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PREVALENCE OF WORK-RELATED DISABILITIES USING
THE ICF DEFINITION IN AN EMPLOYED COHORT
DIAGNOSED WITH BREAST OR PROSTATE CANCER

presented by

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Major Professor's Signature

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PREVALENCE OF WORK-RELATED DISABILITIES USING THE ICF DEFINITION IN AN EMPLOYED COHORT DIAGNOSED WITH BREAST OR PROSTATE CANCER

By

Kathleen Oberst

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ABSTRACT

PREVALENCE OF WORK-RELATED DISABILITIES USING THE ICF DEFINITION IN AN EMPLOYED COHORT DIAGNOSED WITH BREAST OR PROSTATE CANCER

By

Kathleen Oberst

Advances in cancer diagnosis and treatment have resulted in improved survival. Increasing emphasis on early detection has resulted in working individuals having to face the disease. Therefore, effects of cancer treatment may result in employed patients requiring workplace accommodations to minimize absenteeism. This investigation focuses on cognitive and physical disabilities reported at twelve and eighteen months following diagnosis by 447 breast and 267 prostate cancer patients recruited from the Metropolitan Detroit Cancer Surveillance System. Disability was defined to include activity limitation in specified job tasks with labor market participation restriction. Twelve and eighteen month disability prevalence estimates were calculated and compared. Furthermore, influences of personal and environmental factors on disability development in the breast cancer cohort were tested using logistic regression. Participants reported more cognitive work demands than physical demands at both time points. However, respondents reported significantly more physical disabilities compared to cognitive disabilities at twelve and eighteen months ($p<0.05$); yet estimates were below national averages. Women experienced significant reduction in physical (17% to 10%) and cognitive disability (9% to 5%) prevalence estimates from twelve months to eighteen months ($p<0.05$). Men did

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not enjoy significant changes in estimates of physical (8% to 5%) or cognitive (3% to 1%) disability during this time frame. Regression results indicated personal factors such as income or age were not significant predictors of disability in women. However, African-American women were at higher risk for cognitive disability. Much more important to the outcome of disability was cancer stage and treatment. Women diagnosed at later stages had significantly more disability. The most significant environmental factor associated with presence of disability was the absence of paid sick leave as a benefit. Since treatment is reflective of cancer stage, the importance of screening and early detection must be stressed to minimize disability. Also, adequate recovery time is necessary to adjust to the affects of cancer treatments. Individuals who cannot afford to take this time and work through treatment may experience longer lasting impacts. Employers may wish to consider the cost of paid sick leave versus the costs associated with lower productivity to re-evaluate their benefit packages. Limitations of this study included design as a secondary analysis, low power to detect small changes and lack of data regarding accommodation and rehabilitation available to participants. Also, future studies should include mechanisms to track the nature and intensity of limitations and restrictions.

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DEDICATION

This work is dedicated to my husband, Dan. Once again, your support has made this degree possible. I could not have completed this without your love, patience, and finely tuned house-husband skills. I hope this will lead to an even brighter future and I look forward to putting all my energy and time back into us. I love you very much.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

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LIST OF ABBREVIATIONS

International Classification of Functioning, Disability and Health	ICF
World Health Organization	WHO
Americans with Disability Act	ADA
New Freedom Initiative	NFI
Centers for Disease Control and Prevention	CDC
Labor Market Outcomes Study	LMOS
Metropolitan Detroit Cancer Surveillance System	MDCSS
Surveillance, Epidemiology and End-Results	SEER
Health and Retirement Survey	HRS
International Classification of Impairments, Disabilities, and Handicaps	ICIDH
Family Medical Leave Act	FMLA

CHAPTER 1: INTRODUCTION

Twenty percent of the U.S. population is affected by a disability of some kind and societal costs associated with these approach $400 billion dollars. Cancer conditions affect a smaller proportion of the population yet more than $200 billion are invested in care associated with these diagnoses. Potentially, the combination of these conditions accounts for nearly 5% of the U.S. gross domestic product. Therefore, it is fitting that attention be focused on the extent to which these conditions co-exist and factors that may influence their convergence.

This effort is focused on work-related disability in a cohort of breast and prostate cancer survivors. Prevalence estimates of work-related physical and cognitive disabilities at twelve and eighteen months post-diagnosis will be calculated and compared among the enrolled study subjects. One of the unique features of this work is that the term "disability" will be explicitly defined and quantified. After the prevalence estimates have been documented, the focus will shift to identifying contextual variables on the occurrence of disability. Specifically, variables of interest categorized as personal or environmental will be evaluated. Personal factors include socio-demographic (age, gender, race) and disease-related (stage, treatment) variables while environmental factors include employment-related (job satisfaction, employer accommodation, physical nature of job) variables.

This introduction will be organized in a deliberate manner. The foundation for this study will be established with an overview of disability, cancer and work force participation. After describing the preferred theoretical framework, the significance of disability in America in terms of prevalence trends and the relative participation of persons with disabilities in the work force will be discussed. For the interested reader, a review of alternative disability models is presented in Chapter 2. Furthermore, the distinction of disability from perceptions of health or illness will be described.

Next, information regarding breast and prostate cancers will be presented since this study is concerned with disability in previously healthy cancer patients. The description will communicate data regarding prevalence trends, current treatment options and survival expectations.

Lastly, the study proposal will be briefly described. The general nature of the study questions that are the focus of this paper will be illustrated and the overall approach to implementing the study will be explained. Specific details regarding the study methodology will be reserved for Chapter 3.

1.1 Theoretical Framework

A single concept of disability is not universally accepted. Competing theories emphasize physiological, personal, environmental, and societal characteristics to varying degrees. The most comprehensive definitions embrace a *biopsychosocial* model that acknowledges the contribution of each facet on an individual at different points in time.

One consistent trend in the concept of disability is the increasing belief in the notion that *dis*ability does not equate to *inability*. Individuals may experience limitations in particular activities, for example, ambulation, but enjoy full participation with life events, such as maintaining full-time employment.

The *International Classification of Functioning, Disability and Health (ICF)* was selected as the overarching conceptual model to frame this study. The World Health Organization (WHO) published the ICF in 2001 (62). This system was released as a complete revision to their 1980 document entitled the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH).* The ICF acknowledges "mind, body, and environment are not easily separable but rather mutually constitute each other in complex ways." (10, 62) Individual and social characteristics interact between three specific dimensions to establish disability.

The three dimensions of the ICF classification system include: impairment, activity limitation and participation restriction. Impairment refers to the loss or "abnormality" of a body part or function and is conceptualized in a value-neutral manner. According to ICF, "abnormality" refers only to "a significant variation from established statistical norms, i.e. as a deviation from a population mean within measured standard norms." (62) Activity limitation refers to the difficulties a person may have in executing activity. Participation restriction incorporates the problems or difficulties a person experiences with involvement in life situations. Furthermore, the ICF recognizes these three dimensions exist within "contextual factors" such as environmental or personal factors (10, 62). Environmental factors include items such as social systems or services while personal factors include race, gender, or socioeconomic status characteristics. According to the ICF then, disability is established in an individual by the interaction of the three domains: impairments in body functions/structures, activity limitation and participation restriction. The expression of disability may be influenced by the contextual factors. Thus, a key component of this system allows for variation in disability depending on the factors present at any one time (Figure 1). For example, a lack of social services may exacerbate disability but if these become available at a later date, disability may be lessened.

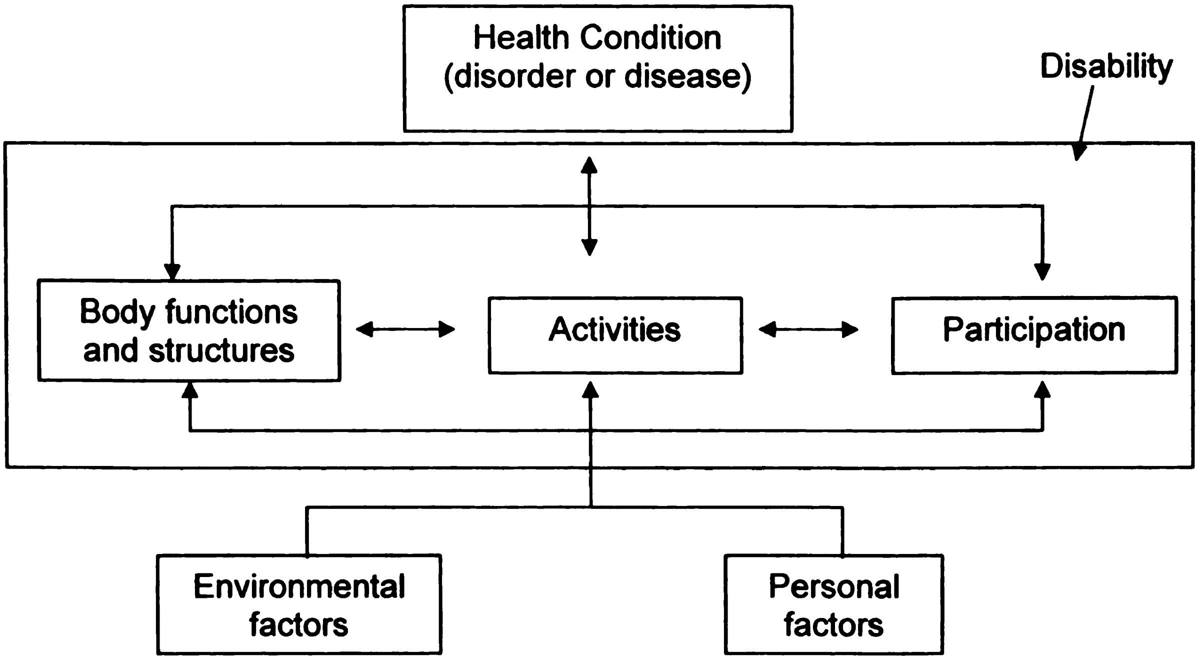

Figure 1: Interactions between the components of the International Classification of Functioning, Disability and Health (adapted)

The ICF model defines disability as limitations in physical or mental functions (e.g. activity limitation), caused by one or more medical conditions (impairment), in carrying out socially defined tasks or roles (participation restriction) (1, 2, 62). Ultimately, disability may be considered as "the negative aspect of the interactions between an individual (with a health condition) and that individual's contextual factors, environmental and personal factors." (62)

The dimensions included in the ICF will be used to describe work-related disability reported by breast and prostate cancer patients twelve and eighteen months after a cancer diagnosis. Work-related disability will be measured by the presence of new *limitations* in a variety of work-related tasks in conjunction with a decrease in work *participation* level that the respondents attribute to their cancer diagnosis and treatment (*impairment).* Therefore, participants in the study will be considered to have a disability if they admit to having a limitation with any of their work-related tasks and they have decreased their level of participation in their work setting from a baseline measurement. In terms of the ICF model, the combination of these elements as a disability represents negative interactions between the individual and their job situation. The various components included in this analysis may be categorized into the ICF model (Figure 2).

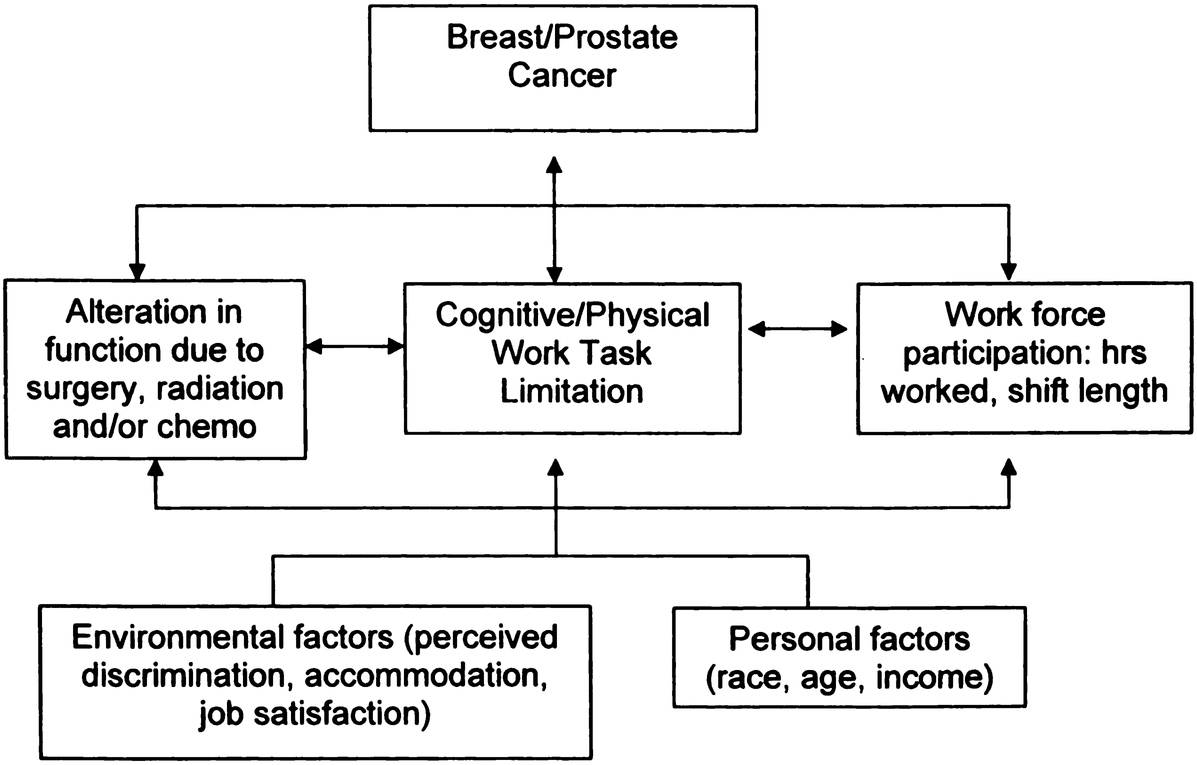

Figure 2: Study components nested within the ICF model

1.2 Overview of Disability

Disability has only recently been recognized as a significant societal issue in the United States. The prevalence of persons with disabilities appears to be increasing. In response to this, the federal government has increased attention to issues affecting these individuals.

1.2.1 Prevalence Trends

The prevalence of persons with disabilities is increasing substantially according to Census and the Behavioral Risk Factor Surveillance System surveys (8,42,96,97). Twenty percent of Americans over five years of age were documented to have some level of disability according to the latest Census (96).

This increase comes with larger costs both to the individual and society arguing for increased research into the disability experience.

According to 2001 Behavioral Risk Factor Surveillance System data, the unadjusted prevalence of disability among adults in Michigan was 19.6%, (95% CI 18.2-21.0) (42). The median prevalence for all 50 states was 18.0% with a range of 10.5% - 25.9% (42). The Detroit Metropolitan Statistical Area unadjusted prevalence of disability among adults was 20.4% (95% CI: 18.0, 22.8) and was significantly higher than the Midwest median prevalence, 17.4% (42).

Disabilities are disproportionately identified within disadvantaged groups although they can occur in a person of any race, age and gender (44). White and Asian Americans suffer less disability within each age strata compared to other racial groups. This relationship may be confounded by socio-economic status. Disability is often correlated with poverty, low education and few social resources. However, the direction of influence continues to be debated. Disability increases with increasing age regardless of race/ethnicity. Per U.S. Census estimates, female disability rates exceed male disability rates after 15 years of age.

1.2.2 Factors Driving Disability Prevalence Trends

The prevalence increase is felt to be a result of several factors. The rise in life expectancy for all persons, including those with disabilities causes the proportion of disabled individuals in the total population to increase. As the baby-boomer generation advances in age, the number of disabilities related to chronic diseases is expected also to rise (8, 97). Finally, formerly fatal conditions such as cancer are now often medically managed so individuals with these conditions are maintained in the population.

One key limitation to published prevalence figures is the assumption that the target audience can be readily identified. Complicating this seemingly straightforward endeavor is the realization that disabilities may be visible or invisible. Disability may involve physical, cognitive, developmental, or sensory components. They may occur acutely or develop over longer time frames. They may be present at birth or acquired over the life span. They may represent permanent conditions or be a transient circumstance. Moreover, the same condition may impact different individuals to different degrees (8). Because of these variations, it is hard to state with certainty what the published disability figures actually represent.

1.2.3 Social Role – Work Force Participation

The social role of interest to this study is participation in the labor market. The vast majority of participants in this study were working at the time of their cancer diagnosis so the opportunity exists to chronicle how their social role changed, if at all.

Nationally, persons with disabilities are poorly represented in the labor market. Of the estimated 49.7 million disabled individuals, 61% are between 21-64 years of age but just over half are employed (44). This pattern holds for males and females. In addition to lower work force participation, men with disabilities have lower median wages compared to men without disabilities,

$1857 vs. $2190, respectively (44). Women's wages follow this pattern but are significantly lower than men's wages, regardless of disability status (44).

Participation restriction in working, the usual social role for this age group, comes at a significant cost to society. Lost productivity attributed to disability accounts for more than $155 billion (1, 8). In addition, government payments to support unemployed persons with disabilities are estimated at over $230 billion annually (92). As disability prevalence increases, ongoing failure to promote integration or re-integration of persons with disability into the working sector will result in higher societal costs.

Therefore, efforts to keep or return individuals to the labor market would be anticipated to be beneficial to the general public. However, the challenge to do so arises from the tremendous variation in the notion of disability. Some individuals may need permanent accommodations to participate. Others, like these study participants, may only require assistance for a defined period of time or with specific elements of their jobs.

1.2.4 Increasing Government Attention and Action

National interest in persons with disabilities has expanded dramatically in the past decade along with increasing awareness of the prevalence trends. Key government reports (e.g. Healthy People 2010, Call to Action, New Freedom Initiative) have focused attention on this population unanimously charging the public to identify opportunities to promote the full integration of persons with disabilities into society.

Legislation supporting persons with disability has been passed in the past fifteen years. The Americans with Disabilities Act (ADA) and the New Freedom Initiative (NFI) promote equal access and inclusion for disabled individuals. The U.S. Department of Health and Human Services has publicized issues related to persons with disabilities through several offices, including the Centers for Disease Control and Prevention (CDC) and the Office of the Surgeon General. In similar fashion, non-governmental agencies dedicated to supporting individuals with disabilities have increased in number and scope over the past decade, i.e. Paws with a Cause (8).

The ADA was signed into law July 26, 1990 with a goal of making American society more accessible to people with disabilities (11, 13). Five major title areas are covered under the ADA: *employment*, public services, public accommodations, and telecommunications. The fifth part prohibits retaliation toward or threatening disabled individuals who avail themselves of the Act to assert their rights or of those that assist disabled persons to assert their rights.

