
<td><strong>Number of days in bed/yr</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 week or less</td>
<td>6,374 [88.3%] 11,537 [76.6%]</td>
<td>204,807 [95.4%] 116,791 [85.3%]</td>
</tr>
<tr>
<td>&gt;1 week</td>
<td>939 [11.7%] 3,355 [23.4%]</td>
<td>9,912 [4.6%] 20,151 [14.7%]</td>
</tr>
</tbody>
</table>

1 Column percentage illustrated
2 All chronic conditions excluding cancer
† Data not applicable

<table>
<thead>
<tr>
<th>Krieger worker categories (n=27,604)</th>
<th>Poor-Fair Health status [OR [95%CI]]</th>
<th>Functional limitations [OR [95%CI]]</th>
<th>Chronic conditions [OR [95%CI]]</th>
<th>Bed-days (&gt;1week) [OR [95%CI]]</th>
</tr>
</thead>
<tbody>
<tr>
<td>All workers with cancer</td>
<td>0.25 [0.24-0.26]</td>
<td>0.37 [0.35-0.38]</td>
<td>0.30 [0.27-0.32]</td>
<td>0.28 [0.27-0.29]</td>
</tr>
<tr>
<td>White collar with cancer</td>
<td>0.29 [0.25-0.33]</td>
<td>0.37 [0.34-0.42]</td>
<td>0.36 [0.28-0.45]</td>
<td>0.36 [0.32-0.41]</td>
</tr>
<tr>
<td>Blue collar with cancer</td>
<td>0.57 [0.45-0.73]</td>
<td>0.48 [0.39-0.59]</td>
<td>0.73 [0.51-1.03]</td>
<td>0.47 [0.36-0.60]</td>
</tr>
<tr>
<td>Farm worker with cancer</td>
<td>0.12 [0.05-0.29]</td>
<td>0.34 [0.20-0.60]</td>
<td>0.44 [0.16-1.27]</td>
<td>0.30 [0.13-0.65]</td>
</tr>
<tr>
<td>Service worker with cancer</td>
<td>0.35 [0.28-0.43]</td>
<td>0.41 [0.34-0.49]</td>
<td>0.47 [0.32-0.69]</td>
<td>0.40 [0.31-0.52]</td>
</tr>
<tr>
<td>Unemployed with cancer</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Krieger worker categories (n=227,539)</th>
<th>Poor-Fair Health status [OR [95%CI]]</th>
<th>Functional limitations [OR [95%CI]]</th>
<th>Chronic conditions [OR [95%CI]]</th>
<th>Bed-days (&gt;1week) [OR [95%CI]]</th>
</tr>
</thead>
<tbody>
<tr>
<td>All workers with cancer</td>
<td>2.06 [1.96-2.17]</td>
<td>1.72 [1.64-1.80]</td>
<td>1.31 [1.22-1.41]</td>
<td>1.89 [1.79-2.01]</td>
</tr>
<tr>
<td>Farm worker with cancer</td>
<td>0.95 [0.40-2.23]</td>
<td>1.64 [0.96-2.83]</td>
<td>1.94 [0.67-5.62]</td>
<td>1.97 [0.89-4.35]</td>
</tr>
<tr>
<td>Employed without cancer</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Between Krieger group comparisons for workers with cancer diagnosis (n=9,302)</th>
<th>Poor-Fair Health status [OR [95%CI]]</th>
<th>Functional limitations [OR [95%CI]]</th>
<th>Chronic conditions [OR [95%CI]]</th>
<th>Bed-days (&gt;1week) [OR [95%CI]]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blue collar vs White collar</td>
<td>1.98 [1.53-2.56]</td>
<td>1.28 [1.04-1.59]</td>
<td>2.03 [1.35-3.05]</td>
<td>1.29 [0.98-1.70]</td>
</tr>
<tr>
<td>Farm vs White collar</td>
<td>0.42 [0.18-1.00]</td>
<td>0.92 [0.53-1.59]</td>
<td>1.24 [0.41-3.75]</td>
<td>0.82 [0.37-1.81]</td>
</tr>
<tr>
<td>Service vs White collar</td>
<td>1.19 [0.92-1.55]</td>
<td>1.10 [0.89-1.36]</td>
<td>1.32 [0.86-2.04]</td>
<td>1.11 [0.85-1.45]</td>
</tr>
<tr>
<td>Farm vs Blue collar</td>
<td>0.21 [0.09-0.52]</td>
<td>0.72 [0.40-1.28]</td>
<td>0.61 [0.20-1.88]</td>
<td>0.63 [0.28-1.41]</td>
</tr>
<tr>
<td>Service vs Blue collar</td>
<td>0.60 [0.43-0.83]</td>
<td>0.86 [0.66-1.10]</td>
<td>0.65 [0.40-1.07]</td>
<td>0.86 [0.61-1.20]</td>
</tr>
<tr>
<td>Service vs Farm</td>
<td>2.82 [1.16-6.86]</td>
<td>1.19 [0.68-2.10]</td>
<td>1.06 [0.35-3.24]</td>
<td>1.360.60-3.10]</td>
</tr>
</tbody>
</table>

1 Model comparisons controlled for socio-demographic characteristics including age, gender, race, ethnicity, education and health insurance.
Chapter IV – Specific Aim / Paper #2

Working with Cancer: Predictors of Health and Labor Force Participation among Cancer Survivors

I. Summary

Cancer affects a significant and growing proportion of U.S. workers. Factors contributing to their continued, or return-to, work include age, physical and mental health, and cancer type. The purpose of this study was to model and assess the complex relationship between health indicators and employment status for working age cancer survivors.

We analyzed data pooled from the 1997-2010 US National Health Interview Survey (NHIS) for adults with a self-reported physician diagnosis of cancer (n = 25,285). Using structural equation modeling, we evaluated the relationship between several predictors (socio-demographic factors, cancer type, and health indicators) on the employment and health status of cancer survivors of working age. The model demonstrated a significant association between the predictors and employment status ($\chi^2 (374) = 3654.727, p <0.0001; \text{CFI} = 0.980; \text{RMSEA} = 0.035$). Survivors with some college education were more likely to be insured and significantly more likely to report good-to-excellent health (odds ratio=1.76; 95%CI= 1.58-1.97). Time since diagnosis had no major effect on good-to-excellent health status (1.03; 1.01-1.05) and no effect on employment. Health insurance was strongly related to health status and employment.

A significant percentage of cancer survivors may continue to work because of job flexibility, social support and access to health insurance. These options are not
equally distributed, and may be dictated by common social determinants such as occupation and educational level. As the working survivor population increases, the need for workplace and insurance policies to address their needs increases.

II. Background

With significant improvements in cancer detection and treatment, increasing numbers of cancer survivors return or continue to work post cancer diagnosis (Hoffman 2005; Horner 2006). Recent literature reflects an increase in return to work among survivors, many of whom continue to work even during active cancer treatment (Grunfeld et al. 2010). However, the ability to work is greatly dependent on one’s underlying health status which is affected by the individual’s age, the type of cancer, stage at diagnosis, sequelae, and treatment (Feuerstein et al. 2007; Short et al. 2005; Spelten et al. 2002; Spelten et al. 2003).

Health status may also be predicted by functional limitations, activities of daily living (ADL) and psychological distress factors. Previous survivorship research has indicated age-related disparities among employment status and functional limitations (Dellapasqua et al. 2006; Sehl et al. 2009; Sweeney et al. 2006). Further, studies have revealed functional limitations, ADL or psychological distress as predictors of health (Braithwaite et al. 2010; Feuerstein et al. 2007; Keating et al. 2005); some have shown a correlation between ADL and functional limitations (Mohile et al. 2009), and others have described the distribution of all three among survivors and their reported health status (Hewitt et al. 2003).
In their study of a cohort of cancer patients, Mustain et al. (2008) found that cancer-related fatigue impaired quality of life by interfering with patients' abilities to perform specific ADLs, such as cooking, bathing, dressing, as well as socializing, engaging in sexual activity and running errands. Hewitt et al., (2003) compared cancer survivors to individuals without a history of cancer and found that survivors were significantly more likely to report poor-fair health, disabilities related to psychological problems, functional limitations, and limitations in performing ADLs. Hewitt also noted that survivors under 65 years were more likely than those without a cancer history to report being unable to work due to a health condition. These findings inform the relationship modeled in figure 1.

The purpose of this study was to identify the complex relationship between three indicators of health, and their relationship to self-reported health status and the employment status of cancer survivors of working age. The hypothesized model (figure 1) displays the proposed direct and indirect relationships examined in this study.

III. Methods

Participants

We analyzed pooled data from the 1997 to 2010 US National Health Interview Survey (NHIS), merging data from the adult files, person files, and the 2000, 2005 and 2010 cancer control modules (Botman & Jack 1995b). The NHIS collects demographic and health information from a representative sample of the non-institutionalized US civilian population annually. Information is collected by household; one adult per family is randomly selected and administered questions related to health, including
questions about cancer history and cancer-related health behaviors such as smoking. Annual adult response rates to the NHIS data used in this study during the study time period averaged 71.3% (range: 69%-80%) (NCHS 2005, 2011).

**Measures**

The outcome variables of interest were employment and self-reported health status. Employment was dichotomously coded as “employed” or “unemployed,” determined by participants’ responses to whether or not they were working during the week prior to the NHIS interview. Health status was self-reported health on a Likert scale and combined to form a dichotomous variable “poor-to-fair” and “good-to-excellent” health for ease of comparison with previous research.

Participants who responded “yes” to the question: “Have you ever been told by a doctor or other health professional that you had...Cancer or a malignancy of any kind?” were categorized as persons with a cancer diagnosis. For those persons who responded “yes” to a physician diagnosis of cancer, subsequent responses to the types of cancer diagnosed permitted stratification by cancer type. For the purposes of this study, we looked at the five most common cancers diagnosed with the greatest frequency in the US, excluding non-melanoma skin cancer and categorized the rest of reported cancers as ‘other,’ our reference category (ACS 2012c). Persons with multiple tumors were categorized according to their first/primary tumor; for example a person with melanoma and later breast cancer was counted as a survivor from melanoma but not from breast cancer.
We controlled for socio-demographic variables including age, education, race/ethnicity and gender. We modeled health insurance as an enabling variable predicting health status. Age was measured on a continuous scale. Education was treated as an ordinal variable with 3 levels (less than high school, high school diploma or equivalent, and some college or higher education). Race/ethnicity were divided into four mutually exclusive categories: non-Hispanic White (referent), non-Hispanic Black, Hispanic, and other. We examined insured status and its relationship to self-reported health status.

We measured the effects of functional limitations, psychological distress and activities of daily living (ADLs) on health status and employment status. Functional limitations, psychological distress and ADLs were latent variables measured by several correlated observable measures described below.

As defined by the NCI (Kessler 1998), ADLs are basic tasks of everyday life. These activities include: preparing meals, eating, getting dressed, getting into or out of a bed or chair, and other necessary social functions. The response categories (ranging from 1-5) were “not at all difficult,” “only a little difficult,” “somewhat difficult,” “very difficult,” and “can’t do at all.” The NHIS addresses social functions, relaxing and shopping; these activities were loaded onto the single factor ADLs. Using the same response categories as for the individual ADLs, respondents were asked about the level of difficulty experienced when performing a named task (such as; walking, standing, stooping, carrying, grasping, climbing, sitting, pushing and reaching) by themselves without using any special equipment. These nine variables were loaded onto the latent factor, Functional Limitations.
Based on the Kessler 6 (K-6) scale of psychological distress (Kessler 1998; QCMHR. 2004; Rehm 1999a) participant responses to six questions “How often did you feel ... (nervous, sad, restless, hopeless, worthless and ‘that everything was an effort’)?” were loaded onto a single latent factor, the K-6 scale; derived from Item Response Theory (IRT), the K-6 is scored using the un-weighted sum of answer responses, where responses were re-coded to range from “none of the time” “a little of the time”, “some of the time”, “most of the time” to “all of the time being,” yielding a score between 1 and 5 (QCMHR. 2004; Rehm 1999a).

**Data Analytic Plan**

Data management and descriptive analyses were conducted using SAS statistical software package version 9.2 which allows the analysis of weighted, complex survey data. We used Mplus version 6.1 (Muthen & Muthen 2010) to test the study hypotheses within a SEM framework. Due to the complex sample survey design, analyses were completed with adjustments for sample weights and design effects using SAS survey procedures (SAS 2008). Records from each survey year were weighted according to person-level weights provided in annual NHIS data files. Weights were adjusted according to the number of representative years used in analyses (NCHS 2011).

Using confirmatory factor analyses (CFA), first individual measurement models were estimated to ascertain the relationship (correlated vs. uncorrelated) among the indicators of ADLs, functional limitations, and psychological distress. Second, the fit of all three latent variables was measured in a three factor model. Thirdly, we estimated the hypothesized structural equation model (SEM) (see Figure 1). The fit of the model
was evaluated in terms of (a) the comparative fit index (CFI), which compares the hypothesized model to a null model with no paths or latent variables; and (b) the root mean square error of approximation (RMSEA), which estimates the extent to which the covariance matrix specified in the model deviates from the covariance matrix observed in the data. CFI values of .95 or greater and RMSEA values of 0.05 or less were used as indicators of good model fit (Kenny 2010; RB 2010).

The chi-square statistic, while reported, was not used in the interpretation due to its sensitivity to testing the null hypothesis of perfect fit when sample size is large (Preacher et al. 2007). Modification indices were used to improve model fit in the measurement model by correlating error variances where appropriate.

IV. Results

The study sample included all persons 18 years and older who had been diagnosed with cancer (n=24,810) and compared them to working adults without a previous cancer diagnosis (n=382,837). Table 4.1 shows that the largest group of working cancer survivors was between 40-64 years of age (45.7%). The prevalence of cancer among women was almost double the rate reported among men. Cancer status did not vary significantly between Hispanics and non-Hispanic Blacks, but approximately 80% of cancers were among non-Hispanic Whites. There was a comparatively higher percentage of survivors with some college or higher education among working cancer survivors compared to their unemployed peers (43.5% vs. 38.7%); this pattern, was similar among individuals without a cancer history. Eighty-three percent of working survivors reported good-to-excellent health; this was
approximately 15% higher than their unemployed peers, but 10% lower than working persons who had never had a cancer diagnosis. A significant proportion of cancer survivors reported having two or more functional limitations, the percentage of functional limitations reported among unemployed survivors was almost twice that of employed survivors (61.6% vs. 36.0% respectively). Only a small proportion of employed survivors reported having two or more chronic conditions in addition to cancer (5.4%); however, this proportion still more than double that of working individuals with no cancer diagnosis with a similar number of chronic conditions (2.4%).

**Confirmatory Factor Analysis**

**Activities of Daily Living:** A CFA indicated the three indicators loaded significantly onto a single latent construct. The loadings were 0.803 for relax, 0.942 for shop and 0.982 for social. This model was saturated (i.e., had 0 degrees of freedom), therefore the fit statistics are not reported.

**Functional Limitations:** Nine indicators were included in this measurement model. The model provided a good fit to the data: $\chi^2 (22) = 1116.561, p <0.0001; \text{CFI} = 0.997; \text{RMSEA} 0.045$. All nine indicators loaded significantly onto a single latent construct; the loadings ranged from 0.755 (grasp) to 1.012 (stand).

**Psychological Distress:** Six indicators were included in this measurement model. The model provided a good fit to the data: $\chi^2 (9) = 2304.047, p <0.0001; \text{CFI} = 0.981; \text{RMSEA} < 0.0001$
All six indicators loaded significantly onto a single latent construct; the loadings ranged from 0.957 (restless) to 1.107 (hopeless).

**Three Factor Model:** The three factors (ADL, functional limitations, and psychological distress) were combined into one model and evaluated. The model provided a good fit to the data: $\chi^2 (125) = 3670.455, p < 0.0001; \text{CFI} = 0.993; \text{RMSEA} = 0.034$, indicating that all three factors (including ADL) were good representations of the data.

**Hypothesized Model:** Overall, the hypothesized model depicted in Figure 1 provided a good fit to the data: $\chi^2 (374) = 3654.727, p < 0.0001; \text{CFI} = 0.980; \text{RMSEA} = 0.035$. The results for each of the hypothesized relationships are reported below. Only significant relationships are shown in Figure 4.1.

Cancer survivors with health insurance coverage were significantly more likely to report experiencing good-to-excellent health post diagnosis (odds ratio=1.77; 95% confidence interval=1.45-2.15). Age was strongly associated with higher levels of functional limitations and inability to perform ADLs; older survivors were also slightly less likely to report good-to-excellent health (0.97; 0.96-0.98). Non-Hispanic Blacks, Hispanics and other race/ethnicities were significantly less likely to report good-to-excellent health (0.53; 0.45-0.61, 0.74; 0.61-0.90, 0.71; 0.53-0.96, respectively) (Table 4.2). There were no differences in reported health status by gender. Compared to survivors who did not graduate from high school, high school graduates (1.32; 1.18-1.49), and those with at least some college education (1.76; 1.58-1.97) were significantly more likely to report good-to-excellent health. Lung cancer survivors were
less likely (0.82; 0.69-0.99), while breast cancer survivors were more likely (1.21; 1.08-1.36), as those with other cancers to report good-to-excellent health.

Cancer survivors who reported good-to-excellent health were significantly more likely to be employed (1.50; 1.36 - 1.65) when compared to those reporting poor-to-fair health. There were no significant differences in reports of employment with regards to time since diagnosis or gender. Non-Hispanic Blacks were significantly less likely to continue to work post diagnosis compared to non-Hispanic Whites (0.82; CI=0.70-0.96). When compared to survivors who had been diagnosed with other types of cancers (our reference category as described above under Measures), those who had a diagnosis of lung or prostate cancer were significantly less likely to be employed (0.82; 0.68-0.99) and (0.81; 0.69-0.93), respectively.

In a model assessing the relationship between health insurance and education, in addition to all other paths modeled, we found that survivors with a high school education were almost 50% more likely (1.46; 1.25-1.70), and those with at least some college level education more than two times more likely (2.27;1.96-2.63), to have insurance. Among survivors, those with insurance were more than 60% more likely (1.63; =1.36-1.94) to report being employed compared to the uninsured.

Survivors who experienced greater functional limitations and psychological distress were less likely to be employed post diagnosis or report having good-to-excellent health.

Finally, employment was positively associated with reported health status ($\beta =0.082, p <0.0001$) and psychological distress ($\beta = 0.073, p <0.0001$), but inversely and significantly related to ADLs ($\beta =-0.330, p <0.0001$) and age ($\beta =-0.034, p <0.0001$).
Health was inversely related to functional limitations ($\beta = -0.311, p <0.0001$) and psychological distress ($\beta = -0.109, p <0.0001$).

V. Discussion

As the U.S. population ages, there has been an increase in the number of persons with cancer, and survivorship has improved due to improved cancer control (Rowland & Yancik 2006). As such, the typical working cancer survivor in the U.S. is a highly educated, middle aged individual, reporting two or more functional limitations. With a significant proportion of the population of cancer survivors of working age, comprehending the effects reported physical and mental health may have on employment is essential to the work environment and society as a whole. Most studies of cancer survivorship lack in-depth investigations of the relationship among reported health status, ADLs, physical and psychological limitations, and employment, despite the need to know more about the complexities affecting working survivors. Functional limitations and the effects of chronic conditions encompass a host of physical and psychosocial factors (including psychological distress) known to affect cancer survivors. These factors have been studied on an individual level (Dellapasqua et al. 2006; Grunfeld et al. 2010; Sehl et al. 2009; Sweeney et al. 2006) and were included in this model to examine their simultaneous impact of predicting health and employment status among cancer survivors.