Title I, Employment, states "business must provide reasonable accommodations to protect the rights of individuals with disabilities in all aspects of employment." Discrimination in most job-related activities is prohibited under the ADA. Discriminatory practices include refusing to hire an individual with a disability for a job, firing a worker without cause, providing unequal compensation, working conditions or benefits, or screening out persons with disability (13). The ADA applies to private employers with at least fifteen

employees as well as state and local governments, unions or employment agencies.

The NFI is an executive order signed by President George W. Bush in 2001 intended to "eliminate the barriers that prevent people with disabilities from participating fully in community life." (8, 86) The overriding emphasis of the order is to promote community-based alternatives for persons with disabilities and to ensure that community-based programs promote independence and community participation. NFI focuses on six areas, one of which is employment. Included as part of this executive order were funds in excess of five million dollars to help small businesses comply with the ADA and encourage them to hire persons with disabilities (86). An additional 145 million dollars were dedicated to promoting transportation programs (86). Lastly, funding for the Office of Disability Employment Policy at the Department of Labor was doubled in an effort to increase the number of persons with disabilities employed in the labor market (86).

The CDC included a chapter focused on people with disabilities in the *Healthy People 2010* document. *Healthy People 2010* is the national plan that promotes government, private and community health promotion and wellness activities and policies to improve the health of Americans and eliminate health disparities (12, 88). Disability status has now been included as a descriptor variable in this latest edition. Available data suggest disability is a risk factor for other health-related conditions (12). As such, *Healthy People 2010* argues that

persons with disability warrant focus, similar to persons of minority racial groups, to reduce and eliminate health disparities (8, 88).

Lastly, the U.S. Surgeon General, Dr. Richard Carmona, MD, MPH, FACS, published a *Call to Action to Improve the Health and Wellness of Persons with Disabilities* in 2005 (8). The document supports the ability of persons with disabilities to *work*, learn and engage in society by identifying barriers and suggesting direction to improve health and wellness. Dr. Carmona also emphasized that research on disability must continue (39). A distinctive feature of the *Call to Action* was that it was written with the input of persons with disabilities, not simply from the health care provider perspective.

Another example of the national focus on persons with disabilities and involvement in social roles is found in the establishment of the Committee on a National Agenda for the Prevention of Disabilities. This committee has been convened through the Institute of Medicine and has issued a number of recommendations including provision of comprehensive vocational rehabilitation (92).

Although most of the government initiatives portray the impression that all disability is a permanent condition, models such as the ICF remind us that the interaction of the individual within their physical and social environments can change. Therefore, it is important to understand that not all disabilities represent lasting situations.

1.2.5 Characteristics of Transient Disabilities

One important distinction of the persons included in this study is the presumably transient nature of their disability. Most of these individuals did not have pre-existing conditions that adversely affected their ability to maintain paid employment. Individuals who only worked part-time were asked the reason for this and only 3 (0.6%) respondents in the breast cohort and none of the prostate cohort participants acknowledged health limitations at the baseline interview encounter.

While disability statistics tend to emphasize permanent conditions, transient conditions are increasingly legitimized. The Family Medical Leave Act (FMLA) of 1993 requires employers who have at least 50 employees to provide eligible workers up to twelve weeks of leave for their own medical illness among other qualifying reasons (120). While this leave need not be paid, if the employer offers medical coverage, they are obligated to continue this during the leave (120).

Thus, the FMLA legislation can be considered to be disability legislation. Individuals who are sick or injured are known to experience restrictions in maintaining participation with working which is one of their social roles. The benefit of this Act is that it permits people to step away from this role for a time to focus their energies on recuperation in the hopes that they are able to return to work.

1.2.6 Disability versus Illness

The emphasis of this study on disability in the presence of a cancer diagnosis may inadvertently implicate a one-to-one relationship between disability and disease. However, disability must be differentiated from the concept of illness. Per the biopsychosocial model, disability does not equate to illness. The cancer diagnosis each participant in this study has received does not automatically confer disability. Recall that disability is the interaction of impairment, activity limitation and participation restriction. Illness often refers to some abnormal physiologic function. Illness, then, can be considered to be just one piece of the puzzle that contributes to disability.

However, it is important to also discuss disability in terms of health. Disability is not simply the opposite of health. Rather, the concept of health encompasses a much broader interpretation of contributing factors. The World Health Organization defines health as a "state of complete physical, mental and social well-being and *not merely the absence of disease, or infirmity*." (62) Krahn (2003) has defined health as "achieving and sustaining an optimal level of wellness, both physical and mental, that promotes a fullness of life." (94)

Definitions such as these point to the importance of the respondent's perspective on the concept of health. Persons with disability can seek their own levels of wellness optimal to their personal situation. It is entirely possible that persons with a disability enjoy well-being in their physical, mental and social endeavors and believe themselves to enjoy good health. Therefore, a participant in this study may be labeled as "disabled" based on their responses to questions about activity limitation or evaluation of work participation restriction. However, this label should not be interpreted as comparable to how the participants' would evaluate their own health status.

1.3 Overview of Breast and Prostate Cancers

1.3.1 Prevalence Trends

Cancer prevalence estimates approach 4% of the population, but the condition receives substantial investment of health care dollars in terms of screening and treatment of disease. The National Institutes of Health reported nearly $74 billion were spent on direct medical costs in 2005 while the overall costs for care in 2005 were estimated at nearly $210 billion (57). The price of lost productivity due to cancer illness is not well defined. Some estimates approximate the cost at $17.5 billion (57).

An estimated 213,000 new cases of female breast cancer were expected for 2006 with nearly 41,000 deaths. New prostate cancer cases were estimated to be nearly 235,000 with over 27,000 deaths (57). New Michigan cases for female breast and prostate cancer were approximated at 7070 and 7370, respectively, in 2006 (57). The incidence rate of female breast cancer in Michigan between the years of 1998-2002 was 132.4 cases per 100,000 while the prostate incidence rate for the same timeframe was 200.6 cases per 100,000. Over half of incident breast cancer cases are expected in women between 20 and 64 years of age while nearly 40% of prostate cancer cases are expected in men of the same age range (111). Thus, the potential impact of disability related to a cancer diagnosis on persons in the work force is significant.

1.3.2 Factors Driving Prevalence Trends

Cancer is one medical condition that has enjoyed significant improvement in treatment efficacy. Screening practices also enable early detection. The combination of early detection with better treatments offers more promising prognoses. These circumstances have resulted in increasing numbers of breast and prostate cancer survivors.

Breast cancer is largely asymptomatic with most cases being diagnosed during screening mammography. Women aged 40 and up are recommended to undergo screening mammography on a regular basis. Under certain circumstances, as with a positive family history of cancer, screening is initiated at even younger ages. The end result of early screening is that diagnosis will occur during a woman's working years.

Prostate cancer is the most frequently diagnosed cancer in men (57). Prostate cancer screening is initiated in most men at age 50 unless personal or family health histories call for earlier screening. Screening involves a blood test for prostate-specific antigen along with digital rectal examination. Most men are employed at age 50 so the potential for impact on work force participation is great.

Available treatments for these cancers are aggressive even when detected at early stages. The breast cancer survival rate (all stages combined) at five and ten years is 88% and 80%, respectively (57). However, the five and ten year survival rate for prostate cancer is 99% and 92%, respectively (105). The number of cancer survivors in the United States is estimated to exceed ten million persons with fourteen percent diagnosed more than two decades earlier (63).

1.3.3 Treatment Options

Treatment of breast cancer includes surgical options as well as adjuvant therapy. Surgery may include lumpectomy, local removal of the tumor, or mastectomy, removal of the affected breast along with some lymph nodes. Adjuvant therapy may include chemotherapy, radiation therapy or hormone therapy (57). Treatment is generally concluded within six months of diagnosis however some hormone therapy may be life long.

Treatments for prostate cancer vary and may include surgery and/or adjuvant therapy as well. Surgery may include transurethral resection of the prostate or prostatectomy. In rarer cases, orchiectomy is another option. Additional therapies include brachytherapy (implantable radiation seeds), hormone therapy, chemotherapy and traditional radiation. In contrast to some breast cancer treatment, men do not maintain therapy on a lifelong basis.

1.4 Rationale for Associating Disability with Cancer

Cancer is now being medically managed and is considered by some a chronic condition. However, the aggressive treatments that help confer the added survival may be accompanied by untoward side effects. As a result, persons surviving their immediate cancer experience may find themselves experiencing restrictions in their usual activities subsequent to diagnosis and treatment. Unfortunately, these limitations may be present for long periods of time or even permanently. Since these persons may be of working age, it is reasonable to suspect these limitations may affect their work force participation.

Increased survival has ushered in a new research focus termed survivorship. The National Cancer Institute has identified interest in "studying adverse long-term or late effects of cancer and its treatment." (63) Potential adverse effects may include work task activity limitation resulting in labor force participation restriction. An exploration of work-related disability and how these vary over time based on race, socio-economic status, age, stage of disease and cancer treatment may lend insight into cancer's disease burden for working-age individuals.

Similarly, the U.S. National Occupational Research Agenda is considering research on cancer survivorship, musculoskeletal disorders and work disability as primary subjects for research (121). Feuerstein and Harrington (2006) argue "Research is needed to identify the barriers that affect cancer survivors at work and evaluate innovative interventions to assist these workers in both their return to work and long term success at work" (121). They go on to describe the following belief that is contributing to the public health burden of cancer with respect to the American workplace.

> "Our culture continues to perpetuate the view that an individual with cancer is somehow now defective. While at this point limitations in function often represent the sequelae of cancer and its treatment, the question we need to be asking is not can he or she do the work, but rather can the cancer survivor perform the essential tasks of his or her job and, if not, can he or she be reasonably accommodated to minimize the impact of the illness on work productivity? Yet employers and supervisors continue to perceive cancer survivors as poor risks for advancement (124) and cancer survivors are at high risk for job loss. These outcomes can regrettably lead to a cascade of problems for the survivor, the workplace and society (121)."

Feuerstein's suggestion to identify specific tasks and then look for reasonable accommodations when necessary is a rationale approach. However, even greater worker productivity may result from specific rehabilitation in conjunction with accommodation. Rehabilitation has been shown to produce improvements in other functional aspects of life, such as ambulating or self-care. Once specific work tasks have been described as being sensitive to cancer and associated therapies, rehabilitation professionals could then identify practices to minimize the complications and support an individual's return to optimal functioning.

1.4.1 Rehabilitation Potential to Ameliorate Adverse Effects

As mentioned, cancer rehabilitation is not a novel concept and has been recommended to address competence with daily tasks. Some of the earlier work comes from Lehmann and colleagues in 1978 focusing on dressing, feeding, personal hygiene, ambulating and transferring (114). The improvements made by patients were so remarkable that referrals for rehabilitation more than doubled and the number of visits for rehabilitative services more than quadrupled. O'Toole and Golden (1991) described an increase in independent ambulation

from 14% to 80% at discharge from a rehabilitation hospital while more than half maintained this improvement for 90 days post-discharge (115). Similarly, bladder continence improved from 38% to 87% (115). Yoshioka (1994) reported similar encouraging results from their six-year prospective study of terminal cancer patients in Japan with significant improvements in transfer and locomotion scores (116). These researchers further documented family satisfaction with the rehabilitation efforts with over 75% reporting satisfaction (26,116).

As cancer becomes a chronic condition, expansion of rehabilitation to additional environments (i.e. the work setting) is a reasonable concept yet requires focused study. Yadav (2007) reports occupational therapists at M.D. Anderson Cancer Center facilitate return to work by simulating work activities for patients (122).

The nature of work activities that seem to be most at-risk needs to be defined. However, it is unclear if the characteristics of the work activities are the sole contributor to disability. Employer related factors likely contribute to disability. Ganz (1990) reported vocational issues were often more serious for individuals in blue-collar occupations compared to white-collar occupations (80). This may reflect the differences in the physical demands usually associated with these types of jobs. Or, this may be due to the fact that white-collar workers generally have the benefit of higher levels of education or employment status with greater flexibility in work assignments and scheduling.

Because health insurance is linked with employment in the U.S., the ability of those with a cancer diagnosis to remain employed is often a fiscal necessity.

Since improvements in functional status subsequent to rehabilitative services have been documented, it is reasonable to expect that continued presence in the workforce is a viable option with vocational rehabilitation.

1.5 Study Objective

The objective of this study is to establish and describe how prevalence estimates of physical and cognitive work-related disabilities vary between twelve and eighteen months in an employed cohort of breast and prostate cancer patients. Furthermore, for individuals participating at both timeframes, the change in physical and cognitive disabilities between twelve and eighteen months will be described. Logistic regression will be used to identify variables that may influence disability. Disability will be deemed present when both activity limitation and participation restriction are observed.

A brief narrative of the key facets of this study is presented below. A more detailed description including specific hypotheses is provided in Chapter 3.

1.5.1 Study Proposal

This study will take advantage of an existing dataset from the Labor Market Outcomes Study (LMOS), PI: Cathy J. Bradley, PhD, NCI R01 CA86045-01A1. This study enrolled an inception cohort of breast and prostate cancer patients from the Metropolitan Detroit Cancer Surveillance System (MDCSS), a participant in the National Cancer Institute's Surveillance, Epidemiology and End-Results (SEER) registry and followed them for eighteen months after diagnosis.

Participants were interviewed approximately six, twelve and eighteen months after diagnosis.

Questions regarding work tasks and new limitations attributed to the cancer diagnosis and treatment were asked of participants during the twelve and eighteen-month interview encounters. Using these responses in conjunction with documented participation restrictions represented by decreases in weekly hours worked, shift lengths or withdrawal from the work force attributed to the disease and treatment, it was possible to identify participants who may be said to have a disability according to the WHO definition.

The prevalence of work-related disability was calculated from those who reported activity limitation with participation restriction. Overall prevalence estimates represented the first cut to describe work-related disability in this population. Once these were calculated for the twelve and eighteen-month timeframes, the change in disability from twelve to eighteen months for participants who had data available at both timeframes was described. Finally, the focus turned to determining which contextual factors (e.g. environmental or personal characteristics) influenced work-related disability through the regression modeling process.

1.5.2 Study Rationale

Increasing attention to disability coupled with the increased detection of cancer in a working population provide motivation for this study. Specifically, literature discussing the impact of cancer on an individual's ability to continue in the workforce is limited. Recent articles published on this cohort document changes in hours worked and wages during treatment and recovery phases.

The next step is to document what factors, if any, contribute to the labor market patterns that have been observed. For instance, do physical or cognitive tasks prove to be more difficult to sustain during the treatment and recovery period? Does treatment type affect the duration of disability? Do individuals with higher socio-economic status experience less disability than persons with lower socio-economic status?

Furthermore, disability is a term that is not well defined. Studies have been published that describe various disability rates. However, disability as a characteristic does not necessarily affect all of life's activities equally. Additionally, the facets that are incorporated into a definition of disability can vary. This study will provide preliminary information regarding disability in work-related tasks using a disability definition that is explicitly defined.

Understanding the relationships between specific factors and disability could set the stage for confirmatory testing through new study proposals designed specifically to address these questions. Ultimately, the recognition of factors that could potentially ameliorate or exacerbate disability could be considered for rehabilitation theory, practices and policies.

This study has the necessary information to address the goals. Participants were followed longitudinally with 90% retention of the original cohort at the eighteen-month interview encounter. Questions on work-related tasks were asked of all participants at twelve and eighteen months regardless of their employment status at that time.

1.6 Summary

This investigation will contribute to the existing research on labor market participation of cancer survivors by describing work related disabilities as defined by the ICF. Disability is reflected by activity limitation in conjunction with participation restriction per this model. Both disability and cancer are significant issues for society and these conditions are expected to exert greater impact as the prevalence of each increase. The enhanced survival rates for breast and prostate cancer argue for more emphasis on the long-term effects of the disease and treatment.

This study supports national cancer and occupational research programs. The intersection of work-related disability in a cancer survivor cohort falls under the cancer survivorship research agenda proposed by the National Cancer Institute and the plan of the U.S. National Occupational Research Agenda. Moreover, the participants in the proposed cohort have been followed over time so that changes in reported disabilities will be evaluated.

This study addresses gaps in the existing literature by focusing on a younger, employed cohort, documenting variation in work-related disability over time, and providing opportunities to assess the impact of a variety of personal and environmental contextual factors on work-related disability.

CHAPTER 2: LITERATURE REVIEW

This review will summarize the literature that has been published regarding the selected conceptual model. Additionally, publications regarding disabilities associated with cancer and employment characteristics of persons with cancer will be studied. A review of disability model evolution is included as well. The advantages of the ICF have been described in Section 1.1 as support for selection of the ICF model as the theoretical model.

2.1 Critiques of ICF as the Selected Theoretical Framework

The ICF system is a comprehensive framework that is useful for identifying key components that may contribute to disability. As mentioned in Section 1.1, the model embraces the biopsychosocial aspects and attempts to represent the varying nature of disability. ICF represents an advantage over the medical model that predominated decades earlier. The medical model tended to focus on physiologic derangement(s) of an individual and the activities they were incapable of performing. The medical model charged an individual to accommodate their behaviors and actions to the norms of society and their surroundings. However, a key component to the ICF includes awareness of the environmental and societal influences on conferring disability.

2.1.1 Activity versus Participation Definition

As mentioned in Chapter 1, the ICF evolved from the ICIDH. Yet despite the improvements, the ICF is not without detractors. Some critics express concern regarding the vague concepts of *activity* or *participation* (7,10,45,104). During the ICF's development, consensus regarding how activities are distinguished between these concepts was not achieved despite the inclusion of definitions of these terms. Generally, *activity* was thought to refer to an individual's ability while *participation* represented a societal role (104). The ICF defined *activity* as "the execution of a task or action by an individual" while *participation* was defined as "involvement in a life situation."

Regardless of providing different definitions for these concepts, the document unfortunately catalogued the same basic areas under both terms. Nine specific elements were linked to each: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. By relying on this single list, the ICF failed to present evidence for how these concepts vary which unfortunately blurred the notions. Breaking down mobility into "ability to ambulate without assistance" and "ability to move about a location such as a store" as examples of activity limitation and participation restriction, respectively, could potentially offer more clarity into the distinction between these concepts. Admittedly, the work involved to ensure every contingency is covered would be burdensome.

Some suggest that the underlying concepts of the terms *activity* and *participation* more accurately represent a measure of action in terms of "capacity" and "opportunity" and recommend this terminology as a better reflection of the concepts incorporated into the model. The critical distinction becomes whether someone has the capacity to carry out some specific task. Then, presuming they do have the capacity, the other element asks if they are afforded the opportunity to accomplish these tasks.

Irrespective of the terminology debate, some critics argue that a method to measure the individual's desire for action is missing from the model. The possible combinations of the terms activity, participation, capacity or opportunity still fail to account for a person's intent or "will" to carry out an activity (45). Nordenfelt suggests that if an individual has no intention of carrying out some action, they cannot be said to be *disabled* with respect to that action (45).

Nordenfelt's argument is understandable yet operationally cumbersome. Many of life's activities are not as uniquely specific as this belief requires. Similar cognitive or motor skills can be used for a multitude of tasks and simply because an individual is not interested in performing some activity does not mean they would not be hampered in their attempts to perform tasks that require similar skills. For example, arthritis in the fingers may affect a person's ability to play the piano. Nordenfelt argues that if they do not want to play the piano, they should not be considered disabled in this action. However, the motor skills necessary to play piano also impact the ability to write, type, deal with buttons on clothing, hold a fork and many other activities. Therefore, while the particular activity of piano playing is mute, the impacts are much further reaching. The attempts to discriminate between every possible task would be onerous at best.

It is regrettable that the ICF authors did not continue the effort to better differentiate these terms. This may be addressed in future evolutions of the model. This study will define activity limitation as an individual's capacity while the notion of participation restriction will reflect involvement in social role. Specifically, activity limitation will reference each particular cognitive or physical task of interest (e.g. analyzing data or lifting heavy objects) performed by an individual while participation restriction will represent a decrease in paid employment status (e.g. fewer hours worked, shorter shifts or withdrawal from the workforce) providing a measure of the individual's social role.

2.1.2 Omission of Quality of Life Component

Some authors feel the most egregious omission in the ICF is the lack of a quality of life category (104). Even at this time, there is no mechanism to include a subjective assessment from the individual with a disability. WHO supports a broad interpretation of quality of life defined as "the perception of individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"(110). An optimum quality of life is not dependent on the fact that an individual would be without any medical conditions (62). A mechanism to incorporate an individual's assessment of his or her own quality of life would provide a more complete measurement of disability.

2.1.3 Influence of Contextual Factors

More work is needed regarding a uniform understanding of the contextual factors, e.g. environmental and personal factors, which may influence the domains of the ICF. Research regarding the role of environmental barriers and participation is relatively sparse and indicates that the relationship is not as unidirectional as believed. Whiteneck (2006) reviewed several studies and concluded both negative and positive correlations were noted between environmental barriers and participation suggesting multiple factors at work (104). Regarding personal factors, current studies rarely go beyond demographic measures (104). The reluctance to venture into areas of personality, psychology, motivation or compliance may be related to the fear of returning to a medical model of disability where problems are blamed on the individual rather than society and/or environmental surroundings (104).

2.1.4 Model Testing and Evaluation

The ICF model as it exists has, as yet, not undergone rigorous testing (10,45,104). It has been available for just a few years and has not been accompanied by tools to help standardize its use. Once tools are developed, they could be validated and then applied to different populations to determine generalizability. In order to be useful beyond just framing a classification system, the model should also provide information for designing interventions and policy to increase the involvement of persons with disabilities in life activities.

The breadth of consideration of external and social factors as contributors to disability is appreciated despite remaining concerns about the utility of the system for classification and enumeration purposes. The addition of domains such as quality of life or intent/desire for activity would certainly enhance the model and should be considered in future revisions. No doubt, the context of disability will continue to evolve as additional research is conducted. However, at this time, the ICF model offers a solid framework with which to investigate work-related disability associated with cancer treatment and recovery (4,11,12). It provides a comprehensive structure by acknowledging the biologic and social (including environment) aspects surrounding the individual (10,62). Furthermore, personal factors as Verbrugge and colleagues recommend are included. Therefore, the ICF's adaptation of a biopsychosocial model and its' inclusion of contextual factors will be used to structure the activities of this investigation.

Despite the concerns raised regarding the ICF conceptual model, the benefit comes in the form of a method to standardize the notion of disability. Currently, authors use the term "disability" without explicitly stating which domains, activity limitation, participation restriction, both or neither, they include in their assessment. Disability rates reported in literature vary widely yet it remains unclear if the variation reflects a real difference in how individuals are affected by some pathology or rather simply a difference in what the researchers considered "disabled."

Since this study is interested in physical and cognitive work-related disabilities according to an ICF definition that requires activity limitation with participation restriction, the literature will be arranged as follows. First, the common untoward effects of cancer and its treatment that affect and limit physical or cognitive activities will be described. Then, the participation of persons with cancer in the labor market will be reported.

2.2 Domain 1: Activity Limitations Associated with Cancer

This section will review common side effects associated with cancer treatment. The goal of this section is to give an overview of the nature of adverse events patients experience due to treatment that may impact an ability to work.

Cancer is among the top ten conditions causing activity limitation despite its' relatively small prevalence compared to other chronic conditions (40). Cancer related limitations currently occur in greater number than limitations resulting from visual and hearing impairments or cerebrovascular disease such as stroke (2,40). Even with early-stage disease, current treatment protocols are more aggressive thus expanding potential for limited activity. As a result of the increased five and ten year survival rates for most cancers, over ten million Americans with a cancer history are in the population (57). Therefore, it is reasonable to anticipate the number of cancer-associated activity limitations will increase as the overall number of persons diagnosed and treated increases. However, the presence of activity limitations in conjunction with social role participation is not as fully documented.

2.2.1 Physical Activity Limitations

Literature describing general physical functioning is available and has documented variables such as age, comorbidity, treatment and symptoms to be associated with decreasing function secondary to a cancer diagnosis (125). Furthermore, recovery of function has been shown to be influenced by cancer site and treatments as well (126, 127). What has not been as carefully

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The literature on general physical functioning is not always comparable in terms of study population or specific environment in which tasks are being assessed (125, 126, 127). The inclusion of participation with work outcomes is more limited since existing literature frequently describes older cohorts that have typically left the work force (17, 23, 24, 125, 126, 127). While broad categories of physical tasks may be replicated among studies, for example, lifting heavy loads, the setting (i.e. the workplace versus the home environment) may include other features that determine whether or not this presents as an activity that is limited.

Specific impairments attributable to a cancer diagnosis and associated treatment vary. Research regarding the nature of “cancer disabilities” has often focused on physiological limitations (i.e. activity limitation) and measured this in terms of impact on activities of daily living (i.e. participation restriction) or quality of life (17,31,32). We now focus on the specific treatments used for breast or prostate cancer and the untoward effects these may have on other aspects of life.

2.2.1.1 Physical Activity Limitations Associated with Cancer Diagnosis and Treatments

Surgery is one treatment option for prostate and breast cancers. Unfortunately, patients often complain of a variety of symptoms after undergoing this treatment. Since the surgical sites are different, the side effects are obviously different. Women with breast cancer often complain of lymphedema (swelling), heaviness, tightness, numbness and stiffness with the arm on the side of surgical intervention (17,31). These symptoms are often more prevalent in the year following treatment but a significant proportion, 40%, continue to describe these effects five years later (17). Men however, report sexual and urinary dysfunction after undergoing surgery for prostate cancer. Urinary incontinence is one of the most common complaints and certainly may interfere with ability to work (32).

Both cancer diagnoses may also be treated with adjuvant therapy including radiation and chemotherapy. These therapies are not without their own untoward effects including anorexia, fatigue, and bowel dysfunction including diarrhea, urgency or bleeding (35). All these conditions have the capacity to adversely affect an employee's presence at or performance of their job. Additionally, many women and men report pain after undergoing cancer treatments.

2.2.1.2 Physical Activity Limitations Reported in Literature – Breast Cancer

As mentioned earlier, surgery as a form of breast cancer therapy is not without side effects. Axillary node dissection accompanying surgical therapy may result in chronic chest wall/axilla pain or lymphedema that can be "disabling" (15,57). Kitamura and associates (2005) projected the number of breast cancer patients in Japan that would suffer disability from surgery in their article (15). Of note is the fact that the age-standardized incidence of breast cancer in Japan is less than Europe or North America, 24.3/100,000 in Japan vs. 103.7/100,000 in non-Hispanic white women in Los Angeles (15). Even among this population at lower risk, the estimates of women with disability due to chest wall pain between

2000-2020 range from over 42,000 to 72,500. Similarly, the number of women expected to report disability due to lymphedema is not trivial, 22,400 in 2000 and 38,600 in 2020 (15).

Limitations of this analysis include the inability to account for improvements in cancer treatment over time or institution of new methods to minimize these adverse effects. The authors estimated cases of breast cancer, proportion of surgical operations, frequency of associated disabilities and crude survival rates to build their models (15). Furthermore, duration of disability was not incorporated into their model. Also, while this article refers to "disability", the ability to quantify how many of these women would end up with limited activity and in turn, a reduced ability to participate with their job is limited.

Upper body tasks have been documented to be especially problematic for women following breast cancer treatment (17). Hayes and associates (2005) asked a sample of women about the frequency and physical demand of 48 daily tasks requiring upper body function. These authors used factor analysis to confirm the general nature of activities that were difficult. Whole body, flexibility, carrying/upper-body strength, hand and weighted flexion tasks were reported to be most burdensome (17). Lymphedema and poor fitness were associated with reports of difficulty.

As with many of these studies, the authors relied on a cross-sectional design and included a convenience sample of respondents to a mailed survey that achieved a response rate of 63%. Of these responses, less than 50% were complete. Time since diagnosis ranged from 0-45 years. The tasks that were incluc

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included in the survey were predominantly activities of daily living (ADLs) or instrumental activities of daily living (IADLs). Activities directly related to possible work environment demands were omitted. Finally, these authors did not collect data regarding potential confounders such as education, income, or comorbidities.

As indicated by the prior literature, lymphedema and restricted shoulder abduction subsequent to surgery are acknowledged to be the primary contributors to breast cancer disability reports (28). Voogd, et al (2003) provide evidence that these clinical conditions are not necessary to confer disability. They measured arm circumference and shoulder abduction in a cohort of consecutive women undergoing axillary lymph node dissection (24). As anticipated, patients with a difference in arm circumference of >2 cm or a 20% reduction in shoulder abduction reported severe physical complaints and limitations in tending to daily chores. However, more than 15% *without* these physical signs also reported adverse conditions as well as moderate to severe pain. This research provides rationale for an inclusive approach to investigating the untoward effects of treatment even in the absence of clinically apparent risk factors.

McWayne and Heiney (2005) conducted a review of the psychological and social sequelae of lymphedema (29). The authors reported pain was a significant predictor of morbidity resulting in compromised quality of life. They note the lack of research focusing on disadvantaged populations and call for additional efforts to describe baseline data. Reitman and colleagues (2004) also focused on shoulder impairments and quality of life and confirmed pain was associated with disability and to a lesser degree, poorer quality of life (28).

Ganz and associates (2002) conducted one of the few longitudinal studies on a breast cancer cohort (30). They took advantage of a cohort assembled for an earlier study by inviting women who had survived at least five years without recurrence to participate in a mailed survey. A response rate of 61% was achieved with responders being predominantly white, better educated and with higher income. Eighty percent of these respondents reported no change in employment status although younger (<60 years at diagnosis) patients reported negative impact on work life or career and financial situation (30). Current physical and emotional well-being and age exerted the greatest impact (30). These authors attributed changes in physical function noted among some respondents to normal age-related changes. Limitations of this study included a modest response rate and the restriction to two urban areas. Furthermore, with respect to work-related disabilities, the authors did not specifically focus on tasks required by an individual's job.

2.2.1.3 Physical Activity Limitations Reported in Literature – Prostate Cancer

Literature focusing on the experience of prostate cancer patients is limited compared to reports regarding breast cancer. Prostate cancer treatment may result in urinary dysfunction as a result of surgical intervention. Additionally, radiation therapy has been associated with bowel dysfunction. Although these sequelae may reduce quality of life and potentially interfere with work activities, Giesler and colleagues (2005) report these untoward effects may be amenable to intervention (21). Patients enrolled in the intervention arm of a randomized clinical trial reported moderate improvements in urinary bother over control patients. If urinary bother had presented as a disability for participants, the evidence that improvements were attainable offer hope that the disability could be reduced. These authors did report some limitations in the power of their study as well as a relatively low participation rate.

Watchful waiting is a viable option for older men diagnosed with prostate cancer. The side effects of treatment associated with surgery and radiation may be too much burden for a man who experiences a localized cancer that is asymptomatic. Steineck and colleagues (2002) compared quality of life measures in men randomized to surgery and watchful waiting (34). These researchers documented statistically more frequent urinary leakage in the surgical group however less frequent urinary obstruction with weak voiding stream. Both conditions may influence ability to carry out work-related tasks and suggest that "no" treatment may contribute to disability as well.

2.2.1.4 Physical Activity Limitations Reported in Literature – Cancer Site Not Specified

Increasing emphasis on cancer related disability accompanies the transition of cancer to a chronic condition. Ness and colleagues (2006) used the 1999-2002 National Health and Nutrition Examination Survey (NHANES) to evaluate physical performance limitations in recent and long-term cancer survivors (1). They also compared the experience of these survey participants with those with no history of cancer (based on self-report). These investigators defined a recent cancer survivor as an individual with less than five years since diagnosis (1).

Physical performance limitations were statistically significantly more prevalent in the respondents with cancer compared to those without cancer regardless of duration since diagnosis, greater than 50% versus 21%, respectively (1). The nature of the limitations most frequently cited included sustained muscle activity (walking ¼ mile or standing two hours) or large whole body movements (e.g. stooping, crouching, lifting, etc). No work specific activities were included in the range of examples for respondents.

Individuals with a recent diagnosis experienced greater activity limitation than those with distant diagnosis. These analyses reported inverse relationships between income and activity limitation while a positive correlation was noted between age and this outcome. These patterns support the relationships between advancing age and greater disability reported in general disability literature as well as the association of persons with fewer social resources or lower socio-economic status experiencing greater disability rates than persons with more resources or higher socio-economic status.

Several limitations of this study were the cross-sectional design and the inability to control analyses for cancer treatment. The population-based nature however was important to provide preliminary estimates of the proportion of persons with a positive cancer history experiencing activity limitation. Ness (2006) however, did not present disability according to the definition suggested by the ICF framework. Although activity limitation and participation restriction were reported, an assessment of the proportion of individuals who had both conditions simultaneously is absent from the analysis (1).

2.2.2 Cognitive Activity Limitations

Several researchers emphasize the importance of understanding cognitive functioning because of the increasing numbers of persons diagnosed with cancer and the potential impact of cognitive dysfunction on education, career and quality of life. Cognitive dysfunction is garnering attention as patients complain of "chemo brain." This phenomenon has been described by patients as an inability to maintain attention or remember things (112).

2.2.2.1 Cognitive Activity Limitations Reported in Literature – Breast Cancer

Silverman and colleagues (2006) demonstrated differences in brain region activity during short term recall tests between patients who had undergone chemotherapy 5-10 years prior and those who did not (112). The chemotherapy group scored 13% lower on average than the non-chemotherapy group during short term memory tasks although results were not statistically significant. However, the association of chemotherapy and lower recall test score followed the trends identified in a larger cohort studied by these same investigators in which the difference in test scores was statistically significant (112).

Other studies documented a majority (75%) of breast cancer patients undergoing systemic chemotherapy experienced lower scores in memory and concentration within six months of treatment (38,109). In addition to short term impacts, some reports document a cumulative effect of chemotherapy lasting for years

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years after the acute phase. Van Dam, et al (1998) demonstrated greater cognitive impairment in women undergoing high dose chemotherapy compared to standard-dose chemotherapy. Women receiving the standard dose regimen in turn had greater impairment than women undergoing local treatment only. Women included in this study averaged two years post-treatment (113).

Ahles and colleagues (2002) focused on neuropsychologic impact in their report (38). They compared cognitive dysfunction in women who received systemic chemotherapy to women who received local therapy (surgery or radiation) and were more than five years post diagnosis. The average time since diagnosis for their cohort was ten years and even for this duration, women undergoing regimens including chemotherapy scored significantly lower on global cognitive scores than women receiving local therapy. These researchers also adjusted for potential confounders including age and educational level and these patterns persisted.

2.2.2.2 Cognitive Activity Limitations Reported in Literature – Prostate Cancer

The literature reporting cognitive effects among prostate cancer patients is not well established. The science presented among the breast cancer cohort suggests the adverse effects occur subsequent to chemotherapy. Since men may receive chemotherapy to a lesser degree in the treatment of prostate cancer, perhaps this adverse effect is not as significant in this group. Even among women, cognitive dysfunction has not been completely described yet. However, thorough comprehension of this experience is necessary so that patients may make informed decisions regarding treatment decisions and rehabilitation approaches may be designed.

2.3 Domain 2: Participation Restriction Associated with Cancer

Ness and colleagues (2006) also evaluated participation restrictions in addition to activity limitations among recent and long-term cancer survivors in the study referenced earlier (1).

Participation restrictions followed similar patterns as activity limitations with persons having a positive history of cancer experiencing more restrictions than those without a cancer history, 30% compared to 13% respectively. Activities requiring sustained participation (e.g. shopping, movies, sporting events) were again most problematic. No work specific activities were included in the range of examples for respondents.

Similar with activity limitation, individuals with a recent diagnosis experienced greater participation restriction than those with distant diagnosis. These analyses reported inverse relationships between income and participation restriction while a positive correlation was noted between age and participation restriction. These patterns support the trends provided in general disability literature.

Although both domains deemed necessary by the ICF model were reported in this study, Ness did not discuss the sample that represented the intersection of these domains, that is, those with activity limitation *and* participation restriction. Furthermore, since the ICF model is relatively recent, the literature specifying activity limitation in conjunction with participation restriction is not as readily available.

This study attempts to contribute to the scarcity and is focused on activity limitation with participation restriction. Moreover, the environment of interest is the labor market. Therefore, literature regarding the employment experience of cancer patients is presented in the next section.

2.4 Employment Experience of Cancer Patients

A review of the literature focused on the employment experience of cancer patients follows. Outcomes of included studies did not necessarily identify an outcome of "disability." This information is provided to provide a background against which the disability measure of the present study may be contrasted.

Twenty years ago, employed persons diagnosed with cancer often faced discrimination. Cancer was a debilitating illness with fatal outcomes. Hoffman (2005) documented concerns regarding lost profits and productivity by insurers and employers (13). In response to prejudicial hiring and employment practices, state and federal legislation such as the ADA, the Federal Rehabilitation Act, the FMLA and the Employee Retirement and Income Security Act were passed to protect workers. Increasing advocacy by patients themselves also promoted additional flexibility in medical care schedules (13).