Independently, functional limitations and psychological distress are significant predictors of health status among survivors, and were strong predictors of employment in this and other research (Hewitt et al. 2003; Keating et al. 2005). There was a
synergistic effect between a combination of any two, or all three of these predictors and reported health status and employment. As expected, cancer survivors who remain in the workforce reported better health than those who are unemployed (Grunfeld et al. 2010; Grunfeld et al. 2008; Pransky 2010). However, looking beyond the healthy worker effect, many survivors return to work out of necessity and reluctantly face daily struggles which make their work environment less conducive to work and recovery.

Though many survivors who return to work may have a reduced work load, the stress of trying to prove they are able to perform their assigned tasks while recuperating from the disease or even undergoing treatment may be daunting (Bouknight et al. 2006; Grunfeld et al. 2008). Some workers reported anxiety as they feel they are being scrutinized by their colleagues (Paraponaris et al. 2010), while others reported feeling helpless or worthless due to their inability to perform tasks in the same capacity as before diagnosis and treatment (Senf et al. 2010). These findings support the higher levels of psychological distress experienced by working survivors in our analysis.

In our final model, functional limitations, psychological distress and ADLs did not act as discrete predictors of health or employment among cancer survivors. As reflected in our descriptive analysis, while some studies have shown that more educated white-collar workers are more apt to return to work post-diagnosis (Berkley Planning Associates 1982; Zwerling et al. 2003), our results reflected no significant difference by education when all other factors were considered. Results were similar among persons with no previous cancer diagnosis.

A significantly lower percentage of Hispanics and non-Hispanic Blacks with a history of cancer reported being employed when compared to their never diagnosed
counterparts. Hispanics and non-Hispanic Blacks tend to dominate the more physically demanding job sectors (blue-collar and service jobs) which may make it challenging to return to work after diagnosis or during treatment. While older, more educated, white-collar workers have access to better retirement or sick-leave options (Clarke et al. 2011; Taskila et al. 2007); many continue to work as they also have flexible schedules and the options for less physically demanding desk jobs. The disparity in ethnic composition may reflect the disproportionate employment benefits such as early retirement packages and disability benefits offered among different occupational sectors. In addition to lost wages, survivors contemplating leaving the labor force, risk losing health insurance (if they had it at all), as well as health-enhancing work-related social relationships and support (Soler-Vilá et al. 2003).

Compared to non-Hispanic Whites, other ethnic groups were significantly less likely to report good-to-excellent health (table 4.1), yet there was no statistically significant difference reflected in employment status. Thus, racial-ethnic minority workers continue to work equal hours as their non-Hispanic White peers, despite reporting poorer health. Based on data collected by the U.S. census bureau (U.S. Dept. of Labor 2009) and other research (Toldson & Snitman 2010), there exists a disproportionate over-representation, not always accounted for by educational disparities, of non-Hispanic Blacks and Hispanics in low-income jobs, particularly in the blue-collar occupational job sector. As such, non-Hispanic Black, and Hispanic survivors are also as likely to remain in the work force as their counterparts with no cancer diagnosis despite their reports of poorer health compared to non-Hispanic
Whites. As aforementioned, this is likely due to insufficient job benefits (particularly health insurance) and the need for income from wages.

These findings hint at the vast differences in accumulated wealth between non-Hispanic Whites and other race/ethnicities in the U.S., independent of educational, occupational, and income level. Avery and Rendall (2002) found that among American Whites, 1 in 3 households were far more likely to receive a substantial inheritance in their lifetimes compared to Blacks (1 in 10 households). These monies are often used to pay off home loans or buffer savings and trust funds; providing financial security which would permit survivors to choose not to return to work. Providing an example of the vastly underestimated wealth inequalities present in the U.S., this and other similar studies highlight reasons for a larger number of non-Hispanic Whites who may report poor health to remain in the workforce (Wilson 1987, 2006).

An assessment of the relationship between health insurance and education was also made and revealed that, education is significantly and positively related to insured status, which in turn influences an individual’s decision to return to work. Thus, both education and health insurance are significant predictors of employment status among cancer survivors of working age. Investigation of the interaction of these variables was not found to be statistically significant, suggesting the two constructs contribute independently to the variance in employment status. While independently, factors such as age, cancer type, time since diagnosis and gender may also have an impact on an individual's potential to enter the workforce post diagnosis, this research suggests that each employment decision may be considerably influenced by a combination of individual characteristics, particularly by education and health insurance. In the U.S.,
the mixed health insurance system is predominantly employment based, as such our model of insurance and working survivors indicated that insured survivors were almost two times more likely to report being employed compared to the uninsured, thus supporting several studies which found that a majority of survivors elect to return to, and or continue to work in order to afford cancer treatment and have access to affordable healthcare (Bradley et al. 2007; Finkelstein et al. 2011; Hewitt et al. 1999). Our analyses included persons who continue to work beyond age 65 years, which has been the traditional age for retirement. The majority of survivors within this age group are however retired and dependent on Social Security and other public benefits. Consequently, a greater disparity was undoubtedly diluted by access to public insurance, such as Medicaid among the older and qualified disabled cancer survivors (Frazier et al. 2009b).

These findings should be interpreted in the context of the study’s limitations. The NHIS data are cross-sectional, which precludes the differentiation between correlative associations and causal relationships when examining persons with a history of cancer. Though the NHIS survey asks persons to report a physician diagnosis of cancer, the data were self-reported, thus current employment and cancer diagnosis were not validated. The use of all other cancers as the reference group for the five most common cancers may slightly diminish the comparative effects, but the large disparity in the percentage of the U.S. population affected by these cancers is mirrored by this comparison. The NHIS does not provide information on employment history prior to diagnosis. Expected differences by cancer type were not evident and may have been diminished by time since diagnosis as well as stage at diagnosis and treatment received.
These important clinical variables, along with recurrences of cancer were not available throughout the 14 years of data used in the study and type of treatment received was made available only in the 2010 NHIS cancer control module. Nevertheless, the NHIS is representative of the U.S. civilian population; as such there are significant strengths to the conclusions derived from these analyses. Our analyses span 14 years of data, and as such we are able to generalize our findings to the U.S. population. While we did not model all possible associations between health indicators and employment, the use of SEM allowed the simultaneous evaluation of all the relationships of the variables completely and simultaneously as opposed to the individual effects of each predictor in a multivariable logistic regression.

VI. Conclusions

In summary, there is a large percentage of survivors who continue to work post diagnosis. Disparities persist among common social determinants such as lack of health insurance, lower education, and lower paying jobs which may translate to lower income. As cancer therapies continue to improve, the number of survivors in our aging population will continue to increase. Health policy analysts, oncologists, epidemiologists, the U.S. Department of Labor, and insurance companies will have to work collectively on various aspects of improving employment-based health insurance for persons diagnosed with cancer across all occupational sectors. The need for care and support is currently greatest among those who can least afford it, and thus continue to work. The issues involving survivorship and unmet needs are far more complex and
intertwined than the scope of this paper, and our findings clearly point to the need for further research on the topic of unmet needs of cancer survivors within the workplace.

Figure 4.1 Diagram illustrating relationship pathways of the tested model using structural equation modeling
# Table 4.1: A comparison of Employment and Socio-demographic characteristics of persons in the United States with and without a cancer diagnosis. National Health Interview Survey, 1997-2010

<table>
<thead>
<tr>
<th>Socio-demographics</th>
<th>Persons with cancer diagnosis (n=24,810)</th>
<th>Persons without cancer (n=382,837)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Employed (n=13,773)</td>
<td>Unemployed (n=11,037)</td>
</tr>
<tr>
<td></td>
<td>Employed (n=283,767)</td>
<td>Unemployed (n=99,070)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>3,086 [22.4%]</td>
<td>947 [8.6%]</td>
</tr>
<tr>
<td>40-64</td>
<td>6,293 [45.7%]</td>
<td>2,721 [24.7%]</td>
</tr>
<tr>
<td>≥ 65</td>
<td>4,394 [31.9%]</td>
<td>7,369 [66.7%]</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5,115 [37.2%]</td>
<td>3,801 [34.4%]</td>
</tr>
<tr>
<td>Female</td>
<td>8,658 [62.8%]</td>
<td>7,236 [65.6%]</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1,139 [8.3%]</td>
<td>821 [7.4%]</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>11,046 [80.1%]</td>
<td>8,780 [79.6%]</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>1,272 [9.4%]</td>
<td>1,156 [10.5%]</td>
</tr>
<tr>
<td>Other</td>
<td>316 [2.2%]</td>
<td>280 [2.5%]</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school</td>
<td>3,680 [29.2%]</td>
<td>3,075 [29.4%]</td>
</tr>
<tr>
<td>High school/GED</td>
<td>3,437 [27.3%]</td>
<td>3,344 [31.9%]</td>
</tr>
<tr>
<td>Some college/higher</td>
<td>5,476 [43.5%]</td>
<td>4,056 [38.7%]</td>
</tr>
<tr>
<td>Health Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good-excellent</td>
<td>11,362 [82.5%]</td>
<td>7,285 [66.1%]</td>
</tr>
<tr>
<td>Poor-fair</td>
<td>2,401 [17.5%]</td>
<td>3,734 [33.9%]</td>
</tr>
<tr>
<td>≥ 2 Functional limitations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4,959 [36.0%]</td>
<td>6,799 [61.6%]</td>
</tr>
<tr>
<td>No</td>
<td>8,815 [64.0%]</td>
<td>4,238 [38.4%]</td>
</tr>
<tr>
<td>≥ 2 Chronic conditions *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>748 [5.4%]</td>
<td>2,474 [22.4%]</td>
</tr>
<tr>
<td>No</td>
<td>13,025 [94.6%]</td>
<td>8,563 [77.6%]</td>
</tr>
</tbody>
</table>