2.4.1 Return to Work for Cancer Patients

Patients historically and currently report the desire and ability to return to work after treatment (13). More than thirty years ago, over 75% of employees of

Bell Telephone diagnosed with cancer returned to work after diagnosis and treatment (117). Moreover, a majority of patients remain in the workforce beyond five years. Bradley and Bednarek (2002) reported 67% employment 5-7 years after diagnosis among a cohort of individuals with varying cancer diagnoses (66). A cohort of young women with breast cancer reported similar employment rates at diagnosis and five years after diagnosis per Bloom (13,118).

A variety of factors can impact work force participation including physical, psychological and social factors (3). These same factors can also influence the decision to remain at work or return to work after cancer treatment. Age, cancer stage, financial status, education, health insurance, transportation access, physical demands of job and comorbid conditions have been identified to be significantly associated with return to work (13). A variety of psychological benefits such as empowerment and maintaining a sense of normalcy and control also contribute to the decision to return to work (13,66).

Health care providers may also influence decisions regarding return to work indirectly. They may assist the patient to develop reasonable expectations of the course and potential side effects of treatment and anticipated speed of recovery (3). Similarly, the workplace itself plays a substantial role in attempts to return to work. The response of the employer to an employee's medical challenge may support or derail the individual's motivation. A supportive, pro-active environment dedicated to assisting the patient to return to work has been identified as a beneficial item. Spelten and colleagues (2002) conducted a literature review to identify factors associated with return to work of cancer survivors (36). They confirmed the negative relationship of a non-supportive work environment with return to work.

In a prospective study, Spelten, et al (2003) identified lower fatigue levels as a predictor of return to work at eighteen months (65). This association was independent of diagnosis or treatment but not of other cancer symptoms. This suggests that adequate symptom management may promote workforce attachment.

2.4.2 Work Limitations Reported by Cancer Patients

Although they express the desire to return to work, some cancer patients acknowledge a limitation in their ability to continue as evidenced by Yabroff and associates' (2004) analysis of the 2000 National Health Interview Survey (60). Working-age respondents with cancer experienced three times the inability to work compared to matched controls, 16% vs. 5% respectively (13,60). Sasser, et al (2005) identified a cohort of employed women with breast cancer and compared their direct medical costs and imputed lost productivity costs to a cohort of employed women without the diagnosis (14). The cancer group missed significantly more days due to medically related absenteeism than the control group, 42 days and 15 days, respectively. The work-loss costs for the cancer group was estimated $5900 greater than the control group, a statistically significant amount.

Estimates of limitations at work hover around 20% for most tasks according to earlier studies. Short, et al (2005) evaluated work-related disability in a cohort of employed persons with a variety of cancers (19). Their study was mostly descriptive and followed up patients from 1-5 years post-diagnosis. Participants were asked retrospectively about disability and if reasons for quitting work were related to cancer. While the overall results documented 20% disability, neither the breast nor prostate cancer sub-samples had statistically significant disability. The authors reported 21% and 16% of women and men, respectively, experienced limitations due to cancer (19). Recall bias may be an issue for participants in this study due to the retrospective nature of the investigation.

The belief is that cancer exerts a greater impact on physical tasks over mental tasks (13). Bradley's (2002) results support this assertion with just 11% describing limitations in cognitive skills while 18% reported limitations in physical tasks (66). Spelten, et al (2002) also supported the belief that physical demands are more compromised than cognitive demands by describing a negative relationship between return to work and manual labor (36).

Greenwald et al (1989) published on work disability in cancer patients and used both job attachment and level of function as measures of disability (71). Patients diagnosed with prostate cancer were included in this study along with patients diagnosed with lung, pancreatic and cervical cancer. Among this cohort, physical demands of work predicted work function disability to a significant degree although prostate cancer was not significantly related to either employment or function outcome. Socio-demographic factors were not statistically significant predictors of either outcome.

In contrast to Greenwald's study, Schultz, et al (2002) documented that socio-demographic variables, e.g. age, gender, ethnicity, as well as cancer type did impact working status (84). Eligible participants were recruited from a major cancer treatment center with diagnosis at least five years prior to recruitment. Breast cancer patients were included in the overall cohort although the study was not powered for this cancer type specifically. This subgroup did experience a statistically significant reduction in employment at follow-up.

2.4.3 Labor Market Outcomes of this Study Population

Bradley and colleagues have published several papers on the cohort that will be used for the proposed study (49,52,53,82). The overarching topic of these papers has revolved around workforce attachment issues rather than investigating the disability associated with the disease and treatment and how it evolves over the duration of the follow-up. They demonstrated in their 2004 work that compared to a control group assembled from the Current Population Survey, women with breast cancer were 17% less likely to work six months following diagnosis with the exception of women diagnosed with in situ cancer (52). Moreover, this effect was noted to vary based on race with minority participants experiencing twice the consequence. Women who remained in the workforce at six months worked seven fewer hours per week than the control group.

Likewise, a 2005 article described the prostate cancer cohort experience; a ten percent reduction in employment at six months compared to a similarly constructed control group (53). Employment was evaluated at twelve months with the finding that many men had returned to work at this time. Some descriptive analysis of twelve-month activity limitation was included in this report for these patients although further analysis of predictors of disability or the nature of change between twelve and eighteen months was not undertaken (53).

Bouknight, Bradley and Luo (2006) investigated correlates of return to work for the breast cancer cohort identified for the proposed study (49). This analysis validated the importance of the employer on decisions to return to work. Perceived employer accommodation was positively associated with return to work at twelve and eighteen months after diagnosis while perceived employer discrimination was negatively associated with return to work at twelve months (49). The critical distinction between this analysis and the proposed study is the outcome variable, return to work versus work-related disability.

2.5 History of Disability Models

A review of the evolution of disability models is presented in this section for the interested reader. Consensus regarding the definition and the concept of disability remains elusive. Disability is used interchangeably with terms such as handicap, impairment or sickness. Sixty-seven different laws offer varying definitions of disability in federal regulations (8,95).

Older theories relate disability to dysfunction of body or organ systems or some underlying biologic issue. These theories were framed as medical or bio-medical models. These models generally predominated pre-1960s, although some still persist. The underlying pathology, be it a result of illness or injury, requires medical care provided by trained health care professionals (8,62). Disability is viewed as a problem of the person with goals of treatment to cure or minimize subsequent pathology. Take as an example, an individual working as an accountant sustaining a spinal cord injury resulting in lower limb paralysis. While cure is not an option, medical treatment would be necessary in order to minimize complications such as pressure sores or pneumonia. Interest in the person's "function" is largely restricted to the physiologic functions of the body, e.g. maintaining good skin integrity and clear lungs. Minimal efforts are expended on other activities, such as social functioning, of the individual.

Interest in rehabilitation began to swell during the 1960s and 1970s (61). Popular advocacy began to promote integration of persons with disabilities into society and to reduce institutionalization or segregation that had been the predominant disability management technique. This advocacy coincided with development of alternative models of disability. Dr. Saad Nagi was one of the first to pay attention to the functional aspect in the disability process (104). He stated "disability is the expression of a physical or a mental limitation in a social context." (128)

Nagi's disablement model distinguished the environment as an entity apart from the individual that could be studied and felt that disability represented a "gap between the person's capabilities and the demands created by the social and physical environment."(61, 92, 128, 129) This led to the expansion of disability theory into models that focused on "...limitations in physical or mental functions, caused by one or more medical conditions, in carrying out socially defined tasks or roles." (8,92) Nagi supported the idea that an impairment or activity limitation does not automatically confer disability, including work disability and he focused on three factors that contribute to but are distinct from disability: active pathology, impairment and functional limitation. Active pathology referred to a disturbance in the normal cellular mechanisms of a body. Impairment was then defined as an abnormality at the tissue, organ or body system level. Finally, functional limitation incorporated restrictions in the performance of the person (129).

A person's role was acknowledged to be multi-faceted thus integration could occur on different levels. For persons 18-65 years of age, which is the age group that roughly corresponds with the study population of this investigation, the "normal" social role would be as a student or working individual (61). Integration areas would reasonably be assumed to be higher education and/or a work setting. According to the social role framework, the treatment of the hypothetical person with the spinal cord injury would be to minimize physical sequelae of the condition *along* with attempts to return that individual to their position as an accountant. Theoretically, the fact that the person is reliant on a wheelchair for mobility should not interfere with the normal daily activities of an accountant that may include writing, key-stroking, reasoning, performing calculations, etc.

Unsuccessful attempts to position persons with disabilities within their usual social milieu supported Nagi's thesis that obstacles beyond the person's biologic dysfunction contributed to disability. Prior to the contemporary acceptance of telecommuting, the accountant would be unable to return to his/her position if he could not physically enter the office. There could be impediments to transporting himself between home and the office, the office building or the physical layout of the office might not be wheelchair accessible.

Therefore, because of environmental constraints, he would be unable to fulfill his usual social role.

Over time, researchers began to appreciate the existence of environments beyond the physical structure. This realization led to the further evolution of current disability theories that began to include social *interaction*, rather than social *role*, as a component of disability (62). Verbrugge and Jette (1994) expanded on the work of Nagi during the 1990s with the Disablement Process (50, 129). Their model incorporated elements of pre-existing risk factors (such as biological factors), and behavior and attributes (50,129). They identified both intra-individual (e.g. lifestyle, coping skills, psychosocial attributes, etc) and extra-individual (rehabilitation services, medications, social support, physical environment, etc) factors that could increase or decrease the risk of disability (41,50,104). Accordingly, perceptions of the individual and others around him/her could accelerate or slow down the path between pathology and disability (41).

These expanded theories essentially focused on two factors that could result in a disabled condition, activity and participation (8). Activity, or the actual performance of some task, is a necessary consideration for disability. Simply because the legs do not work does not necessarily mean the accountant is disabled since he can perform his work. His work activity need not be restricted or limited as a result of his physical condition. The second critical concept is participation within some environment (8). For example, our accountant is capable of the task yet unable to perform it because he cannot access the built environment surrounding his office. Inaccessibility is merely due to the fact that building norms rely on multi-story construction. In essence, he is not disabled but rather, society has placed him at a disability.

While the progression from a solely biological model was largely positive, some advocates supported the social construct to the exclusion of biology. These individuals argued that disability was a social phenomenon used to oppress individuals that were different (10,106). Despite the best intentions of these proponents, failure to include the biologic components of disability operated as a disservice to persons with disability. Not recognizing the biology underlying a physiologic dysfunction eliminates incentives to invest in medical research or develop new prevention and/or treatment strategies. Therefore, models failing to acknowledge all contributing facets of life offer nothing more than incomplete assessments of a disability concept. Deficient appraisals then result in imprecise recommendations or solutions to problems associated with disability.

WHO published their original classification system entitled *the International Classification of Impairments, Disabilities, and Handicaps (ICIDH)* in 1980 as one of the first attempts to define and enumerate disability (107). Although lauded for the effort to provide a systematic method to track disability worldwide, it was criticized for the heavy reliance on the medical framework despite the inclusion of social role fulfillment.

According to the ICIDH, the focal point for determining disability was the limitation(s) of an individual (9,10). Impairment was defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (107). Impairment led to disability via a unidirectional pathway. Disability was defined as "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (107). Finally, disability could result in handicap. Handicap was defined as "a disadvantage for a given individual, resulting from impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" (107).

Despite mounting awareness of the influence of environment on conferring disability, the first classification system had failed to incorporate this element. As Figure 3 shows, the root of disability remained with the individual and the pathologic condition rather than some combination of pathology and environment. Critics charged that another significant omission was the failure to "acknowledge the presence of social barriers in influencing disability" (10,108). Social barriers included a variety of conditions from a lack of public transportation that was accessible to an individual in a wheelchair to the failure of agencies to provide TTY/TDD service. A further criticism was that the terminology used was pejorative in nature, i.e. handicap (Figure 3).

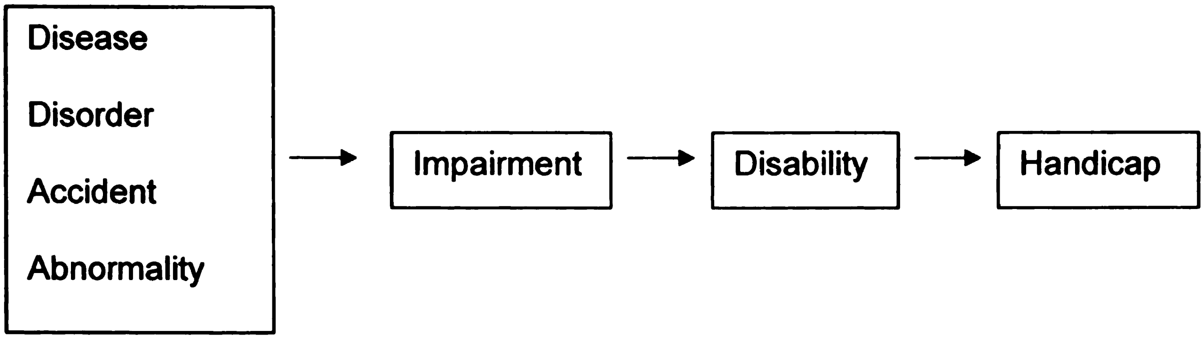


Figure 3: International Classification of Impairments, Disabilities, and Handicaps Linear Structure of Consequence of Disease

Considering the participants in this study, this earlier version of a classification system is less flexible than the ICF model. If the subjects were unable to carry out their activities "normally" because of some impairment arising from their cancer treatment, they would be considered disabled. This system appears to emphasize activity limitation as the major determinant of disability. The notion of participation restriction may be more closely aligned with the "handicap" terminology. However, this model does not allow for someone to receive help or accommodation with a particular task which may essentially move them back along the continuum so they are no longer considered disabled. It also fails to explicitly show the importance of other characteristics such as personal or environmental factors that can influence the expression of disability.

In recognition of the importance of a broader context, WHO spent nearly a decade revising the ICIDH and released *the International Classification of Functioning, Disability and Health (ICF)* in 2001 (62). Perhaps as an attempt to distance the new classification system from the earlier version, the ICF advocated "the presence of impairment does not necessarily indicate that a disease is present or that the individual should be regarded as sick" (62).

Details regarding the ICF have been presented in Section 1.1. However, as has been discussed, the interpretation of disability continues to generate discussion. Valid criticisms of the ICF have been published and key issues are currently omitted from the ICF (e.g. quality of life or will/intent to carry out some activity). Tools to assess various domains of the model are not yet available. The field of disability is still relatively young and tremendous opportunities exist to contribute to the theoretical foundations. It will be interesting to observe the nature of ongoing evolution.

2.6 Literature Review Summary

The main research questions included were: the prevalence and direction of disability change over time, the degree to which prevalence estimates varied using two common disability definitions, and evaluating the association of contextual factors on disability. The contextual factors included personal factors such as socio-demographic variables (e.g. race, income) and disease-related variables (stage, treatment). Environmental factors included employment-related variables (e.g. physical nature of job, occupational category and job satisfaction). This study will discriminate between physical disability and cognitive disability.

2.6.1 Prevalence and Direction of Disability Change

The literature presented has discussed short and long-term disabilities associated with cancer diagnoses. Hayes and colleagues (2005) reported mostly physical disabilities in patients 0-45 years beyond diagnosis. Ness, et al (2006) documented more physical disabilities in cancer patients compared to a population of non-cancer individuals both within 5 years of diagnosis (short term) and beyond 5 years of diagnosis (long term). Moreover, Ness provides one estimate of the change in disability over time by noting a decrease in reported physical disability in those with a recent diagnosis compared to a more distant diagnosis. Silverman, et al (2006), van Dam, et al (1998) and Ahles and colleagues (2002) also documented cognitive disability in women undergoing chemotherapy for breast cancer.

A common difficulty with all these studies is the lack of definition provided for the term disability. The reader cannot be certain what aspect(s) of disability are being assessed. Activity limitation appears to be a driving force for a majority yet the authors infrequently explicitly describe their outcome variable. Moreover, these studies were cross-sectional in nature and were unable to document the change in disability over the same sample. Finally, several of these studies failed to collect data on potential confounders such as education or income. This study however, defines the outcome of interest and includes collects data on a number of potential confounders collected at multiple timeframes.

2.6.2 Comparison of Disability Estimates using Two Definitions

Disabilities associated with cancer diagnoses are fairly widely reported in various sources yet the prevalence estimates vary. Inconsistencies in estimates may be valid due to real differences in cancer sites or populations under study. However, the failure of many authors to clearly describe what characteristics make up their “disability” variable prevents the reader from evaluating to what degree changes in estimates may be real. This study will report disability prevalence estimates on the same population using two definitions. This comparison will illustrate to what degree a change in definition may impact results.

2.6.3 Association of Contextual Variables with Disability

Analysis of BRFSS and census data provide evidence of associations between personal factors (such as socio-demographic characteristics) and disability. White and Asian-Americans experience less disability than all other racial groups. Furthermore, disability is often correlated with poverty and low education. However, the direction of influence regarding these variables is not well-established. Conversely, some authors including Greenwald, et al (1989) fail to document an association of disability with socio-demographic factors. This study will contribute by giving some evidence of the evolution of disability among different groups.

Various disabilities have been documented in persons diagnosed with breast cancer and Ahles and colleagues (2002) documented greater disability in women undergoing chemotherapy compared to women having localized treatments. However, no literature discussing the impact of chemotherapy on men with prostate cancer was available and therefore any association remains unknown. This study takes advantage of SEER data as well as patient report to obtain a comprehensive overview of all therapies received for each individual’s diagnosis. Specific attention on the relationship between these variables may provide some preliminary estimates for men.

The second type of contextual factor is environmental. Regarding disability and work demands, Bradley, et al (2002) and Spelten and colleagues (2002) report greater limitations with physical tasks and manual labor compared to cognitive tasks. This study contains data regarding specific physical or cognitive tasks and will be able to examine if these patterns hold for these participants and if/how they evolve over time.

2.6.4 Additional Contributions of Proposed Study

Research regarding the nature of cancer-related disabilities has often focused on physiological limitations and is measured in terms of impact on activities of daily living and quality of life. This study will expand the environment of the patient to include a work setting. By examining factors associated with employment, this also provides a younger-aged cohort than that usually targeted for these particular cancer sites.

Available data permits the focus on the time period beyond the acute treatment phase when adverse effects of therapies may be maximized. Participants were followed at twelve and eighteen months post-diagnosis. This study would provide some sense of the longer term adverse effects of breast and prostate cancer on the ability to maintain pre-diagnosis employment patterns.

Ultimately, this study will contribute to the topical areas currently being emphasized nationally. The National Cancer Institute has identified priority cancer survivorship topics (58,63). Bradley (2005) notes effects of treatment options on work-related measures are absent from most electronically available cancer information sites (22). Steiner and colleagues (2004) argue "more and better research on the work impact of cancer is necessary to inform the decisions of cancer survivors and their treatment providers" (58). Employment matters, such as potential for disability with job functions, are key to the topic of "chronic and late effects of cancer and its treatment" (63).

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Human Subjects Review

The LMOS that served as the source study for this disability analysis was reviewed and approved by the Michigan State University and Wayne State University institutional review boards. Karmanos Cancer Institute also reviewed and approved the protocol followed for the study. Informed consent was obtained from all participants. The focus of this paper, the disability study, was submitted separately to the Michigan State University institutional review board and approved.

3.2 Data: Source Study Overview

This study is a secondary analysis of the LMOS. The following sections describe the characteristics of that source study along with participant recruitment and retention.

3.2.1 LMOS as Source Study

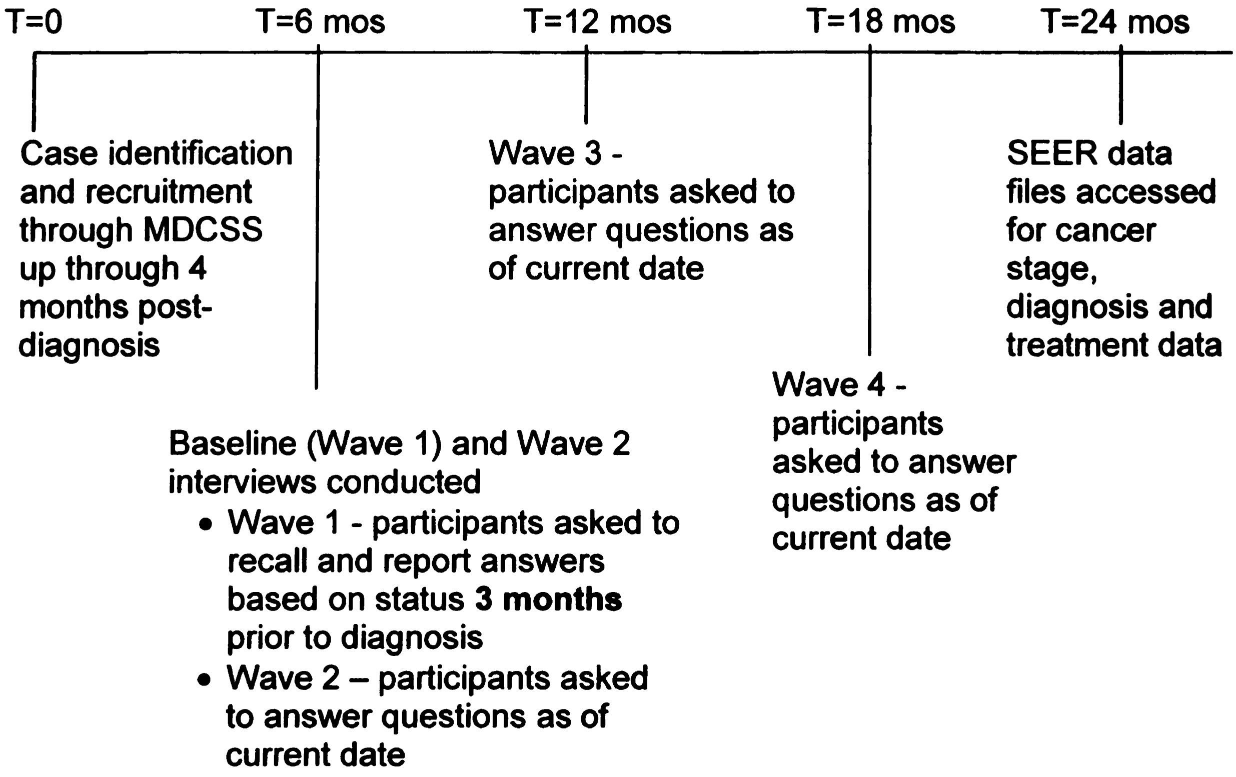
As mentioned earlier, the LMOS, PI: Cathy J. Bradley, PhD, NCI R01 CA86045-01A1, will serve as the information source for the proposed study. This study enrolled an inception cohort of women diagnosed with breast cancer and men diagnosed with prostate cancer. The goal of the LMOS was to investigate work force participation including hours worked and hourly wage of participants and their spouses as they moved through the diagnosis, treatment and recovery process of their condition. Sample size estimations were powered for these research questions.

The LMOS sample was drawn from the MDCSS, a participant in the National Cancer Institute's SEER registry. The MDCSS was chosen for several reasons including the high standards for its case ascertainment and reporting accuracy as a member of the NCI's SEER network. The location of the registry in Metropolitan Detroit also provides data on a greater African-American population than other registries. Eligible participants included those with newly diagnosed, incident breast or prostate cancer aged 30 to 64, English-speaking and employed or had an employed spouse at the time of diagnosis.

3.2.2 LMOS Subject Recruitment and Retention

Potential participants were identified through the MDCSS Rapid Reporting system that identified cases within four months of diagnosis. The four-month restriction was necessary in order to secure the provider and patient consents by the targeted six-month interview. Telephone interviews were conducted approximately six, twelve, and eighteen months post-diagnosis. However, the six-month interview also included a *retrospective* component that asked the participants about job characteristics three months before their diagnosis, i.e. the baseline interview. Subjects were offered a $25 incentive payment to complete the study. Nearly 500 (n=495) women and 300 (n=294) men enrolled between June 2001 and April 2002 resulting in recruitment rates of 83.2% and 76%, respectively. Figure 4 shows the timeline of the interview encounters throughout the LMOS. Time zero (T=0) refers to diagnosis date. The baseline (Wave 1) and

Wave 2 interviews were usually conducted at the same encounter. However, the time commitment for both interviews could exceed thirty minutes. Therefore, if the participant requested to postpone Wave 2 to another day, this request was accommodated.



Case identification and recruitment through MDCSS up through 4 months post-diagnosis

Baseline (Wave 1) and Wave 2 interviews conducted

- Wave 1 - participants asked to recall and report answers based on status **3 months** prior to diagnosis
- Wave 2 – participants asked to answer questions as of current date

Wave 3 - participants asked to answer questions as of current date

Wave 4 - participants asked to answer questions as of current date

SEER data files accessed for cancer stage, diagnosis and treatment data

Figure 4: Data Collection Timeline

Reminder notices were mailed to participants to remind them of the Wave 3 (twelve month) and Wave 4 (eighteen month) interview appointments. Efforts to maintain the interest of participants were successful as evidenced by the retention rates at both twelve and eighteen months, 92.5% and 89.6% respectively.

Refer to Figure 5 for the LMOS Breast Cancer Recruitment Flowchart.

The LMOS Prostate Cancer Recruitment Flowchart is displayed in Figure 6.

Figure 5: LMOS Breast Cancer Recruitment Flowchart

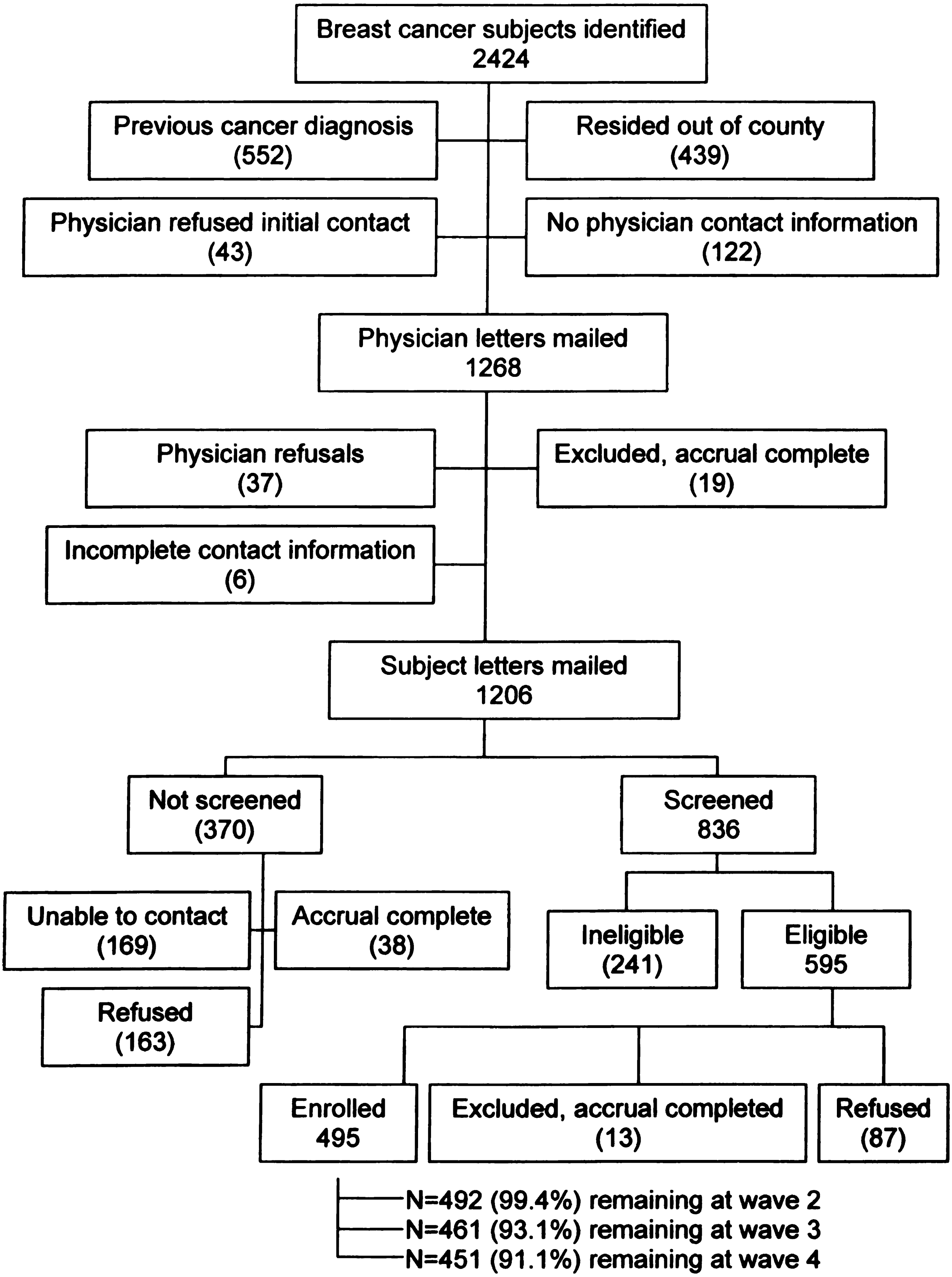
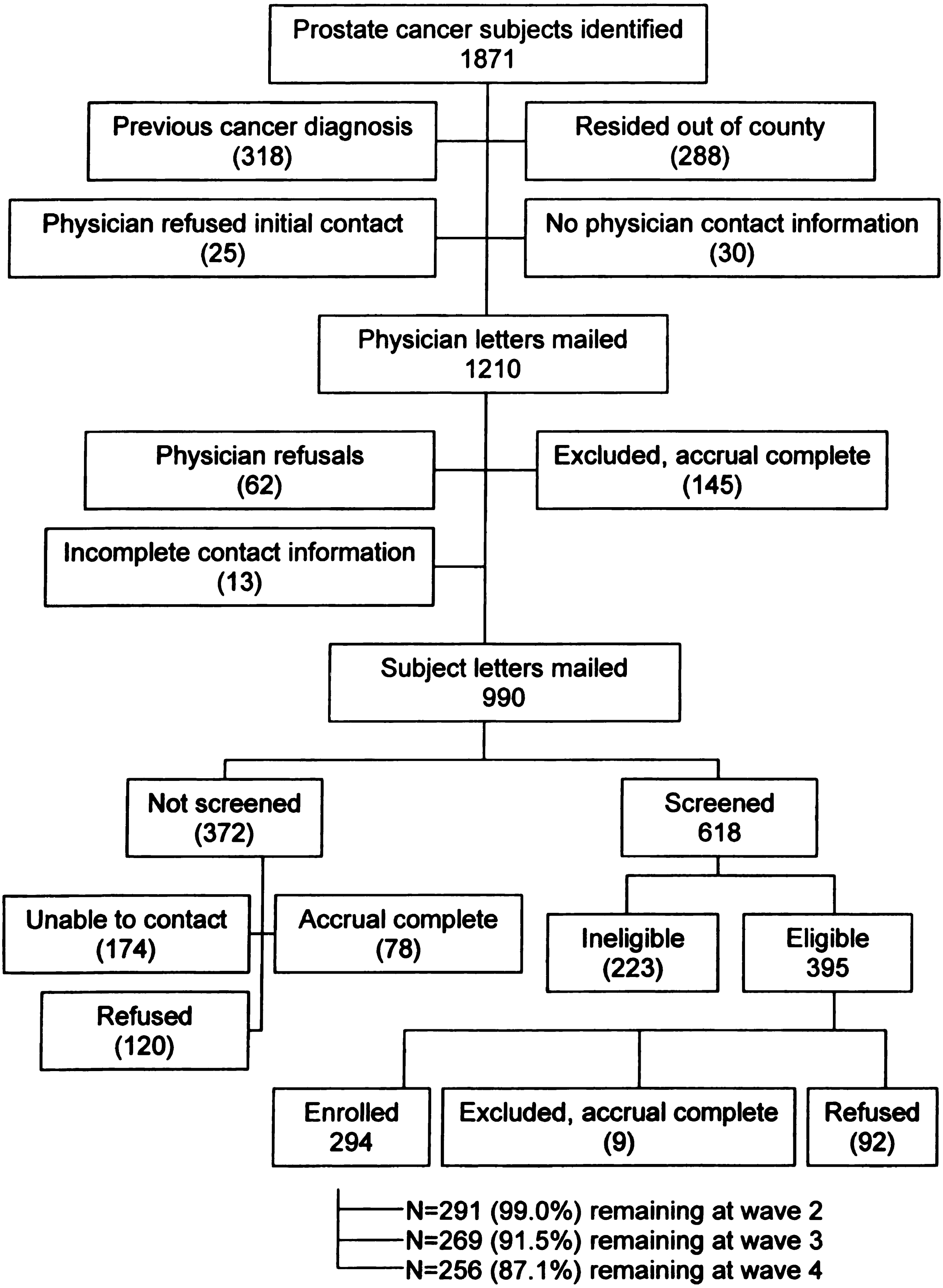


Figure 6: LMOS Prostate Cancer Recruitment Flowchart



3.2.3 LMOS Interview Subject Matter

The interview structure remained relatively uniform throughout the four interview waves of the study. The questions on work tasks and associated limitations were first asked during the Wave 3 (twelve month) interview. This timeframe was selected because most participants would have completed their treatments by this time and the acute effects of therapy might be avoided. The job task and activity limitation question wording is presented in Appendix A. Weekly hours worked and shift lengths were variables collected at all four waves so that comparisons at twelve and eighteen-months against baseline would be possible. Table 1 describes the nature of the interview variables that were included in the interviews and the waves in which the questions were asked.

Table 1: General Nature of Interview Variables Collected

Interview Data	Wave 1	Wave 2	Wave 3	Wave 4
Demographic				
Age	x			
Race/ethnicity	x			
Education	x			
Marital status	x	x	x	x
Children in home	x	x	x	x
General activity level	x	x	x	x
Perceived health status	x	x	x	x
Household income	x		x	x
Participant Employment				
Employment status and why	x	x	x	x
Weeks worked in past year	x			x

Table 1 (cont'd).

Hours worked per week	x	x	x	x
Why hours changed		x	x	x
Occupation	x	x	x	x
Employer description	x	x	x	x
Wages	x	x	x	x
Why wages changed		x	x	x
Retirement benefits	x	x	x	x
Sick leave benefits	x	x	x	x
Missed work due to treatment		x	x	x
Last worked	x	x	x	x
Break types and length	x	x	x	x
Shift length	x	x	x	x
Job satisfaction			x	x
Job discrimination			x	x
Job tasks			x	x
Task limitations			x	x
Treatment				
Count and type surgery		x	x	x
Chemotherapy		x	x	x
Radiation		x	x	x
Hormone therapy		x	x	x
Health Insurance				
Employer based insurance available	x	x	x	x
Who covered by insurance	x	x	x	x
Who carries policies	x	x	x	x
Available insurance coverage source	x	x	x	x
Covered by government insurance	x	x	x	x
Comorbidity			x	x

3.3 Data: Disability Study Subject Restriction

The disability study imposed additional eligibility restrictions upon the participants recruited for the LMOS study. This was necessary because of the focus on how work-related disability may present in these individuals.

Therefore, this disability analysis was restricted to participants that were working or not currently working but had a job at the baseline interview (Wave 1) and were retained at twelve and eighteen months. The interview first asked individuals if they worked for pay or profit. Those who stated they were not currently working were subsequently asked if they had a job either full or part-time. If they responded they did not, they were excluded from the study. If they did have a job, the reason for not working was assessed. Reasons for not working but having a job may include being on layoff or participating in seasonal jobs (i.e. a teacher not working during the summer months). If the participant stated they did not work at baseline because of a medical condition, they were excluded from the study. Individuals who reported they were retired, disabled or unable to work at Wave 1 were excluded from this disability study since the interest was in the possible development of work-related disability after the cancer diagnosis and treatment. These criteria left n=447 employed women in the breast cancer cohort and n=267 employed men in the prostate cancer cohort.

Overall retention rate for the duration of the study exceeded 85%. As other research has documented, retention among women was greater than that for men. The interviews conducted at twelve and eighteen months asked participants about job tasks, limitations and perceived employer accommodations regardless of their employment status at that time. Therefore, only the persons lost to follow-up between the baseline interview and the twelve and eighteen - month interviews were eliminated from analyses. This left 93% (n=418) of the targeted breast cohort retained at twelve months and 91.5% (n=409) retained at eighteen months. Slightly less, 91.0% (n=243) of men were retained at twelve months and 86.1% (n=230) were retained at eighteen months. Table 2 displays how the sub-samples of breast and prostate cancer participants, respectively, were categorized during follow-up periods. Shading indicates participants in this category were excluded from the disability study.