*a Column percentage illustrated

*b All chronic conditions excluding cancer
<table>
<thead>
<tr>
<th>Table 4.2. Structural equation model of Health and Employment among cancer survivors: NHIS 1997-2010 (n=24,810)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Status</strong></td>
</tr>
<tr>
<td>Health Status</td>
</tr>
<tr>
<td>Insurance</td>
</tr>
<tr>
<td>Time since diagnosis</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Gender (ref= Male)</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Race/ethnicity (ref= Non-Hispanic White)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Education (ref= less than high school)</td>
</tr>
<tr>
<td>High school/GED</td>
</tr>
<tr>
<td>Some college/ Graduate</td>
</tr>
<tr>
<td>Cancer type (ref= all other cancers not listed below)</td>
</tr>
<tr>
<td>Lung</td>
</tr>
<tr>
<td>Prostate</td>
</tr>
<tr>
<td>Breast</td>
</tr>
<tr>
<td>Colorectal</td>
</tr>
<tr>
<td>Bladder</td>
</tr>
<tr>
<td>Latent factors</td>
</tr>
<tr>
<td>ADL</td>
</tr>
<tr>
<td>Functional limitation</td>
</tr>
<tr>
<td>Psychological distress</td>
</tr>
</tbody>
</table>
Chapter V– Specific Aim / Paper # 3

A Decade of Change in Adherence to Recommended Screening among Cancer Survivors

I. Summary

Over the last decade, reports of adherence to US cancer screening recommendations have not shown a consistent increase. The US population met the Healthy people 2010 goal for mammography and colorectal cancer screening, with cancer survivors exceeding them since 1999. We investigated a decade of screening trends among working survivors by occupation, as well as compared them to the general population. Trends in adherence to recommended screening were analyzed by site-specific cancer. We selected participants ≥ 18 years from 1997 to 2010 National Health Interview Survey (NHIS) for survey years where detailed cancer screening information was available. In general, cancer survivors had consistently higher screening rates than the general population. There were 8,294 cancer survivors representing 3.5 million U.S. workers.

Between 1999 and 2010, among working survivors reporting not adhering to recommended mammography guidelines, there was an average annual 1.1% decline among white-collar workers, 3.1% decline among service workers, but a 4.5% increase among blue-collar workers. The results confirm that cancer survivors report higher screening rates than the general population. Nevertheless, national screening rates are still lower than recommended, and disparities exist between occupations with distinct influences from other social determinants. Understanding the impact of cancer screening in cancer survivors, as well as the existing disparities, is crucial as the number of survivors returning to work continues to grow.
II. Background

Worldwide, there is a growing cancer burden associated with population growth and aging, yet in the past decade the United States has seen a significant decline in the diagnoses of advanced stages of the most common cancers (Jemal et al. 2010a). This decrease may in part be attributed to changes in health behaviors, such as decreased smoking prevalence, dietary changes, and/or increased adherence to recommended cancer screening leading to early detection and removal of premalignant lesions (Jemal et al. 2011). However, cancer is still one of the most prominent chronic diseases, claiming more than 570,000 US lives in 2011. The need for increased cancer prevention efforts in the US is evident.

The decreased number of advanced stage diagnoses and improved treatment methods has resulted in a growing number of cancer survivors (Jemal et al. 2010b; Lansdorp-Vogelaar et al. 2012), many of whom continue to work. For the purpose of this research we have defined a cancer survivor as anyone who has had a cancer diagnosis, and is continuing to live out the balance of his or her life after undergoing treatment for the disease (NCCS 1986). As more survivors return to work, their illness and related experiences impact co-workers and are expected to influence attitudes towards screening within the workplace. In 2010, the National Cancer Institute (NCI) reported an average annual increase of 4% in colorectal screening among the general population, yet Breen et al. (2011) reported a slight decrease in mammography screening among women between 2000 and 2008.
The collective goals for national screening rates have been set by the U.S. Department of Health and Human Services (USDHHS). These benchmarks are put forward as the ‘Healthy People objectives’ and serve to guide individuals toward making informed health decisions, as well as measure the impact of health related prevention activities. This study uses Healthy People 2010 (HP2010) objectives as the benchmark for screening adherence among the US population between 1999 and 2010.

We assessed the adherence to recommended colorectal, breast, cervical and prostate cancer screening among the general population compared to all cancer survivors and compared to the subpopulation of working cancer survivors. Over the decade under study, we expected small variations in cancer screening behavior in the general population over the decade, whereas we expected a significant increase among persons living with cancer. According to Mayer et al. (2007), 10% of all new cancers are diagnosed in cancer survivors, and these second primaries are the sixth leading cause of cancer deaths. Though survivors have first-hand knowledge of the benefits of early detection, and appreciate the ability to continue to or return to work post diagnosis, we expected that there would be disparate screening behaviors among occupational sectors within this subset of the population. These differences would be related to the perpetual differences in health insurance, job flexibility, etc. among occupations.
III. Methods

Study Population

The study population was divided by cancer status; cancer survivors were extracted and then compared to the general population. In order to do so, from the general population, participants responding “Yes” to “Have you EVER been told by a doctor or other health professional that you had...Cancer or a malignancy of any kind?” were defined as cancer survivors (n= 12,990) throughout this study. We included all NHIS records between 1997 and 2010 which provided detailed information on screening behavior; such information was contained in the 1999, 2003 and the 2008 adult surveys in addition to the 2000, 2005 and 2010 cancer control supplements. Using the recommendations from the American Cancer Society (ACS) as a guide, we identified individuals ≥ 18 years who adhered to the recommended screening guidelines for cancers amenable to screening between 1997 and 2010, where data were available (n= 174,393).

Using the four occupational sectors (white-collar, blue-collar, farm and service) characterized by the National Center for Health Statistics (NCHS) (Krieger et al., 2005; Sorerholm, 2006), disparities in screening across occupational sectors were observed over the decade among working cancer survivors (n= 8,294). Estimates for the farming sector were not presented in results because sample size was too small after stratification by cancer specific screening.

Measuring Adherence to Screening Recommendations

The United States Preventive Services Task Force (USPSTF) provides cancer screening recommendations based on comprehensive and systematic reviews of clinical evidence.
However the American populace is more familiar with the American Cancer Society (ACS) and the National Cancer Institute (NCI) and their web pages which offer general information to the public. Thus, the information disseminated by these agencies is likely to influence the screening behaviors of those acting independent of physician recommendations and will reinforce population screening behavior towards meeting the HP2020 goals. For this reason, in this study we use ACS guidelines to assess the adherence to recommended screening in the US population. These guidelines are derived from the USPSTF and differ from them only in that ACS recommends an age for first screening mammography 10 years younger than the USPSTF (Smith et al. 2012).

Survey participants were asked information regarding relevant screening tests according to their age and gender, regardless of their cancer history. Where appropriate, analyses incorporated changes to recommendations during the course of the study period. For example, historic recommendations for Papanicolaou (Pap)tests were “testing should be initiated among women 18 years of age or among those who are sexually active (whichever is first) once every 2 years if the conventional cervical cells smear was used and every 3 years if the newer liquid based test was used.” However, in 2009 in accordance with the USPSTF, the ACS changed the recommended age at initial screening to 21 years among women regardless of prior sexual activity, while maintaining the same screening interval. General trends for Pap tests were conducted through 2010 with the old recommendations (illustrated in figures 5a and 5b), as well as adjusted to incorporate the change in 2009. Despite Prostate Specific Antigen (PSA) testing not being endorsed as a general screening test by the USPSTF, we included it in
our analyses since prostate cancer is the most commonly diagnosed non-skin cancer and the second leading cause of cancer deaths (after lung cancer) in US men (ACS, 2012).

Adherence (outcome of interest) was measured as abiding by any of the recommended guidelines within the specified time frame and age group for a particular gender. Persons within the qualifying age and gender categories but whose screening fell outside of the recommended timeframe or who reported not being screened were recorded as none adherent. For screening recommendations during study period see Appendix I.

Healthy People 2010

The HP2010 objectives were set to achieve a 10% improvement in particular health characteristics within a 10 year period. The baseline was January 2000 figures (the first year of the decade) based on data gathered from the NCHS and other health statistics agencies. In an effort to reduce cancer morbidity and mortality, the USDHHS put forth a set of HP2010 objectives aimed at increasing cancer screening among the US population by 2010.

As Appendix I illustrates, colorectal screening encompasses a variety of screening methods at different intervals. Using the recommendations of the ACS, we examined Fecal Occult Blood Test (FOBT), colonoscopy and sigmoidoscopy jointly. The HP2010 goal was to increase to 50% the proportion of adults aged 50 and older who had had a fecal occult blood test (FOBT) within the previous 2 years as well as the
proportion of persons in the same age group who had ever had a sigmoidoscopy. There were no separate HP2010 goals for colonoscopy.

Regarding breast cancer screening, the HP2010 goal was to increase to 70% the proportion of women aged 40 and older who had received a mammogram within the previous 2 years. No separate goals were set to address clinical breast exams for 2010. For cervical cancer screening, the goal was to increase to 90 percent the proportion of women aged 18 and older who had received a Pap test within the previous 3 years (HP2010, 2000). Finally, HP2010 did not set any targets for PSA screening as it is not recommended by any of the governing bodies. The majority of HP2010 goals are consistent with the recommendations used to guide analyses in this study (Appendix I).

NHIS data

NHIS questionnaires did not field all cancer screening questions each year; however, we used one common method of variable response coding for all data years when the questions of interest were available. This allowed for the use of the same computational procedures across all years. The method chosen was guided by Breen et al. (2011). The NCHS uses three different formats for recording information related to reported cancer screening behavior in order to maximize the precision of information obtained as well as the completeness of the data files.

The general questioning across the years included in these analyses was as follows: “When did you have your MOST RECENT (screening exam)?” We examined each format and used complementary but mutually exclusive categories to report adherence to screening guidelines for each year. Participants responses to “date”,
“number of time units” and “time interval” since last screening were recoded using methods similar to Breen et al. (2011). The appropriate time interval was chosen for each cancer specific screening according to ACS guidelines. In coding the occupational sectors, The NHIS records information by job type, and industry which can then be classified into the four broad occupational sectors. Between 1997 and 2004, the NHIS used the 1990 Census codes for occupation. In 2004, the NHIS switched to the 2000 Census codes for occupation, which were slightly different. The crosswalk for occupation was determined by the notes presented in the Appendix of the adult file and guided by previous studies (Krieger et al., 2005; Sorerholm, 2006).