Table 2: Employment Categories Reported by Employed Participants at 12 and 18 months

Timeframe	Does work	Doesn't work		Retired	Disabled*	Unable to work	Lost to follow-up
		Has a job	No job				
Breast (n=495 originally enrolled in LMOS)							
Baseline Employed (n=447)	444 (89.7)	3 (0.6)	33 (6.7)	7 (1.4)	3 (0.6)	5 (1.0)	0
12 mos (n=418)	342 (76.5)	20 (4.5)	18 (4.0)	17 (3.8)	11 (2.5)	10 (2.2)	29 (6.5)
18 mos (n=409)	336 (75.2)	11 (2.5)	21 (4.7)	21 (4.7)	18 (4.0)	2 (0.4)	38 (8.5)
Prostate (n=294 originally enrolled in LMOS)							
Baseline Employed (n=267)	267 (90.8)	0 (0.0)	3 (1.0)	20 (6.8)	2 (0.7)	2 (0.7)	0
12 mos (n=243)	198 (74.2)	8 (3.0)	8 (3.0)	27 (10.1)	0	2 (0.8)	24 (9.0)
18 mos (n=230)	194 (72.7)	1 (0.4)	9 (3.4)	24 (9.0)	2 (0.8)	0	37 (13.9)

*Participants were not provided a definition of "disabled" and it is unknown to what extent they used the definition set forth in this study.

3.3.1 Disability Study Descriptive Data

Baseline socio-demographic characteristics of the breast and prostate cohorts are displayed in Table 3. Race was obtained through a recoding of reported race into categories of White/Other and African-American. The decision to combine the other race category with the White/Caucasian category was due to the fact that the majority of "other" reported their race as Asian. According to cancer statistics, persons of Asian ancestry experience incidence rates more similar to White/Caucasian individuals. However, the total number of participants reporting "other" race was too small to maintain them as a separate category (n=15). Education was categorized as less than or equal to high school diploma, some college or college degree. Similarly, marital status was recoded into three categories; currently married, never married, or formerly married (widowed/divorced/separated).

Comorbidity count was tallied based on participant report. The nature or perceived severity of the comorbid condition was not available so the decision was made to simply count the number of conditions. Participants were also asked to evaluate their own health status. Excellent and very good scores were combined as were fair/poor scores. Perceived health status at twelve months is also presented to indicate how health status had changed from baseline to twelve months post-diagnosis and treatment.

Annual income levels were categorized as low (<20,000), mid-range (20,000-74,999) or high (≥75,000). Similar to the health status, the twelve-month reports are also presented. A general measure of activity level per week was asked of participants at all waves and the baseline and twelve month reports are included in Table 3.

Table 3: Study Participant Descriptive Statistics

Characteristic	**Breast Cohort (n=447)**	**Prostate Cohort (n=267)**
Mean age (SD)	49.9 (7.7)	55.4 (5.9)
Age range	31-65	34-65
Race		
White/Other	350 (78.3)	202 (75.7)
African-American	97 (21.7)	65 (24.3)
Education		
≤ High school	121 (27.1)	62 (23.2)
College, no degree	124 (27.7)	66 (24.7)
College graduate	202 (45.2)	139 (52.1)
Marital Status		
Married	270 (60.4)	213 (79.8)
Formerly married	133 (29.8)	36 (13.5)
Never married	44 (9.8)	18 (6.7)
Comorbidities (measured at 12 mos)*		
None	238 (56.9)	133 (54.7)
1-2	153 (36.6)	86 (35.4)
3+	27 (6.5)	24 (9.9)
Baseline Health Status		
Excellent/very good	314 (70.2)	194 (72.7)
Good	90 (20.1)	59 (22.1)
Fair/poor	43 (9.6)	14 (5.2)
Health Status (12 mos)*		
Excellent/very good	251 (60.0)	161 (66.3)
Good	118 (28.2)	64 (26.3)
Fair/poor	49 (11.7)	18 (7.4)
Baseline annual household income		
<20,000	31 (6.9)	7 (2.6)
20,000-74,999	222 (49.7)	90 (33.7)
≥75,000	179 (40.0)	161 (60.3)

Table 3 (cont'd).

Characteristic	Breast Cohort (n=447)	Prostate Cohort (n=267)
Annual household income (12 mos)*		
<20,000	26 (6.2)	7 (2.9)
20,000-74,999	226 (54.1)	90 (37.0)
≥75,000	151 (36.1)	131 (53.9)
Engage in mild activity more than 3 days	79 (17.7)	52 (19.5)
Engage in mild activity more than 3 days (12 mos)*	69 (16.5)	36 (14.8)
Engage in moderate activity more than 3 days	88 (19.7)	54 (20.2)
Engage in moderate activity more than 3 days (12 mos)*	86 (20.6)	45 (18.5)
Engage in strenuous activity more than 3 days	29 (6.5)	36 (13.5)
Engage in strenuous activity more than 3 days (12 mos)*	28 (6.7)	26 (10.7)
Work up a sweat sometimes/always	316 (70.7)	228 (85.4)
Work up a sweat sometimes/always (12 mos)*	284 (67.9)	184 (75.7)

*Breast cohort at 12 months, n=418, Prostate cohort at 12 months, n=243

As has been cited, one of the reasons the MDCSS was selected as the patient source pool was the over-representation of minority cases. Unfortunately, the participants recruited into the study for both the breast and prostate cohorts were predominantly white, 78% and 76%, respectively. Moreover, approximately half of the participants were well educated with college degrees. Forty percent of the women reported an annual income greater than $75,000. A larger proportion of men, 60%, documented this level of household income. Approximately five percent of both cohorts in the high-income group shifted to the mid-range income group at twelve months. This decrease was statistically significant for women but not statistically significant for men. No statistically significant changes occurred in household income between twelve and eighteen months (data not shown). More than sixty percent of both cohorts were married, 60% and 80% for the women and men, respectively. Although the same age range was targeted in both cohorts, the men were statistically significantly older than the women, 55.4 years vs. 49.9 years (ttest $p<0.01$), respectively.

Participants appeared to be relatively healthy other than their cancer diagnosis. More than half of each cohort reported no comorbid conditions (57% and 55%) for the women and men, respectively. At least seventy percent of respondents in both cohorts rated themselves as having *very good* or *excellent* overall health status before they were diagnosed and 60% maintained this opinion at twelve months post-diagnosis. However, the shift from very good/excellent health status to good or fair/poor was statistically significant for women ($p<0.01$). Health status category shifts among the men were not statistically significant.

3.3.2 Disability Study Disease-Related Characteristics

Cancer stage information was obtained from SEER data files. Most individuals were diagnosed before the cancer had metastasized. Treatment information came from both the patient and the SEER data. Neither source may be considered a gold standard. SEER treatment data may not include all the treatments a patient received, especially in cases where individuals sought treatment outside the SEER catchment area or if treatment was delivered in outpatient settings. Alternatively, patients may not accurately report their treatment protocols.

Therefore, SEER and patient reports were combined to determine the individuals receiving the following treatments. In the event that the SEER report and the patient report contradicted, the positive report of treatment was accepted. That is, if SEER data suggested that a particular treatment was not provided but the patient claimed to have received the treatment in question, the individual was coded as having received the treatment. Medical record review to confirm treatment was not an option. The hormone category of treatment was restricted to hormones used as a therapeutic option rather than prophylactic and was asked only of the men. Table 4 presents the disease-related information of the participants.

Table 4: Study Participant Disease Statistics

Characteristic	Breast Cohort (n=447)	Prostate Cohort (n=267)
Stage		
In-situ	118 (26.4)	0
Local	192 (43.0)	209 (78.3)
Regional	126 (28.2)	55 (20.6)
Distant/unknown	11 (2.5)	3 (1.1)
Treatment		
No treatment	1 (0.2)	9 (3.4)
Surgery only	85 (19.0)	171 (64.0)
Radiation (+/- surgery)	96 (21.5)	67 (25.1)
Chemotherapy (+/- radiation, surgery)	265 (59.3)	8 (3.0)
Hormone therapy (+/- surgery)	--	12 (4.5)

Slightly more than two-thirds of each cohort was diagnosed early in their cancer pathology. Sixty-nine percent of women had either in-situ or locally staged disease at diagnosis while 78% of men had locally staged disease at diagnosis. The majority, 59%, of women underwent treatment regimens that included chemotherapy. In contrast, a minority of the men, just 3%, had chemotherapy. In fact, the proportion of men not having treatment of any sort exceeded the proportion that received chemotherapy. The treatment of choice for the majority of the men was surgery without additional therapy, 64%.

3.3.3 Disability Study Employment-Related Characteristics

3.3.3.1 General Employment

The purpose of this study was to evaluate the impact of cancer diagnosis and treatment on the participants' job-related tasks. A variety of job related variables that could impact disability were included in the interviews. Baseline information related to general employment characteristics and type of occupation are presented in Table 5.

Table 5: Study Participant Employment Statistics at Baseline

Characteristic	**Breast Cohort (n=447)**	**Prostate Cohort (n=267)**
Sick leave available	288 (64.4)	205 (76.8)
White collar occupation	304 (68.0)	175 (65.5)
Mean hours worked per week	37.7 (11.3)	44.6 (11.6)
Mean shift length	8.0 (1.7)	8.8 (1.8)
Union member	117 (26.2)	76 (28.5)
Mean percent of shift spent sitting	45.4 (30.2)	47.7 (30.1)

Employment status at twelve and eighteen months was reviewed. Essentially three-quarters of both cohorts remained employed at twelve months with just a small percent of the prostate cohort dropping out of the workforce at eighteen months. Table 6 presents the employment categories for breast and prostate cohorts at twelve months. The categories were based on participant self-report. Shading indicates that individuals were not included in analyses.

Table 6: Employment Categories Reported by Employed Participants at 12 and 18 months

Timeframe	Does work	Doesn't work		Retired	Disabled*	Unable to work	Lost to follow-up
		Has a job	No job				
Breast (n=447 employed at baseline)							
12 mos (n=418)	342 (76.5)	20 (4.5)	18 (4.0)	17 (3.8)	11 (2.5)	10 (2.2)	29 (6.5)
18 mos (n=409)	336 (75.2)	11 (2.5)	21 (4.7)	21 (4.7)	18 (4.0)	2 (0.4)	38 (8.5)
Prostate (n=267 employed at baseline)							
12 mos (n=243)	198 (74.2)	8 (3.0)	8 (3.0)	27 (10.1)	0	2 (0.8)	24 (9.0)
18 mos (n=230)	194 (72.7)	1 (0.4)	9 (3.4)	24 (9.0)	2 (0.8)	0	37 (13.9)

*Participants were not provided a definition of "disabled" and it is unknown to what extent they used the definition set forth in this study.

As mentioned earlier, several plausible explanations exist to explain why an individual did not work yet had a job. Of these participants, women were more likely to identify their illness as the reason for not working. Fourteen (70%) of the twenty women at twelve months who had a job but weren't working stated the reason was their cancer. At eighteen months, seven (63.6%) of the eleven blamed their illness as the reason they were not working. Less than forty percent of the men who had a job but were not working at twelve months blamed their illness (3 of out 8, 37.5%). At eighteen months, the one individual remaining with a job but not working did *not* identify his illness as the reason.

3.3.3.2 Job Satisfaction and Employer Accommodation

Participants were asked to evaluate job satisfaction and employer accommodation at twelve months. Satisfaction and accommodation questions were asked using a 4-point Likert scale response option. Eligible responses included strongly agree, agree, disagree, or strongly disagree. The options strongly agree and agree were collapsed while strongly disagree and disagree were collapsed. Information related to these employment characteristics is displayed in Table 7.

Table 7: Participant Report of Job Satisfaction and Employer Accommodation at 12 months

Characteristic	**Breast Cohort (n=418*)**	**Prostate Cohort (n=243*)**
Job Satisfaction Statement		
Satisfaction in life from job (agree)	219 (52.4)	132 (54.3)
Most important things involve work (agree)	126 (30.1)	86 (35.4)
Perfectionist about work (agree)	367 (87.8)	209 (86.0)
Live, eat and breathe job (agree)	66 (15.8)	47 (19.3)
Involved personally in work (agree)	334 (79.9)	207 (85.2)
Interest in new job if assured of comparable benefits (agree)	171 (40.9)	73 (30.0)
Employer Accommodation		
Employer accommodating (agree)	364 (87.1)	197 (81.1)
Employer discriminated (agree)	28 (6.7)	4 (1.6)

*All participants remaining at twelve months were asked these questions regardless of their employment status at twelve months.

A review of the participants' ratings of employment characteristics indicates most are attached to their existing jobs. At least half of both cohorts reported their satisfaction in life came from their job, 52% for women and 54% for men. Over eighty percent, 88% and 86% for women and men respectively, considered themselves to be perfectionists about their work. More than three-quarters of the women, 80%, and 85% of the men were personally involved in their work. When asked if they would look for a new job if they would be guaranteed similar benefits, 41% of the women and 30% of the men, reported they would be interested in a new position. In contrast to what has been reported historically, the majority, 87% for women and 81% for men, reported their employers to be accommodating to their illness.

Although participants were attached to their jobs, it appears that job attachment was not all consuming. Less than twenty percent acknowledged that they "live, eat, and breathe" their jobs, 16% for women and 19% for men. Similarly, the minority expressed the opinion that the most important things involved work, 30% for women and 35% for men.

3.3.3.3 Activity Requirement: Job Tasks

Twelve months was the timeframe at which specific job tasks were first assessed. Participants were asked if particular activities were required for their jobs regardless of their current employment status at the time of the twelve and eighteen month interviews. Table 8 displays the proportion of breast cancer participants reporting a specific task was required for their job at twelve months. Table 9 shows similar information for the prostate cancer cohort.

Table 8: Job Task Frequency Reported at Twelve Months by Breast Cohort

Site	**Job Task**	**Job Task Frequency Response Options**			
		All or almost all of the time	**Most of the time**	**Some of the time**	**None or almost none of the time**
Breast (n=418)*	Physical effort	76 (18.2)	62 (14.8)	118 (28.2)	151 (36.1)
	Heavy lifting	24 (5.7)	20 (4.8)	89 (21.3)	274 (65.6)
	Stooping/crawling/ kneeling	43 (10.3)	37 (8.8)	139 (33.2)	188 (45.0)
	Keep up with pace set by others	113 (27.0)	83 (19.9)	75 (17.9)	136 (32.5)
	Concentrate	176 (42.1)	126 (30.1)	73 (17.5)	32 (7.7)
	Analyze data	125 (29.9)	83 (19.9)	105 (25.1)	94 (22.5)
	Learn new things	96 (23.0)	73 (17.5)	182 (43.5)	56 (13.4)

*All participants remaining at 12 months were asked questions regardless of employment status at that time.

Table 9: Job Task Frequency Reported at Twelve Months by Prostate Cohort

Site	Job Task	Job Task Frequency Response Options			
		All or almost all of the time	Most of the time	Some of the time	None or almost none of the time
Prostate (n=243)*	Physical effort	31 (12.8)	30 (12.4)	65 (26.8)	113 (46.5)
	Heavy lifting	6 (2.5)	8 (3.3)	60 (24.7)	165 (67.9)
	Stooping/crawling/ kneeling	18 (7.4)	15 (6.2)	86 (35.4)	119 (49.0)
	Keep up with pace set by others	44 (18.1)	45 (18.5)	60 (24.7)	90 (37.0)
	Concentrate	85 (35.0)	87 (35.8)	49 (20.2)	18 (7.4)
	Analyze data	81 (33.3)	62 (25.5)	55 (22.6)	41 (16.9)
	Learn new things	51 (21.0)	47 (19.3)	115 (47.3)	26 (10.7)

*All participants remaining at 12 months were asked questions regardless of employment status at that time.

These same questions were asked at the eighteen-month interview. Tables 10 and 11 present the range of responses to the job task questions asked at this time. As with the twelve-month responses, these questions were asked of all participants, even if they had withdrawn from the workforce by this interview encounter.

Table 10: Job Task Frequency Reported by Breast Cohort at Eighteen Months

Site	**Job Task**	**Job Task Frequency Response Options**			
		All or almost all of the time	**Most of the time**	**Some of the time**	**None or almost none of the time**
Breast (n=409)*	Physical effort	58 (14.2)	45 (11.0)	113 (27.6)	152 (37.2)
	Heavy lifting	11 (2.7)	25 (6.1)	86 (21.0)	246 (60.2)
	Stooping/crawling/ kneeling	29 (7.1)	19 (4.6)	158 (38.6)	162 (39.6)
	Keep up with pace set by others	90 (22.0)	69 (16.9)	76 (18.6)	133 (32.5)
	Concentrate	115 (28.1)	130 (31.8)	80 (19.6)	43 (10.5)
	Analyze data	86 (21.0)	88 (21.5)	101 (24.7)	93 (22.7)
	Learn new things	84 (20.5)	80 (19.6)	162 (39.6)	42 (10.3)

*All participants remaining at 18 months were asked questions regardless of employment status at that time.

Table 11: Job Task Frequency Reported by Prostate Cohort at Eighteen Months

Site	Job Task	Job Task Frequency Response Options			
		All or almost all of the time	**Most of the time**	**Some of the time**	**None or almost none of the time**
Prostate (n=230)*	Physical effort	22 (9.6)	19 (8.3)	70 (30.4)	92 (40.0)
	Heavy lifting	4 (1.7)	7 (3.0)	53 (23.0)	139 (60.4)
	Stooping/crawling/ kneeling	13 (5.6)	17 (7.4)	75 (32.6)	98 (42.6)
	Keep up with pace set by others	33 (14.4)	39 (17.0)	51 (22.2)	80 (34.8)
	Concentrate	57 (24.8)	74 (32.2)	54 (23.5)	18 (7.8)
	Analyze data	50 (21.7)	73 (31.7)	52 (22.6)	20 (12.2)
	Learn new things	43 (18.7)	49 (21.3)	94 (40.9)	17 (7.4)

*All participants remaining at 18 months were asked questions regardless of employment status at that time.

3.4 Research Questions and Hypotheses

3.4.1 Prevalence and Direction of Disability Change

The aggressive nature of cancer treatment is expected to result in disability with work-related tasks. Furthermore, if the nature of these disabilities represents a transient condition, it is reasonable to presume prevalence estimates would decrease as time since treatment increases. The study will test this presumption with the following hypothesis applied to physical and cognitive disability:

- H_1: Cancer related physical and cognitive disabilities will decrease as the timeframe from diagnosis increases from twelve months after diagnosis to eighteen months after diagnosis.