Analyses
Using a combination of survey and multivariate analytical methods, we calculated the prevalence of adherence to recommended cancer screening for the general population as well as for working and non-working cancer survivors over the past decade. The line graphs in figures 5.1a and 5.1b display the resulting screening rates. The prevalence of cancer specific screening was computed by cancer status, and then by occupational subgroup within the working cancer survivors separately for each year. The SAS survey frequency procedure (SURVEYFREQ) was used to apply the appropriate weights and adjustments for the complex sampling design of the NHIS (SAS, 2003). To assess for cancer screening trends among working cancer survivors, we used SAS general linear model procedure (GLM) to perform a weighted linear regression within each survey year. The model was fitted to the annual design-adjusted rates within occupational groups. The weight used for each annual rate was the inverse
of its design-adjusted variance. Using stratification weights, the results presented below yield nationally representative estimates for noninstitutionalized adults in the US. Statistical significance was established at the 0.05 probability level.

IV. Results

Trends among the General Population

Colorectal cancer screening: Within the general population (cancer survivors included), colorectal screening rates increased by a significant 18.4% representing more than 1.1 million Americans over the past decade (Table 5.1a, Figure 5.1a). Although the increase was not linear, there was an average annual 10% change, with a decline from 43.7% ± 1.1% in 2003 to 30.9% ± 1.1% in 2005. The 2010 prevalence was 54.6%± 1.2%

Breast cancer screening: The rates for mammography screening showed little change over the 11-year period from 1999 to 2010, with an average reported adherence of 69.9%. U.S. women over the age of 40 years meeting the HP2010 goal of 70% prevalence of having received a mammogram in the past 2 years in 2010. Though no goal was set for clinical breast exam, in conjunction with the HP2010 ‘holistic approach to breast and mammary health’, women failed to meet the HP goals with average annual change of -6.0% and a prevalence of 61.8% ± 1.2 % in 2010.

Cervical cancer screening: There was a slight annual average change of 0.02% in Pap test self-report among women 18 years and older. The HP2010 goal for cervical cancer
screening in women above 18 years was 90%. When screening adherence was defined based on the recommendations issued earlier in the decade, 81.4% of the population in 2010 reported adherence to Pap test guidelines. However, when adherence was evaluated using 2009 recommendations, the prevalence of adherence to guidelines in the same population fell to 66.2%. Regardless of the definition used for “adherence,” the population under study failed to meet HP2010 goals.

_Prostate cancer screening_: In 1999, the male population eligible for PSA testing reported a prevalence of PSA testing of 65.7%. There was an average annual decline (-5.9%) in PSA screening between 1999 and 2010 with a resulting reported prevalence of 46.4%.

*Trends among Cancer Survivors*

Overall, Cancer survivors demonstrated a comparatively higher adherence to recommended screening than the general population (Table 5.1b, Figure 5.1b).

_Colorectal cancer screening_: There was a lower average annual increase in colorectal screening among survivors (6.1%; 55,008 persons) compared to the general population, but the baseline screening rates were on average approximately 10% higher. Survivors were consistently above the HP2010 colorectal screening goal throughout the entire decade.
Breast cancer screening: Among survivors, mammography declined between 2000 and 2003 (76.9% ± 2.8% to 72.9% ± 2.8%) and again between 2005 and 2008 (77.4% ± 2.8% to 75.3% ± 2.8%), but increased to 77.5% in 2010. Despite the decade long fluctuation in screening prevalence, cancer survivors surpassed the HP2010 goal for mammography screening. Clinical breast exam followed a similar trend to mammography screening among survivors up to 2005 then declined to 64.3% ± 3.1% in 2010. No clinical breast exam screening data were available for 2003 and 2008.

Cervical cancer screening: There was an annual average decline of 1.2%, representing 6,984 fewer women who received recommended cervical cancer screening between 1999 and 2010. There was however a 5.1% increase from 1999 to 2000, but this quickly fell by 6.4% to 74.5% ± 2.9% in 2003.

Prostate cancer screening: Compared to the general population, survivors’ received PSA testing at a consistently 10-20% higher rate. Within this group the trend across the years showed a decline from 76.5% ± 4.1% in 1999 to 64.3% ± 2.9% in 2010.

Trends among Working Survivors
Table 5.2 shows that the rates of cancer screening among working cancer survivors significantly increased for only 4 of 15 cancer screening/occupation subgroups over the period 1999–2010. The percent change is a summary measure of the difference in prevalence of adherent screening between 1999 and 2010.
**Colorectal cancer screening:** Based on the average population, the increase among working survivors white-collar (10.0%), blue-collar (24.4%) and service workers (6.9%) who received colorectal screening is representative of an estimated 25,437; 187,852 and 2,730 Americans within each sector, who reported following recommended guidelines.

**Breast cancer screening:** There was an average annual 1.1% decline among white-collar workers representing 2,301 fewer women who reported not receiving mammograms in 2010 when compared to their 1999 cohort. There was an even larger average annual decline (-3.1%) in the service sector, but an average increase of 4.5% among blue-collar workers. There was a decline in clinical breast exams between 1999 and 2010 across all sectors with the largest average change occurring in the service sector (-10.0%) and the smallest change within the blue-collar sector (-5.3%).

**Cervical cancer screening:** There was a decrease in adherence to Pap tests recommendations across all occupation sectors. The decline was consistent within the white-collar occupation sector, but there were undulations in the blue-collar sector with a 2.9% increase in adherence between 2000 and 2003. This slight rise was followed by a decline of 86.1% to 62.5% in 2005. In 1999, survivors employed in the service sector reported receiving recommended Pap tests at 1% below the HP2010 goal. They achieved the mark in 2000 at a prevalence of 93.1%. This was the peak of adherence to cervical screening among this subgroup, which soon showed a steady decline to 79.3% in 2010.
Prostate cancer screening: An average 158,850 male working cancer survivors over the age of 50 years reported having a PSA test within one year of the NHIS interview. All occupational sectors were characterized by a greater than 70% adherence to annual PSA testing guidelines among working male survivors in this age group. Whereas there was an average decline between 1999 and 2010 within all occupations, there were fluctuations in trends across time.

Graphical illustrations of cancer screening trend over time. NHIS 1997-2010

Figure 5.1a Cancer screening for the 5 most common (incident) cancers among the general population in the US. N= 174,393
V. Discussion

Although cancer-related mortality has declined in part due to early detection, there has been continued debate regarding the adequacy of screening and the over-diagnosis of indolent cancers. This controversy has reached the media and popular science publications (e.g., Kaplan, 2009), and may impact some persons’ decisions to seek screening. Our results indicate that there has been a fluctuation in adherence to recommended screening throughout the decade, and that the general US population was unable to meet the HP2010 goal for most targeted screening exams.

While colorectal screening remained below 50% for the first half of the decade, in 2008 the US population achieved, and maintained through 2010, the HP2010 goal of 50% adherence according to ACS guidelines. Figures 3a and 3b illustrate a substantial and positive increase in colorectal screening, although the current levels are still
disproportionate to the proven benefits of early detection. Routine screening can reduce the number of people who die from colorectal cancer by at least 60% (USDHHS 2010), a reality well understood by cancer survivors who consistently exceeded population rates by just over an average 10% throughout the past decade.

There are a myriad of determinants affecting a person’s decision to seek cancer screening, among which perceived vulnerability to cancer may act as a deterrent or a motivator to screen (Rutten et al. 2005). Figures 3a and 3b illustrate a minimal increase in mammograms and a decrease in clinical breast exams within the general population. Breen et al. (2011) found a similar trend, and suggested that differences in rates could be attributed to differing levels of acceptability of screening practices within the population.

Cancer screening is of outmost importance to survivors as their risk of developing another cancer may be higher than the average person. The higher screening rates exhibited by cancer survivors may be indicative of their knowledge of increased risk due to treatment or genetic mutations (Nichols et al. 2003). Unfortunately, screening practices differed among survivors; brief comparisons between occupational sectors among survivors and sociodemographic characteristics indicated that the likelihood of screening increased with education. Unfortunately, data also reflected that education was higher among white-collar workers who were more likely to be non-white Hispanics, regardless of cancer history. As such the disparities in screening within occupational settings may be more complex than modeled in this paper. It is assumed that survivors are more likely to seek recommended cancer screening because they have a more intimate experience with the disease. Early detection and improved treatment is
the reason many survivors are able to work during treatment and/or soon after the disease, and this recent historical fact is why employment disparities among survivors must be addressed (Messner & Vera 2011).

In general, the more highly educated, white-collar cancer survivor employed in an occupation which provides comprehensive private health insurance is more likely to be among the early adopters of screening practices. White-collar workers had significantly higher screening rates of mammography, clinical breast exams and pap tests compared to blue-collar workers, but were comparable to service workers. Rates remained high until 2003 when they fluctuated and a decline in adherence to recommended guidelines began to occur.

As is evident in the delayed increase in colorectal and mammography screening displayed by blue-collar working survivors, over time an increased trend in screening among peers in more prestigious occupations; survivors in the white-collar and service sectors generates second-order changes (Christ et al. 2012). The adoption of existing screening guidelines among working survivors who may have had less information on the benefits of continued screening post-diagnosis, or who would have not sacrificed vacation or work time and wages for preventive care, is indicative of a fundamental, transformational shift in their values and beliefs about the benefits of screening. This may be a reflection of a lag in increased health insurance benefits within in blue-collar occupational sector, however,(Kaiser 2010) in their report on the unemployed in the US, indicated that employment-based health insurance had declined between 1999 and 2010 and that the current recession is hastened the trend. Kaiser (2010) also reported
that in the last 3 years of the decade, 10 million persons lost health coverage and more than 80% of the uninsured workers are in blue-collar jobs.

White-collar survivors, similar to their colleagues without a cancer diagnosis, appear to be more receptive to cancer screening than survivors employed in the service and blue-collar sectors. Service workers do not fare much worse than white-collar workers with regards to many known health benefits (CEPR, 2009), and did not fall far behind in adherence to screening, especially for pap tests and PSA screening. In an effort to overcome any existing structural inequalities existing within working cancer survivors, it is important to promote policies aimed at meeting the needs of all employed groups (Dani and Haan, 2008). This is a challenging recommendation as most laws and policies written to serve the public are written broadly for the US population as a whole. Unfortunately, a “one-size-fits-all” approach will not lead to a decrease in occupation-related cancer screening disparities.

Public debate over the value of cancer screening will continue as new scientific discoveries lead to changing guidelines. This may or may not translate into reduced adherence to screening. In fact, the US achieved the HP2010 goal of 50% adherence to recommended colorectal screening and 70% adherence to mammography screening despite the change in recommendations along the decade. On the other hand, women 18 years and older experienced a decline in pap tests over the past few years and the HP2010 goal remained unmet. Whether the new mammography and Pap test guidelines will influence future screening decisions is uncertain. It is also unknown if the USPSTF’s reiteration of the ineffectiveness of PSA as a population-wide cancer screening tool will lead to further reductions in testing. It is however clear that cancer
survivors demonstrated a slight decline in screening rates and are in need of continued medical advice post treatment and diagnosis. Screening rates are higher among working survivors, but perhaps the best approach to increase this preventive behavior among this group is through targeted workplace interventions.

**Limitations**

Our study is limited by the use of medical information obtained through self-reports. However, because our primary goal was to analyze trends over time, the accuracy of self-reported information, i.e., the bias introduced by over-reporting, is not essential to our main findings. We have no reason to suspect that the rate of over-reporting a “desirable behavior,” such as cancer screening, would vary significantly across survey years. And, thus, we assume that our results regarding percent change in screening behaviors reflect actual trends.

Our original intention was to study screening trends across the four main occupational sectors; however, due to the limited number of cancer survivors employed in the farming sector, the sample size was too small for analysis. Thus, our analyses are limited to the three other main occupational sectors: white-collar, blue-collar, and service.

With regards to screening guidelines, we do not know if women who received cervical cancer screening were administered the liquid based Pap test or the traditional glass smear; thus there may be an under- or over-estimate of those rates as there is a 2- or 3-year screening cycle depending on the diagnostic technique used. We do not know
the age of first coitus, and Pap test recommendations started at 18 years of age or 3 years after first sexual activity.

Our research is strengthened by the use of the NHIS, a nationally representative sample of the entire US population, which yielded a pooled sample of more than 8,200 working cancer survivors available for analysis. Consequently, the data reflect similar screening rates in the general population presented by the NCI in earlier years for some of the cancers assessed in this research (NCI 2010). The use of a trend analysis to investigate changes provides a systematic review of historical patterns in screening behavior while permitting the assessment of occupational differences within each year.

The need to increase screening within the general population is underscored by the healthy people 2020 goals which now aim to increase colorectal screening to 70.5%, using a modeling projection technique (HP2020, 2012). This exceeds the traditional 10% change usually set for each decade. By 2020, the goal is to reach an 81.1% adherence to mammography and a 93% adherence to Pap test among women in the US population. HP2020 was created to increase education, “breast self-awareness”, clinical breast exam, and mammography (Depke, 2011) thus it is expected that there will be an increase in clinical breast exams. Though no target has been set, there is a developmental goal to increase the proportion of men who have discussed PSA testing to screen for prostate cancer with their health care provider (HP2020, 2012).

Future studies should examine the combined effect of other social determinants that may influence screening decisions and further perpetuate occupational disparities in cancer prevention particularly among special working populations such as cancer survivors. In order to be effective, programs that promote cancer screening should
target the different needs of workers in various occupations and work-related exposures. It may be pertinent to the advancement of public health to promote cancer screening within workplace wellness programs either through education, screening or both. This approach would allow the tailoring of interventions specific to each worker group.
### Table 5.1.a. Adherence to recommended cancer screening for most common cancers among the general population in the US. \(N= 174,393\). NHIS 1999-2010

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td>Unwt n</td>
<td>Wt%</td>
<td>95% CI</td>
<td>Unwt n</td>
<td>Wt%</td>
<td>95% CI</td>
<td>Unwt n</td>
</tr>
<tr>
<td>Colorectal screening</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>4,645</td>
<td>38.0</td>
<td>37.0-39.1</td>
<td>5,292</td>
</tr>
<tr>
<td>Mammogram</td>
<td>6,968</td>
<td>70.1</td>
<td>69.1-71.1</td>
<td>6,826</td>
<td>69</td>
<td>67.9-70.1</td>
<td>6,837</td>
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<tr>
<td>Clinical Breast Exam</td>
<td>12,235</td>
<td>75.3</td>
<td>74.6-76.1</td>
<td>8,756</td>
<td>68.1</td>
<td>67.1-69.1</td>
<td>N/A</td>
</tr>
<tr>
<td>Pap test</td>
<td>12,708</td>
<td>80.5</td>
<td>81.8-83.2</td>
<td>12,977</td>
<td>80.0</td>
<td>79.1-80.8</td>
<td>12,350</td>
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<tr>
<td>PSA</td>
<td>2,237</td>
<td>65.7</td>
<td>63.8-67.5</td>
<td>1,927</td>
<td>56.9</td>
<td>54.9-58.9</td>
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### Table 5.1.b. Adherence to recommended cancer screening for most common cancers among persons with a prior physician diagnosis of cancer in the US. \(N= 19,091\). NHIS 1999-2010

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Unwt n</td>
<td>Wt%</td>
<td>95% CI</td>
<td>Unwt n</td>
<td>Wt%</td>
<td>95% CI</td>
</tr>
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<td>Colorectal screening</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>901</td>
<td>54.7</td>
<td>52.1-57.4</td>
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<td>Mammogram</td>
<td>841</td>
<td>78.0</td>
<td>75.1-80.9</td>
<td>840</td>
<td>76.9</td>
<td>74.1-79.7</td>
</tr>
<tr>
<td>Clinical Breast Exam</td>
<td>951</td>
<td>78.5</td>
<td>76.0-81.1</td>
<td>887</td>
<td>74.9</td>
<td>72.1-77.8</td>
</tr>
<tr>
<td>Pap test</td>
<td>877</td>
<td>75.8</td>
<td>73.0-78.7</td>
<td>967</td>
<td>80.9</td>
<td>78.3-83.6</td>
</tr>
<tr>
<td>PSA</td>
<td>442</td>
<td>76.5</td>
<td>72.4-80.6</td>
<td>354</td>
<td>69.8</td>
<td>65.4-74.3</td>
</tr>
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</table>
Table 5.2. Trends in Recommended screening among working cancer survivors (National Health Interview Survey 1999-2010)

<table>
<thead>
<tr>
<th>Survey year</th>
<th>Average *</th>
<th>Percent adherent to screening</th>
<th>%</th>
<th>Regression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Colorectal screening</strong> b c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White-collar</td>
<td>437</td>
<td>254,368</td>
<td>n/a</td>
<td>51.3</td>
</tr>
<tr>
<td>Blue-collar</td>
<td>135</td>
<td>76,985</td>
<td>n/a</td>
<td>32.1</td>
</tr>
<tr>
<td>Service</td>
<td>73</td>
<td>39,551</td>
<td>n/a</td>
<td>48.9</td>
</tr>
<tr>
<td><strong>Mammogram</strong> b c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White-collar</td>
<td>390</td>
<td>209,112</td>
<td>84.1</td>
<td>80.7</td>
</tr>
<tr>
<td>Blue-collar</td>
<td>61</td>
<td>30,288</td>
<td>63.6</td>
<td>55.7</td>
</tr>
<tr>
<td>Service</td>
<td>71</td>
<td>36,275</td>
<td>88.4</td>
<td>88.0</td>
</tr>
<tr>
<td><strong>Clinical Breast Exam</strong> b c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White-collar</td>
<td>420</td>
<td>206,817</td>
<td>88.9</td>
<td>83.0</td>
</tr>
<tr>
<td>Blue-collar</td>
<td>62</td>
<td>31,878</td>
<td>79.2</td>
<td>63.3</td>
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<tr>
<td>Service</td>
<td>76</td>
<td>36,177</td>
<td>89.3</td>
<td>71.3</td>
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<tr>
<td><strong>Pap test</strong> b c</td>
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<td></td>
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<tr>
<td>White-collar</td>
<td>423</td>
<td>225,571</td>
<td>89.0</td>
<td>87.6</td>
</tr>
<tr>
<td>Blue-collar</td>
<td>68</td>
<td>33,247</td>
<td>80.6</td>
<td>83.2</td>
</tr>
<tr>
<td>Service</td>
<td>85</td>
<td>45,926</td>
<td>89.0</td>
<td>93.1</td>
</tr>
<tr>
<td><strong>Prostate Specific Antigen Test</strong> b c</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White-collar</td>
<td>152</td>
<td>95,410</td>
<td>78.4</td>
<td>70.0</td>
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<tr>
<td>Blue-collar</td>
<td>78</td>
<td>46,138</td>
<td>78.9</td>
<td>52.5</td>
</tr>
<tr>
<td>Service</td>
<td>32</td>
<td>17,302</td>
<td>74.2</td>
<td>64.5</td>
</tr>
</tbody>
</table>

*Population specified down to the nearest hundred for samples <1,000 or thousand for samples >1,000.

b The average yearly observed and population estimates may not be accurate for the NCHS occupational sectors because the sample was not stratified on these categories.

c Too few observations in Farming sector.

d Standard error of the mean

e p-value, where α=0.05
I. Overview of Major Findings

Spanning over a decade, this research described the population of cancer survivors in the US; their sociodemographic components and health disparities by occupation and employment. We modeled the physical and psychosocial components of cancer and examined the effects on health status and employment; we controlled for predisposing factors which exert their effects prior to behavioral changes (such as age, gender, race/ethnicity, etc.), reinforcing factors which might encourage or discourage cancer- and/or other health-related behavior (such as time since diagnosis) and enabling factors that facilitate and an individual’s cancer- and/or health-behavior (such as health insurance and income). Our research has filled an existing gap by identifying and examining the factors that contribute to the disparities in return to and continuation of work among cancer survivors.