Since disability was not measured directly through the interview process, it was necessary to construct this variable using existing data elements. Activity limitation and participation restriction are the two domains that make up the outcome of disability per the ICF. The following sections describe the methodology used to generate the activity limitation and participation restriction indicator variables and then describe how these were combined to generate the outcome variable of interest.

3.4.1.1 Methodology: Document Required Job Activities

3.4.1.1.1 Classify Job Activities as Physical or Cognitive

A review of the particular job tasks included in the interviews indicated they might reasonably be collapsed into two categories such as physical or cognitive. Several methods were employed to test if this were the case. STATA v9.2 was used for all analyses.

Factor analysis was performed to assess the degree to which these distinct tasks reflected an underlying work response dimension (59). After the initial factor structure was determined, orthogonal (i.e. varimax) rotation was carried out to further simplify the factor structure. Orthogonal rotation was selected rather than oblique rotation as the factors were presumed to be uncorrelated.

The factor analysis results suggested two main dimensions were represented by the seven tasks. Three of the items loaded heavily on the first dimension while three loaded heavily on the second dimension. The first dimension included the physical effort, heavy lifting and stooping/crawling/kneeling tasks. The second dimension included the individual tasks of concentration, data analysis and learning new things. The interpretation of these dimensions were categorized as physical (Factor 1) and cognitive (Factor 2).

The remaining job task, "keeping up with others" loaded slightly more heavily on Factor 2 yet the split between the dimensions was not to the degree of the other job task variables. Similar results were obtained for the wave 3 activities and the wave 4 activities. Table 12 gives the rotated factor loadings of all seven variables for both factors.

Table 12: Rotated Factor Loadings for *All* Job Tasks

Job Task	**Wave 3 Activities**		**Wave 4 Activities**	
	Factor 1 Loading	**Factor 2 Loading**	**Factor 1 Loading**	**Factor 2 Loading**
Physical effort	0.7629	-0.0790	0.7682	-0.0913
Heavy lifting	0.7129	0.0309	0.6908	-0.0205
Stoop/crawl or kneel	0.6677	0.0231	0.6245	0.0296
Keep up with others	0.2041	0.4114	0.2025	0.3170
Concentrate	0.0382	0.5596	0.0214	0.5876
Analysis	-0.2222	0.5993	-0.2810	0.5850
Learn new things	0.0581	0.5319	0.0186	0.5843

Since the variable "keep up with others" did not load as strongly, further attempts to categorize this variable were conducted. Sensitivity analyses were conducted which compared this variable with the other work-related task variables. The highest sensitivity values were obtained with the lifting (70.5%) and physical effort (69.4%) variables as the "true" status. This pattern was observed for the twelve-month and eighteen-month accrual points. Due to the apparent conflicting results between the factor analysis and the sensitivity analysis, the decision was made to exclude the "keep up with others" variable as a component of either the physical or cognitive dimensions.

Factor analysis was then re-run excluding the "keep up with others" variable with similar results. Table 13 gives the rotated factor loadings for the six retained variables for both factors.

Table 13: Rotated Factor Loadings for *Targeted* Job Tasks

Job Task	Wave 3 Activities		Wave 4 Activities	
	Factor 1 Loading (n=645)	**Factor 2 Loading (n=645)**	**Factor 1 Loading (n=571)**	**Factor 2 Loading (n=571)**
Physical effort	0.7471	-0.1263	0.7619	-0.1155
Heavy lifting	0.7161	0.0122	0.6972	-0.0259
Stoop/crawl or kneel	0.6775	0.0228	0.6231	0.0118
Concentrate	0.0530	0.5429	0.0312	0.5727
Analysis	-0.1950	0.6221	-0.2562	0.6109
Learn new things	0.0660	0.4971	0.0257	0.5639

These loadings were then used to generate factor scores that were saved as new variables. As expected, due to their nature as standardized variables,

the means of each factor score were essentially zero with standard deviations close to one (59). The physical dimension at both waves was somewhat negatively skewed while the cognitive dimension was more symmetrical. Table 14 shows the summary statistics for each factor score.

Table 14: Summary statistics for factor scores

	Wave 3 Activities		**Wave 4 Activities**	
Factor Score characteristic	**Factor 1 (Physical)**	**Factor 2 (Cognitive)**	**Factor 1 (Physical)**	**Factor 2 (Cognitive)**
Mean (± SD)	0.0 (0.85)	0.0 (0.74)	0.0 (0.85)	0.0 (0.76)
Skewness	-1.12	0.11	-1.04	0.03
Kurtosis	3.66	2.24	3.48	2.34

3.4.1.1.2 Generate Composite Physical or Cognitive Variable

A physical task composite variable was created from the three specific tasks identified from the factor analysis. Participants were classified as having to perform a physical task if they claimed to perform any combination of physical effort, heavy lifting and/or stooping/crawling/kneeling at least some of the time.

A similarly constructed composite cognitive task was created from the three particular tasks (concentration, analysis and learn new things) shown to load on the second factor.

It should be mentioned the scoring associated with the factor analysis provided a mechanism to create composite variables that would have been continuous in nature. However, in order to facilitate outcome interpretation, the composite variables were retained as dichotomous measures. A value of zero was associated with "no disability" while a value of one was associated with "disability". Table 15 displays the prevalence rates of the composite job task variables at twelve and eighteen months for both cohorts.

Table 15: Composite Activity Requirements for Cohorts

Activity Requirement	12 months	18 months
Breast	**(n=418)**	**(n=409)**
Composite Physical Task	298 (71.3)	261 (63.8)
Composite Cognitive Task	398 (95.2)	357 (87.3)
Prostate	**(n=243)**	**(n=230)**
Composite Physical Task	154 (63.4)	134 (58.3)
Composite Cognitive Task	398 (95.2)	357 (87.3)

3.4.1.1.3 Compare Physical or Cognitive Job Activities between 12 and 18 Months

These comparisons were conducted to act as a reference for the forthcoming analyses regarding activity limitation and disability that will address the hypotheses. Several individuals were lost to follow-up during this study and others changed their employment status between twelve and eighteen months. Therefore, it was necessary to determine if the prevalence of having to perform these activities changed over this timeframe. If the prevalence of a task changed significantly, it would be difficult to evaluate any changes in activity limitation that might be detected during the forthcoming analyses. Recall that the variable "keep up with others" was dropped after the conflicting findings regarding its association as either a physical or cognitive task.

Two comparisons were carried out for each task. The overall prevalence reported by all available respondents at twelve and eighteen months was compared first. The subsequent comparison was then restricted to the individuals who had paired data available for both timeframes. Stated another way, the second comparison was conducted only on individuals reporting at both twelve and eighteen-months. STATA v9.2 was used for all analyses.

3.4.1.2 Methodology: Create Indicator Variable

The ICF model of disability includes two domains that contribute to disability, activity limitation and participation restriction. In order to establish if these two elements were present for the participants, indicator variables were created for each domain. The indicator variables were established as dichotomous variables with 0=domain absent and 1=domain present. This coding scheme would then allow for multiplication to establish the outcome of interest, i.e. disability. The resulting outcome would then also be a dichotomous variable with similar interpretation of 0=disability absent and 1=disability present.

3.4.1.2.1 Domain 1: Document Activity Limitation in Job Activities

Assessing activity limitation for specific job tasks was relatively straightforward. If the participants stated they performed each task at least some of the time, they were immediately asked if their ability to carry out this task was limited subsequent to their diagnosis and treatment. However, summary variables representing overall activity limitation for the composite physical and cognitive task variables were created for the twelve and eighteen-month interviews.

The composite variable for "limitation in physical task" was based on the responses to the activity limitation responses from the three specific physical tasks. A similar strategy was carried out to generate a cognitive task limitation variable. The presence of limitation in any one or combination of specific tasks denoted presence of limitation in the related composite variable. Activity limitation in the specific and composite variables were established as dichotomous variables with 0=absence of limitation, 1=presence of limitation. An example of one participant's coding is displayed in Tables 16 and 17.

Table 16: Activity Limitation Coding Example – Physical Task

Specific Task Required by Job	Participant Response	Participant States Task Limited by Treatment
Physical effort	Some of the time	Yes
Heavy lifting	None of the time	n/a
Stoop/crouch/kneel	All of the time	No
Composite Physical Scoring		
Physical Task required	Yes (1)	
Activity Limitation Present	Yes (1)	

Table 17: Activity Limitation Coding Example – Cognitive Task

Specific Task Required by Job	Participant Response	Participant States Task Limited by Treatment
Concentrate	Some of the time	No
Analysis	None of the time	n/a
Learn new things	All of the time	No
Composite Cognitive Scoring		
Cognitive Task required	Yes (1)	
Activity Limitation Present	No (0)	

3.4.1.2.2 Domain 2: Document Participation Restriction in Labor Market Participation

Participation restriction was defined as an indicator variable focusing on decreases in specific measures of employment attachment that were confirmed by the participants to be a result of their diagnosis and treatment. Since a global question regarding participation restriction was not asked, other variables that could be used as proxies for restricted work participation were combined.

The variables used to create a proxy variable for participation restriction included the following: number of hours worked weekly, reason for new unemployment, reason for working only part time and reason for earnings decreasing. After determining if these conditions were present, the survey further queried the participants if the decrease in hours, earnings, or job status was a result of their cancer and treatment. The participation restriction variable was coded as "1" if the patient stated the participation restriction was due to diagnosis and treatment. Alternatively, participation restriction was coded as "0" if the participant did not report participation restriction *or* if the respondent identified the participation restriction to be related to some cause other than their cancer. Appendix B contains the wording of the questions used to generate the participation restriction variable.

3.4.1.3 Methodology: Generate Disability Variable

After creating the indicator variables for the domains of interest (e.g. activity limitation and participation restriction), these were multiplied to create the outcome variables for physical disability and cognitive disability. Due to the 0/1 coding convention selected, simple multiplication allowed the disability variables to reflect 1 if the participant reported an activity limitation with participation restriction and 0 if one or both of the domains were not impacted. Table 18 shows the possible outcomes from the multiplication of both indicator variables.

Table 18: Disability Coding Example

Activity Limitation Status	Participation Restriction Status	Disability Status
No activity limitation (=0)	No participation restriction (=0)	No disability (=0)
Activity limited (=1)	No participation restriction (=0)	No disability (=0)
No activity limitation (=0)	Restricted work participation (=1)	No disability (=0)
Activity limited (=1)	Restricted work participation (=1)	Disabled (=1)

3.4.1.3.1 Evaluate Prevalence and Change of Disability

The overall change in disability prevalence between the time periods was compared using two methods. First, comparisons of the overall rates between twelve and eighteen months including all possible respondents (not just those with paired data from twelve and eighteen months available) were tested using the Pearson chi-square. Secondly, the change for respondents in each cohort that were included in both time periods was calculated using paired analyses, i.e. comparing each individual's status from twelve months to eighteen months.

After the disability status for each participant at twelve and eighteen months was established, the direction of disability status change was categorized. This required that the participant have a valid assessment of disability at both twelve and eighteen months. If the participant was not disabled at twelve months but was disabled at eighteen months, they were categorized as "worsen". If a participant was disabled at twelve months but not disabled at eighteen months, they were classified as "improved". Finally, if a participant was disabled at twelve and eighteen months, they were classified as "unchanged". Individuals who were not disabled at twelve and eighteen months were excluded from this evaluation. Methods to investigate characteristics of participants who improved or worsened from twelve to eighteen months were considered including ordered logistic regression. Unfortunately, small cell sizes prohibited this form of analysis. Unadjusted tests for association with potentially influential variables were conducted using Fisher's Exact Test.

3.4.2 Disability Prevalence Disparities Based on Definition

The second study question was to evaluate and compare the physical and cognitive disability estimates obtained from an activity limitation definition with the estimates obtained from the ICF (activity limitation with participation restriction) definition. Due to the more comprehensive nature of disability supported by the ICF model, it is expected that this definition would result in a lower prevalence. The second hypothesis will be tested for both physical and cognitive disabilities.

- H_2: Cancer related physical and cognitive disabilities will be more prevalent at twelve and eighteen months using an activity limitation definition of disability compared to an ICF definition requiring activity limitation and participation restriction.

3.4.2.1 Methodology: Compare Disability Prevalence

The difference between reporting a disability using just an activity limitation definition and a combined activity limitation/participation restriction definition as per the ICF model was compared using Pearson Chi-Square in an unadjusted analysis.

3.4.3 Contextual Factor Association with Disability

The last study question seeks to describe associations between a number of contextual factors with disability. The contextual factors may be categorized as personal or environmental. Although cancer treatment is not necessarily a personal characteristic, it was included as a personal factor because of the association with cancer stage. Patterns of influence will be tested using the following hypotheses against both outcomes, physical and cognitive disability.

- H_3: Personal factors that will place individuals at risk for physical and cognitive disability include minority race, low annual household income, chemotherapy and later staged disease.
- H_4: Environmental factors (associated with employment) that will place individuals at risk for physical and cognitive disability include blue-collar employment, less sedentary job, no employer accommodation and low job satisfaction.

3.4.3.1 Methodology: Multivariate Analysis using Logistic Regression

The goal of the multivariable analysis was to predict which contextual factors influenced the presence of disability in the participants. Some variables may be amenable to intervention that could assist patients to select among treatment options or plan for rehabilitation. Logistic regression was used since the dependent variables of interest were dichotomous in nature, i.e. a physical/cognitive disability was either present (=1) or absent (=0). As the hypotheses suggest, personal factors such as minority race, low income, late staged disease or chemotherapy were of particular interest (hypothesis #3). The remaining factors were environmental with respect to the work setting. These included job classification, physical demands of the job, employer accommodation and job satisfaction (hypothesis #4).

Logistic regression permits users to "assess the probability of a disease or health condition as a function of a risk factor and covariates." (130) Otherwise stated, logistic regression is used to estimate the probability that a person has a particular outcome (131). Another feature of logistic regression is that the slope coefficients can be transformed into odds ratios (131). The odds ratio obtained for each variable represents its influence when controlling for all other independent covariates included in the model (131, 132). The logit function used in logistic regression allows the values of independent variables to be linked to the probability of the dependent or outcome variable. The logistic regression model can be written as follows where Y is a binomial variable with probability of success = p:

$$\text{Logit}(E(Y_i)) = \text{logit}\,(p) = \ln\left(\frac{p}{1-p}\right) = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \ldots + \beta_k X_k$$

The X's represent the independent variables of interest while the coefficients are constants representing unknown parameters, which may be estimated by using the dataset (110). The coefficient β_0 is said to give the log of the "baseline" or "background" odds, i.e. the odds occurring if there were no X's (110). The interpretation of the β coefficients is understood as the "change in the log odds that would result from one unit change in the variable X when all other X's are fixed" (110).

Selection of potential variables to include in the modeling procedure was guided by the variables discussed in existing literature. As described in Chapter 2, personal variables that are socio-demographic in nature (e.g. age, race, income, and poor fitness) have been associated with activity limitation or participation restriction. Similarly, disease-related covariates including treatment and stage have been linked with activity limitation. Finally, items that would indicate a supportive work environment, e.g. sick leave benefit, perception of employer accommodation were included for their documented association with return to work. The physical nature of the job was assessed by the duration of shift length and percent of shift length spent sitting. Table 19 displays the variables considered for inclusion in the modeling process.

Table 19: Variables considered for inclusion in modeling procedures

Personal Contextual Factor		**Environmental Contextual Factor**
Socio-demographic	*Disease*	*Employment*
Age	Stage at diagnosis	Sick leave benefit
Race	Treatment category	Occupational classification
Education		Employer accommodating*
Marital status		Satisfaction in life from job*
Annual household income		Most important things involve work*
Routine physical activity		Perfectionist about work*
		Live, eat, and breathe the job*
		Involved personally in work*
		Interest in a new job*
		Duration of work day
		Percent work day seated

*Variables focused on job satisfaction

However, the full complement of potentially explanatory variables was considerable, numbering close to twenty. Therefore, in the interest of parsimony, factor analysis was performed to assess the degree to which the seven distinct variables asking about job satisfaction reflected a fewer number of underlying dimensions (59).

The factor analysis results suggested one main dimension was represented by the variables based on Eigenvalue (1.75 for factor 1 and 0.34 for factor 2). Three of the items loaded heavily on the first dimension. The first dimension included satisfaction in life from job, most important things involve work and live, eat and breathe the job.

Three of the remaining satisfaction variables, perfectionist about work, involved personally in work and interest in approaching a new job loaded slightly more heavily on Factor 1 yet the split between the dimensions was not to the degree of the other satisfaction variables. The remaining variable, employer accommodating, actually loaded more heavily on factor 2 yet again, the split was not extreme. Table 20 gives the rotated factor loadings of all seven variables for both factors.

Table 20: Rotated Factor Loadings for Job Satisfaction Variables

Satisfaction	**Wave 3 Satisfaction**	
	Factor 1 Loading (n=579)	**Factor 2 Loading (n=579)**
Employer accommodating	0.0689	0.3915
Satisfaction in life from job	0.7038	0.0972
Most important things involve work	0.7315	0.0226
Perfectionist about work	0.2496	0.0085
Live, eat, and breathe the job	0.6603	-0.0548
Involved personally in work	0.4653	0.1411
Approach a new job	-0.0465	-0.3968

Factor analysis was then re-run retaining just the three satisfaction variables that reflected the same dimension. Table 21 gives the rotated factor loadings for the retained variables for Factor 1.

Table 21: Rotated Factor Loadings for Retained Job Satisfaction

Satisfaction	Wave 3 Satisfaction Factor 1 Loading (n=651)
Satisfaction in life from job	0.7205
Most important things involve work	0.7554
Live, eat, and breathe the job	0.6400

These loadings were used to generate a factor score that was saved as a new variable. As expected due to their nature as standardized variables, the means of the factor score was essentially zero with standard deviations close to one (59). Table 2 shows the summary statistics for the satisfaction factor score. This score was included in the regression modeling in lieu of the individual satisfaction variables. However, employer accommodation was retained as a separate variable for the modeling procedures since the factor association appeared to contradict the other satisfaction related variables.

Table 22: Rotated Factor Loadings for Job Tasks

Factor Score characteristic	Wave 3 Satisfaction Factor 1
Mean (± SD)	0.0 (0.85)
Skewness	-0.19
Kurtosis	3.02

The influence of socio-demographic, disease-related and employment covariates on the presence of physical or cognitive disability at twelve and eighteen months was tested using backward selection logistic regression. Separate analyses were conducted for the breast and prostate cohorts, therefore gender was not included as a covariate in the regressions. Robust standard errors were used as these are able to provide variance estimates and confidence intervals for models that are not well specified.