This study was a guided assessment of the preventive effort applied to cancer among cancer survivors, specifically those of working age. We note that differences in health behaviors with regards to secondary prevention efforts (such as screening) between survivors and their undiagnosed peers reflect the apparent differences in perceived risks and susceptibility. Finally, disparities within the population of cancer survivors as they relate to return to work, and to acceptability and adherence to recommended screening over time were evaluated.
II. The Growing Population of Cancer Survivors

Some of the earliest reports from the CDC and SEER estimated there were approximately 3.0 million cancer survivors, i.e. 1.5% of the U.S. population, in 1971 (MMWR 2004). Our study has recorded an estimated 15.1 million survivors, which, based on the 2010 census is approximately 4.9% of the US population. In our description of this small but growing population, we have identified the need to address existing health disparities when compared to persons without a cancer history, as well as disparities within the group of survivors.

Differences in some of the main determinants of access to care, such as health insurance and income, have played a significant role in the notable health disparities among cancer survivors. The majority of survivors were insured throughout the one year prior to the NHIS interview; an estimated 6.1 million (48.4%) survivors reported having private insurance, and 4.5 million (36.3%) had public insurance. There were over 800 thousand (6.5%) survivors who reported not having insurance for part of the year, while 1.1 million (8.7%) were uninsured. Uninsured and part-year insured survivors were less likely to report good-excellent health.

Reflecting disparities by race-ethnicities, education, and occupational group (blue-collar, white-collar, farm, service), this research has acknowledged the complex relationship between the factors that increase or decrease a person’s motivation to participate in preventive cancer behavior. In our assessment of the trend in screening behavior over the decade, we found that cancer survivors demonstrated a significantly higher screening rate for all cancers amenable to screening under the ACS guidelines as
suggested by the USPSTF. However an increase in screening is needed among the general population.

The demographics of cancer survivors in the US is changing as more young and middle aged persons are afflicted by the disease. The results of this study recognized employment as an indicator of physical and psychological well-being, as well as providing support to other research suggesting that continued employment promotes health and contributes to the overall wellbeing of cancer survivors.

III. The Working Survivor

Our data reflect an estimated 6.3 million cancer survivors who continue to work post diagnosis. The majority of these working survivors (45.7%) are between 40 and 64 years of age. Our data showed that, within the population, the incidence of cancer has been slightly greater among males (Figure 6.1.), yet a significantly larger number of women continue to work post diagnosis compared to men. There were an estimated 172, 501 female cancer survivors who continued to work despite more frequent reports of functional limitations compared to an estimated 95, 692 working male survivors. A greater proportion of working survivors reported good-excellent health compared to unemployed survivors. Working survivors were less likely to have chronic conditions and had a significantly lower prevalence of functional limitations. There were no racial/ethnic differences between working and non-working survivors, however most survivors were employed in white-collar occupations. Little research is available on the spectrum of new job-related tasks survivors face that are precipitated by a cancer
diagnosis (Frazier et al. 2009a). But existing gender and occupational differences suggests that jobs within certain occupational sectors may better accommodate survivors and their needs/limitations either due to their characteristics or due to the work culture or environment. This is of particular importance to cancer survivors who are single parents and/or have no other means of financial support.

To cancer survivors, the benefits of working post-diagnosis are multifaceted. The work environment may represent the return to some normalcy in their lives (Peteet 2000; Ross et al. 2012). As such, reducing barriers to continued employment is of utmost importance among this special group of workers. Most importantly, in the employment-based U.S. health insurance system, continued employment for survivors may mean the difference between being able to access timely treatment, or waiting to qualify for any available public program. The workplace has also served as a source of routine social interaction, and is most beneficial if survivors are afforded a reduced workload (Anema et al. 2007; Korstjens et al. 2006), which would allow them to heal and continue to contribute to society. There have been disparate reports of flexibility and accommodation among the occupational sectors, thus an accommodating work environment may not be what the majority of working survivors experienced (Lightfoot & Lum 2006; Loprest & Maag 2001).

Working survivors reported better health status, less functional limitations and spend fewer sick days in bed. However, differences exist within this group: blue-collar cancer workers were almost twice as likely as white-collar working survivors to report poor health, and having another chronic condition. There were no major differences between occupations for the aforementioned health indicators among working survivors.
when compared to unemployed cancer survivors. All employed survivors were significantly less likely to report any negative health indicators compared to unemployed survivors.

Figure 6.1. Prevalence of the most common cancers by gender among working cancer survivors.*

* Some cancers are gender specific

Gynecological cancers include (cervical, ovarian and uterine cancers)

IV. Trends among Working Survivors

While there was a decline in the overall US worker population between 1997 and 2010, mainly attributed to an estimated decrease of 5.1 million workers without a prior cancer diagnosis. The proportion of working cancer survivors increased from 39.3% to 44.0% of all survivors, representing an estimated 3.6 million persons throughout the 14 years of the study. We found disparate cancer rates across
occupational groups. These disparities were closely related to education, age and certain race/ethnicities.

Blue-collar working survivors demonstrated the most significant growth over the 14 years; they almost doubled in proportion from 12.7% in 1997 representing 38,862 working blue-collar survivors, to 22.3%, representing 296,115 blue-collar employees with a prior cancer diagnosis. Blue-collar survivors were twice as likely as white-collar, and 1.2 times as likely as service workers to report poor-fair health. The physically demanding nature and lower flexibility with regards to time when compared to white-collar jobs may contribute to higher reports of poor health among blue-collar survivors (Toppinen-Tanner et al. 2002).

V. Working for Financial Independence and Social Support

We found that a large proportion of blue-collar workers continued to work post diagnosis when compared to persons in white-collar occupations. For cancer survivors employment serves as a means to financial stability, an organized social routine, the ability to function as a bread-winner for the family, and/or a contributing member of society (Cooper et al. 2012).

Employment facilitates access to monetary funds to cover the cost of treatment as well as continue to pay monthly bills such as rent or mortgage, utilities and insurance (Bradley et al. 2012). The cost of survival post diagnosis and fees directly associated with care are taxing, regardless of insurance coverage. Our study shows that the type of insurance has been shown to make a significant difference in health behaviors through use of various indicators. A significantly lower proportion of working survivors, 9.0% representing 682,381 persons, reported not having any health insurance, compared to
14.1% of working persons without a prior diagnosis representing over 19 million persons. Our findings are supported by longitudinal studies, and personal accounts from cancer survivors on numerous cancer blogs, that employment is their means to much needed health insurance (Amir and Brocky 2009; CandiJo et al. 2011; Tunceli et al. 2009). If the current trends in cancer incidence, survival, and costs of care continue, the total cost of cancer care in 2020 is expected to be $173 billion (Mariotto et al. 2011). This is a projected 40% increase in the cost of care from that of 2010, which only underscores the importance of financial self-reliance among survivors and the need for continued employment.

VI. Factors Affecting Work

In this study, working survivors reported lower functional limitations and psychological distress than unemployed survivors. Physically demanding work has been identified as an important factor decreasing the likelihood of return to work after diagnosis (Bouknight et al. 2006). This difference is evident in the distinctly large proportion of survivors employed in white-collar occupations as compared to persons without a prior diagnosis (Clarke et al. 2011). There is also increasing evidence indicating that employers' support, physicians’ advice on issues related to return to work and employers' willingness to accommodate changes in workability due to cancer illness and treatment are beneficial for survivors' return to work (Amir et al. 2008; Bouknight et al. 2006; de Boer et al. 2011). While investigating labor force participation among working survivors, we noted that survivors were significantly
impacted by functional limitations and impaired performance in activities of daily living on their decision to return to work. These two factors are however surpassed in impact by psychological distress. On average, cancer survivors experience greater psychological distress than their undiagnosed peers. Hoffman et al. (2009) noted in their study among long-term cancer survivors, that after adjustment for other clinical and sociodemographic variables, long-term survivors who were younger, were unmarried, had less than a high school education, were uninsured, had more co-morbidities and had difficulty performing instrumental activities of daily living were more likely to experience serious psychological distress.

Given that cancer survivors with more chronic medical conditions tended to be those most at risk for psychological distress in this study, the findings also underscore the need to integrate medical and behavioral health care for survivors. Specifically, cancer survivorship clinics may benefit from having mental health providers on staff for a multidisciplinary approach to the care of these persons (Daily 2009).

VII. Screening beyond Cancer Diagnosis

Survivors usually express interest in post-diagnostic care plans (Irwin 2009; Pedersen et al. 2009). They are also more mindful of health behaviors such as screening which are needed to prevent a late stage diagnosis of a recurrence of the disease (Satia et al. 2004; Yaw et al. 2011). Our data reflected that cancer survivors exceeded the HP2010 goal set for all colorectal screening, mammography and pap tests.

The acceptance of screening as a necessary cancer health behavior was discussed in Chapter 5. In this study, cancer survivors exhibited a higher adherence to
screening compared to persons without a diagnosis. Among cancer survivors, screening rates are high among working survivors. White-collar and service workers demonstrated higher screening rates compared to other survivors and while the trend over the decade has not been positive for all cancers, Colorectal screening increased between 1999 to 2010 across all occupational sectors,

Screening behavior was the main secondary prevention of interest in this study; however, future studies should examine cancer risk behaviors such as smoking and excessive drinking among working survivors. Of note, Rowland et al (2006), Bellizzi et al. (2005), and others have examined risky behaviors among childhood cancer survivors, and recommend that they engage in healthy behaviors. The screening rates among working survivors, and survivors on a whole are well below the HP2020 goals for colorectal screening, mammography, and cervical cancer screening (USDHHS & Services 2010). In 2010, white-collar working survivors surpassed the HP2010 goals for colorectal screening and met the HP2020 goal at 71.8%.

VIII. Implications for Public Policy

Tantamount to successful research on the socio-epidemiological issues facing working survivors in the US are the understanding and identification of the dynamic changes in holism (macro-social determinants and outcomes) among cancer survivors as they relate to the current social and economic climate (Galea 2007). Effective change will require a ‘systematic approach’; otherwise, we may arrive at inefficient solutions. Evidence-based policy involves a series of systematic processes and scientific research is but a small part of this system. The findings from our research indicate the need for a
collaborative effort among several stakeholders pertinent to making changes in health policy. With less than two thirds of survivors reporting receiving information on continued care from their primary healthcare provider, the need arises for cancer prevention experts to involve key members of the governing medical board in order to devise a post-diagnosis treatment guide for primary physicians and oncology practitioners.

The majority of cancer drugs are not covered by public health insurance such as Medicaid, hence survivors depend on employer-subsidized private insurance to afford treatment (ACS 2011). Thus, for those too ill to return to work, and too young to qualify for Medicare, treatment remains extremely costly. With chronic disease being the number one reason for bankruptcy in the US (Arnst, 2009), and cancer being among the most expensive of these chronic illnesses to treat, new health policies must continue to include issues such as affordable healthcare regardless of pre-existing illnesses for persons who have been insured but must also include the subsidy of medication pertinent to health and recovery for grossly debilitating diseases such as cancer.

We acknowledge the added psychological stresses and challenges faced by survivors within this economic climate when fiscal insecurity spurs the need to return to work. Although there are existing policies (such as short term disability and the federal medical leave act) that facilitate protected time for healing, many survivors are extremely anxious to return to work as quickly as possible, and promptly resume their full workload for fear of job loss or lack of promotion (Nachreiner 2012). This opportunity exists only within occupations involving tasks manageable during treatment or those that offer flexible work schedules. Identification of the continued growth of
the cancer survivor workforce, and apparent disparities among occupational sectors, indicates the need for the inclusion of the Department of Labor in decisions specifically related to cancer survivors within the workplace. This may include employment directives and/or occupational health policies created by companies specifically for cancer survivors.

Our research highlights the need to revisit existing policies concerning cancer survivors, addressing the challenges encountered by the growing number that choose to work post diagnosis.

IX. The Future of Working Survivors

Our data showed that an estimated 67,000 cancer survivors reported undergoing treatment in 2010. Approximately 22,000 of these survivors continued to work during treatment. The NHIS only provides information on traditional cancer treatments, but evidence has shown that employed patients with cancer experience return-to-work benefits from multidisciplinary interventions compared to standard care (Burgio et al. 2006; Ell et al. 2008; Main et al. 2005). More high quality randomized controlled trials aimed at enhancing return-to-work in cancer patients are needed (de Boer et al. 2011). In our study we found higher levels of psychological distress among working survivors. Research also suggests that management of symptoms of fatigue and psychological distress may benefit from different approaches when improvement in cognitive function at work is a desired outcome (Todd et al. 2011).
Three gaps in existing knowledge related to the practical and physical problems associated with employment and cancer survivorship have been identified in our research:

- key occupational disparities in modifiable risk behaviors among working survivors;
- differences in symptomatologies associated with cancer by occupation; and
- health insurance and unmet supportive care needs (data available in 2010 supplement only).

These should be addressed by future research. Work is also needed to address the system of principles, procedures and terms used in survivorship research and to improve the methodologies employed in research on working cancer survivors (including standardized measures, theoretical frameworks, longitudinal design, inclusion of older working survivors and studies with age-matched controls for comparison), to increase comparability across studies.

Our research reflected that almost 50% of working survivors were between 45 and 65 years. Key cancer research agencies such as the NCI should encourage funding of collaborative longitudinal studies on working cancer survivors to better understand their health behaviors and needs as they age and continue to contribute to the social and economic development of the US. Finally, our study highlighted the need for better research within the identified areas in order to improve the experiences of working survivors.
X. Study Strengths and Limitations

The findings in this report are subject to several limitations. First, reported occupation within the past year (post diagnosis) may not be reflective of returning to the job held before the cancer. Second, projection of race- and age-specific proportions from NHIS to the US population does not account for other prognostic factors (e.g., genetics, environmental exposures and gene-environment interactions). Third, persons with multiple tumors were categorized according to their first tumor; i.e., a person with melanoma and later breast cancer was counted as a survivor from melanoma but not from breast cancer. Estimators of the number of persons with cancer using different methods of counting multiple tumors are available (NCHS 2011). Fourth, the estimates did not include broader health-status data that might indicate a survivor’s stage at diagnosis and treatment chosen, or whether respondents were dying from cancer. Methods that relate these factors to the trajectory of disease are being studied and can be addressed using other data sources as a proxy such as the SEER database (for disease stage) and the Medical Expenditure Panel Survey (for treatment and associated costs). Finally, though a nationally representative database of the noninstitutionalized US civilian population, the NHIS is a series of cross-sectional data, as such, we cannot determine causation. The data collected are self-reported but the NHIS is a probability sample representative of the target population.

The main objective of the NHIS is to monitor the health of the US population through the collection and analysis of data on a broad range of health topics. A major strength of this survey lies in the ability to display these health characteristics by many demographic and socioeconomic characteristics.
Recommendations

The findings raise critical issues for public health practitioners. A growing need exists to promote health, prevent secondary disease, and ensure the social, psychological, and economic well-being of long-term cancer survivors and their place in work environment (Warren 2012). Public health initiatives have typically addressed the prevention and early detection of cancer, and the change in cancer survival in part reflects the success of these efforts. Acknowledging the growing numbers of cancer survivors, and the increasing proportion that continue to work post diagnosis; public health practitioners are expanding efforts to address cancer survivorship and translate research findings into practice. Programs are needed to support working survivors and their families across the continuum of cancer treatment, health promotion, and survival. Long-term surveillance that monitors the health and social well-being of survivors after 5 years could provide a knowledge base for cancer survivorship. Development of clinical guidelines could help health-care practitioners provide follow-up care and advice to working survivors. Policymakers should be educated about economic concerns faced by survivors, such as employment and insurance discrimination (Dechery 1996; Messner & Patterson 2001; Messner & Vera 2011).

Though some common components of return to work processes can be applied across multiple cancer types, it should be noted that gender, age, treatment and side-effects, as well as the physiological, psychological and social consequences depend on the type of cancer (Johansen 2007). Therefore, work arrangements, for example, should be flexible and tailored to meet the particular needs of patients with specific types of
cancer. Longitudinal intervention-based studies are also needed to delineate to what extent work adjustment helps to buffer negative physical or psychological health outcomes such as fatigue and stress (Pryce et al. 2007). Future intervention studies should be designed with a better structuring of the components of the intervention. Modifiable factors should be a primary focus and include different aspects of the work environment, including both the physical and mental aspects of work. Continued or improved healthcare access and utilization is integral to a rapid recovery and return to work among survivors. Universal healthcare would be most beneficial to working survivors who are too young to qualify for Medicare and are not covered through employer subsidized insurance.
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### Appendix I. Recommendations for Cancer screening as suggested by the American Cancer Society under the guidance of the United States Preventive Services Task Force.

<table>
<thead>
<tr>
<th>Screening exam</th>
<th>Recommendations (1999-2010)</th>
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<tr>
<td>Breast cancer screening</td>
<td><strong>Mammography</strong> (an digital or film x ray picture of the breast) <strong>Clinical breast exam</strong>&lt;br&gt;Women ≥ 40 years should have mammograms every 1 to 2 years.&lt;br&gt;Women with a higher than average risk of breast cancer- discuss frequency and of age at first screening with their health care providers.&lt;br&gt;Every 3 years for women in their 20s and 30s and every year for women &gt; 40 years</td>
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<td><strong>Pap test</strong>&lt;br&gt;Women at least 3 years after first vaginal intercourse, but no later than 21 years old.&lt;br&gt;Regular Pap test every 1 year or newer liquid-based Pap test every 2 years.&lt;br&gt;Women ≥30 with 3 consecutive normal Pap test results may get screened every 2 to 3 years. Women &gt; 30 years may also get screened every 3 years with either the conventional or liquid-based Pap test, in addition to the human papillomavirus (HPV) test.&lt;br&gt;Women ≥70 years with 3 or more consecutive normal Pap tests and no abnormal Pap test results in the last 10 years may discontinue testing.&lt;br&gt;Women who have had a total hysterectomy for non-cancer related reasons may discontinue testing.</td>
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<td><strong>Flexible sigmoidoscopy</strong>&lt;br&gt;<strong>Colonoscopy</strong>&lt;br&gt;<strong>CT colonography (virtual colonoscopy)</strong>&lt;br&gt;<strong>Double-contrast barium enema</strong>&lt;br&gt;<strong>Fecal occult blood test (gFOBT)</strong>&lt;br&gt;<strong>Fecal immunochemical test (iFOBT/FIT)</strong>&lt;br&gt;<strong>Stool DNA test (sDNA)</strong>&lt;br&gt;Men and women ≥ 50 years&lt;br&gt;Every 5 years*, or&lt;br&gt;Every 10 years, or&lt;br&gt;Every 5 years*&lt;br&gt;Annually** or&lt;br&gt;Annually <strong>, or&lt;br&gt;Interval uncertain (possibly 3-5 years)</strong></td>
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<td><strong>Prostate specific antigen (PSA) blood test</strong>&lt;br&gt;<strong>PSA velocity test</strong> [How PSA measures rise over time]&lt;br&gt;<strong>PSA density test</strong> [Ratio of PSA level to size of prostate gland]&lt;br&gt;<strong>Percent free PSA</strong> [ratio of unattached PSA in blood to total PSA]&lt;br&gt;<strong>Age-specific PSA range</strong>&lt;br&gt;<strong>Digital rectal exam</strong>&lt;br&gt;Discuss with physician the pros and cons of receiving a baseline PSA and if conducted, when another test would be necessary.&lt;br&gt;Men at higher than normal risk (Blacks, men whose father, brother or son have been diagnosed with prostate cancer) Discuss screening with physician at 45 years&lt;br&gt;Men ≥50 years discuss the harms and benefits of PSA screening with physician.&lt;br&gt;Men with a previous PSA of ≥4 ng/ml in the blood, should be retested if discussion with physician dictates a necessity.</td>
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