CHAPTER 4: RESULTS

4.1 Study Question 1: Prevalence and Direction of Disability Change

4.1.1 Hypothesis 1: Comparison of Physical and Cognitive Disability

The first hypothesis set down for this study was stated as:

- H_1: Cancer related physical and cognitive disabilities will decrease as the timeframe from diagnosis increases from twelve months after diagnosis to eighteen months after diagnosis.

In order to evaluate the changes in disability, it was necessary to first investigate patterns associated with the components that made up the outcome variable. Specifically, activity requirement, activity limitation and participation restriction needed to be compared from twelve to eighteen months to inform interpretation of the disability results.

4.1.1.1 Comparison of Physical and Cognitive Activity Requirements Between 12 and 18 Months

Seventy percent of the breast cohort and 64% of the prostate cohort reported their jobs required physical activity at twelve months. However, more than 95% of men and women described a cognitive role to their job. The proportion of individuals requiring cognitive tasks was statistically significantly greater than those requiring physical tasks for women and men.

Table 23 displays the proportions of breast cohort respondents documenting specific and composite task requirements at twelve and eighteen months. The differences between overall proportion of specific physical tasks and the composite physical task from twelve to eighteen months were not statistically significant. Similarly, the apparent decreases in two of the specific cognitive tasks, analysis and learning new things, as well as the composite cognitive task were not statistically significant. However, the decrease in the concentration requirement from twelve to eighteen months reached statistical significance at the $p<0.05$ level for the sub-group of women with paired data available.

Table 23: Activity Requirements for Breast Cohort

Task	**12 months (n=418)**	**18 months (n=409)**	**p-value**	**p-value (paired)**
Physical effort	256 (61.2)	216 (52.8)	0.23	0.28
Heavy lifting	133 (31.8)	122 (29.8)	0.89	0.48
Stoop/crawl or kneel	219 (52.4)	206 (50.4)	0.54	0.32
Composite Physical Task Required	*298 (71.3)*	*261 (63.8)*	*0.48*	*0.54*
Concentrate	375 (89.7)	325 (79.5)	0.07	0.04*
Analysis	313 (74.9)	275 (67.2)	0.48	0.40
Learn new things	351 (84.0)	326 (79.7)	0.33	0.11
Composite Cognitive Task Required	*398 (95.2)*	*357 (87.3)*	*0.50*	*0.54^*

*Statistically significant at $p<0.05$
^Fisher Exact Test used due to cell size<5

One possible explanation for a significant change in activity requirement would be changes in the proportion of women working between twelve and eighteen months. It is important to note the activity requirements were asked of *all* eligible participants *without* the condition they be employed at the time of the interview. This introduces the possibility that recall bias may affect the proportion of respondents who report having to perform the tasks, i.e. it is possible that persons who retired or were no longer employed may remember their job tasks differently then someone who is still employed.

In order to assess if recall bias could have affected the concentration task, employment status was categorized as working, not working or left the job market and compared against concentration task performance using Fisher's Exact test due to small cell sizes. Reporting of concentration as a job requirement was not significantly associated with employment category at either twelve or eighteen months. Moreover, concentration was not significantly associated with a change in employment status from twelve to eighteen months (e.g. leaving the workforce, no change or returning to the workforce). A statistically significant association between these characteristics was not documented with the majority, 84%, remaining employed at both waves. Therefore, the women who no longer worked for some reason were not responsible for the decline in task requirements.

Another possible reason for the decrease in concentration tasks might be because the woman changed positions within the same employer and this activity was simply not required to the degree it once was. The interview prompted for additional industry or occupation specifics only in the event that the individual changed employers from wave to wave. Therefore, this impact cannot be quantified.

However, since the decrease in the concentration task among those women who reported at both twelve and eighteen months was statistically significant, the characteristics of the women who reported a change in their concentration requirement were evaluated in greater detail.

A total of 39 individuals reporting at both timeframes changed their answers from the twelve to the eighteen-month interview. However, the majority (n=32, 82.0%) of these respondents remained employed. This provides some reassurance that the change was probably not due to a large group of respondents leaving the workforce and introducing some bias to their reporting although this potential cannot be ruled out.

Table 24 presents similar data for the prostate cohort. None of the changes in proportion of men performing the individual and the composite tasks were statistically significant at the p<0.05 level.

Table 24: Activity Requirements for Prostate Cohort

Task	12 months (n=243)	18 months (n=230)	p-value	p-value (paired)
Physical effort	126 (51.8)	111 (48.3)	0.68	0.31
Heavy lifting	74 (30.4)	64 (27.8)	0.90	0.53
Stoop/crawl or kneel	119 (49.0)	105 (45.6)	0.71	0.59
Composite Physical Task Required	*154 (63.4)*	*134 (58.3)*	*0.73*	*0.54*
Concentrate	221 (91.0)	185 (80.4)	0.61	0.64
Analysis	198 (81.5)	175 (76.1)	0.33	0.08^
Learn new things	213 (87.6)	186 (80.9)	0.38	0.12
Composite Cognitive Task Required	*234 (96.3)*	*199 (86.5)*	*1.0^*	*1.0^*

^Fisher Exact Test used due to cell size<5

4.1.1.2 Comparison of Domain 1: Activity Limitation

Once the proportions of tasks were calculated and compared, the focus turned to presence of activity limitation for each task caused by the cancer diagnosis and treatment. Activity limitation was measured directly for the discrete tasks included in the survey. As would be expected, limitation in any task was only possible among those individuals who reported having to perform the task. Table 25 displays the results for the proportion of breast cohort respondents who report experiencing a limitation. Heavy lifting was most problematic for women followed by general physical effort. This pattern was observed both at twelve and eighteen months. Regarding cognitive tasks, concentration had the most limitations among the women at both time points.

The decline in the composite physical and cognitive activity limitations from twelve to eighteen months for the individual items and the composite tasks were statistically significant at $p<0.01$. Thus, while the relative proportion of these required tasks did not change significantly from twelve to eighteen months (as evidenced by Table 23), the limitations that women reported decreased over this timeframe. The significant declines were observed in the samples of all respondents and the participants with paired data.

Table 25: Activity Limitation for Breast Cohort

Task	12 months	18 months	p-value	p-value (paired)
Physical effort	133 (52.0)	71 (32.9)	<0.01**	<0.01**
Heavy lifting	88 (66.2)	53 (43.4)	<0.01**	<0.01**^
Stoop/crawl or kneel	76 (34.7)	30 (14.6)	<0.01**	<0.01**
Composite Physical Task Limitation	*176 (59.5)*	*94 (36.3)*	*<0.01***	*<0.01***
Concentrate	121 (32.3)	66 (20.3)	<0.01**	<0.01**
Analysis	92 (29.4)	37 (13.4)	<0.01**	<0.01**^
Learn new things	71 (20.2)	42 (12.9)	<0.01**	<0.01**
Composite Cognitive Task Limitation	*136 (34.3)*	*78 (22.0)*	*<0.01***	*<0.01***

* Statistically significant at p<0.05
**Statistically significant at p<0.01
^Fisher Exact Test used due to cell size<5

Similar to the direction of limitations noted among the women, the proportions of limitations in the individual and composite tasks decreased from twelve to eighteen months among the prostate cohort. The nature of the affected tasks was similar to that documented in the breast cohort. Heavy lifting and physical effort encountered the most limitations for the physical activities while the concentration presented as the most limited task among the cognitive tasks. Overall, fewer of the specific task decreases were statistically significant.

The men only experienced significant decreases in the composite physical limitation (p<0.05). The decrease observed in the composite cognitive limitation was not statistically significant. These same patterns were detected in the group of men with paired data. The results of the limitation analyses for the prostate cohort are displayed in Table 26.

Table 26: Activity Limitation for Prostate Cohort

Task	12 months	18 months	p-value	p-value (paired)
Physical effort	33 (26.2)	16 (14.4)	0.04*	0.06^
Heavy lifting	22 (29.7)	11 (17.2)	0.08	0.18^
Stoop/crawl or kneel	26 (21.8)	6 (5.7)	0.01**^	0.02*^
Composite Physical Task Limitation	*44 (28.6)*	*23 (17.2)*	*0.02**	*0.04**
Concentrate	26 (11.8)	13 (7.0)	0.10	0.15^
Analysis	17 (8.6)	6 (3.4)	0.04*	0.09^
Learn new things	11 (5.2)	5 (2.7)	0.16^	0.22^
Composite Cognitive Task Limitation	*28 (12.1)*	*14 (7.0)*	*0.08*	*0.07*

*Statistically significant at p<.05
**Statistically significant at p<0.01
^Fisher Exact Test used due to cell size<5

4.1.1.3 Comparison of Domain 2: Participation Restriction

The second domain in our disability definition included participation restriction. Women in the breast cohort reported more participation restriction compared to the men. At twelve months, eighteen percent of the women indicated participation restriction vs. nine percent of the men. Fifteen percent of the women continued to report participation restriction at eighteen months compared to 7% of the men. Both groups experienced a decline in participation restriction from twelve to eighteen months. In both cohorts, however, the declines were not statistically significant at p<0.05. The decline remained not statistically significant for the samples with paired data. Table 27 shows the proportion of respondents in both cohorts reporting participation restriction.

Table 27: Participation Restriction Reporting

Cohort	12 months	18 months	p-value	p-value (paired)
Breast	75 (17.9)	60 (14.7)	0.20	0.10
Prostate	22 (9.0)	16 (7.0)	0.40	0.30

Now that the results of the constituents making up the outcome variable, i.e. disability, have been presented, focus can turn to the results of the disability analyses.

4.1.2 Comparison of Physical Disability

Physical disabilities decreased from twelve to eighteen months for both cohorts. However, only the disability decline in the breast cohort from 18% to 10% was statistically significant at $p<0.05$. The confidence in this pattern of decline increased with the paired sample as the significance level increased to 99%. Overall, women experienced significantly greater physical disability compared to men. This trend was anticipated for several reasons. First, women experienced greater proportions of the domains that make up disability, e.g. activity limitation and participation restriction. The second reason for expecting more disability was the more aggressive treatment regimens the women experienced both in terms of receiving chemotherapy and in terms of undergoing multiple treatment types (surgery in addition to radiation and/or chemotherapy). Table 28 displays the proportion of individuals in each cohort having physical disability per the ICF definition (activity limitation with participation restriction).

Table 28: Physical Disability Reporting in those Performing the Task

Variable	12 months	18 months	p-value	p-value (paired)
Breast	51 (17.2)	25 (9.6)	0.01*	<0.01**
Prostate	12 (7.8)	6 (4.5)	0.25	0.70

*Statistically significant at p<0.05
**Statistically significant at p<0.01

4.1.2.1 Physical Disability Status Change

Forty-one women experienced a change in physical disability status between twelve and eighteen months. Of these, 19 (46%) reported their disability improved or resolved from twelve to eighteen months. Sixteen (39%) identified no change in their disability while a lesser proportion, 15% (n=6) stated they developed the physical disability between twelve and eighteen months.

Just nine men experienced a change in physical disability between twelve or eighteen months. Nearly half (44%) of these men enjoyed improvement in their disability status. Unfortunately, the next larger proportion identified a decline in disability status (33%) while the fewest experienced no change (22%).

It became of interest to identify variables that could be associated with worsening or improvement in disability status over time. No association between change in physical status (worsen, stay the same, resolve) and the following variables were noted for the women: cancer stage, treatment, race, physical nature of job as measured by shift length and percent of shift seated, occupation type, availability of sick leave, age or baseline perceived health status. However, baseline income level was significantly associated with the change in physical disability (p<0.05). Women with the lowest income levels were more likely to report physical disability worsened from twelve to eighteen months while women with the highest incomes reported improvement in their physical disability. Also of interest was the degree to which changes in physical disability status accompanied *changes* in perceived health status reports from twelve to eighteen months. Despite reporting physical disability status changes from twelve to eighteen months, these women did not report statistically significant changes in perceived health status evaluations.

In similar fashion, no association between change in physical status (worsen, stay the same, resolve) and the following variables were noted for the prostate cohort: cancer stage, treatment, race, income level, physical nature of job as measured by shift length and percent of shift seated, occupation type, sick leave benefit, age or baseline perceived health status. Also, no significant associations were observed between changes in perceived health reports with disability status change among the prostate cohort.

When evaluating the relationship between disability reporting and employment status at twelve months, a statistically significant association was noted. Individuals not identified to have physical disability at twelve months were more likely to remain employed at twelve months (93%) compared to not working (4%) or leaving the workforce altogether (3%), ($p<0.01$). Women who did report disability were more evenly split with only 1/3 remaining employed, 30% not being employed and 37% leaving the workforce. Similar patterns were observed at the eighteen month timeframe. Fewer individuals with disability worked compared to individuals without disability (96% vs. 24%).

The relationship between disability and employment among the men was similar to what had been observed in the women. A majority (85%) of men without disability were more likely to be employed at twelve months compared to those who did not work (6%) or left the workforce (8%). However, only 42% of those with a disability were employed while 33% did not work and 25% left the workforce. These trends were continued at eighteen months. Most of the men without disabilities (97%) worked compared to just half of those with disabilities (50%).

4.1.3 Comparison of Cognitive Disability

Cognitive disabilities decreased from twelve to eighteen months for both cohorts in a similar fashion to the physical disabilities although the decline from 9% to 5% was only statistically significant for women ($p<0.05$). Again, women experienced significantly greater cognitive disability compared to men, which is likely a result of the same factors identified previously (i.e. greater activity limitation, participation restriction and aggressive treatment). Table 29 displays the proportion of individuals in each cohort having cognitive disability per the ICF definition (activity limitation with participation restriction).

Table 29: Cognitive Disability Reporting

Variable	12 months	18 months	p-value	p-value (paired)
Breast	39 (9.3)	20 (4.9)	0.03*	0.02*
Prostate	7 (2.9)	2 (0.9)	0.19^	0.25^

*Statistically significant at $p<0.05$
^Fisher Exact Test used due to cell size<5

Physical disability was more prevalent than cognitive disability in the breast and prostate cohorts. This relationship is contrasted to the relative proportion of required activity classification where cognitive skills were in more demand than physical skills. Women experienced statistically significantly greater physical disability compared to cognitive disability at twelve months ($p<0.01$). However, although more physical disability was reported at eighteen months compared to cognitive disability by the women, the difference was not statistically significant.

Similarly, men reported more physical disability than cognitive disability at both twelve and eighteen months. As the women experienced, the proportion of physical disability was statistically significantly greater than the proportion of cognitive disability at twelve months ($p<0.05$). The difference between these was no longer statistically significant at eighteen months.

4.1.3.1 Cognitive Disability Status Change

Fewer individuals complained of cognitive disability over the duration of follow-up compared to physical disability. Thirty-six women experienced a change in cognitive disability status between twelve and eighteen months. Nearly half (47%) benefited from an improvement in this type of disability by the eighteen-month interview. Fourteen individuals (39%) had no change while 5 (14%) declined.

Five men complained of cognitive disability at twelve or eighteen months however none worsened over time. Most (60%) improved while the remainder was unchanged.

No associations between changes in cognitive status for the breast cohort and the following variables were detected: cancer stage, treatment, income, race, physical nature of job, occupation, sick leave, age, or baseline perceived health status. Like the pattern observed for physical disability status change, the evolution of cognitive disability status was unaccompanied by significant changes in perceived health status.

Similarly, the prostate cohort had no apparent associations between cognitive disability status change and cancer stage, treatment, income, race, physical nature of job, occupation, sick leave, age, or baseline perceived health status. No association between cognitive disability status change and change in perceived health status was observed for the prostate cohort.

Breast cancer participants with cognitive disability were less likely to be employed compared to participants without cognitive disability at twelve months (33% vs. 90%, $p<0.01$) and eighteen months (40% vs. 94%, $p<0.01$).

The relationship between disability and employment among the men was similar to what had been observed in the women. A majority (84%) of men without disability were more likely to be employed at twelve months compared to only 43% of those with a cognitive disability ($p<0.01$). These trends continued at eighteen months with neither (0%) of the two individuals identified with a cognitive disability working at eighteen months compared to 96% of those without a cognitive disability (p<0.01).

4.2 Study Question 2: Disability Prevalence Disparity Based on Definition

4.2.1 Hypothesis 2: Comparison of Disability Prevalence

The hypothesis regarding variation in prevalence estimates of disability depending on definition was written as:

- H_2: Cancer related physical and cognitive disabilities will be more prevalent at twelve and eighteen months using an activity limitation definition of disability compared to an ICF definition requiring activity limitation and participation restriction.

4.2.1.1 Physical Disability

Activity limitation as a measure of disability results in greater proportions of participants having the label *disability* compared to a definition requiring a combination of activity limitation with participation restriction. This pattern is true for physical tasks at both twelve and eighteen months. The difference in proportions for physical tasks at both timeframes was statistically significant at p<0.01. These results were unchanged when the samples with paired data available were used. Table 30 summarizes the proportions obtained using each definition for the cohorts.

Table 30: Physical Disability Prevalence Comparisons Among the Cohorts

Variable	Activity Limitation	Activity Limitation & Participation Restriction	p-value	p-value (paired)
Breast				
12 Months	176 (59.5)	51 (17.2)	<0.01**	<0.01**
18 Months	94 (36.3)	25 (9.6)	<0.01**	<0.01**
Prostate				
12 Months	44 (28.6)	12 (7.8)	<0.01**	<0.01**
18 Months	23 (17.2)	6 (4.5)	<0.01**	<0.01**

**Statistically significant at p<0.01

4.2.1.2 Cognitive Disability

Again, the definition used to establish disability significantly affects the reported prevalence. An activity limitation definition provides a higher estimate than the ICF definition. Both the breast and prostate cancer cohorts experienced statistically significant decreases (p<0.01) in reported disability between the estimate calculated by the activity limitation definition and the estimate compared to the ICF definition, regardless of timeframe. This relationship held when the individuals with paired data were tested separately. Table 31 demonstrates the reported prevalence estimates for the cohorts based on disability definition.

Table 31: Cognitive Disability Prevalence Comparisons Among the Cohorts

Variable	**Activity Limitation**	**ICF: Activity Limitation & Participation Restriction**	**p-value**	**p-value (paired)**
Breast				
12 Months	136 (34.3)	39 (9.3)	<0.01**	<0.01**
18 Months	78 (22.0)	20 (4.9)	<0.01**	<0.01**
Prostate				
12 Months	28 (12.1)	7 (2.9)	<0.01**	<0.01**
18 Months	14 (7.0)	2 (0.9)	<0.01**	<0.01**

**Statistically significant at p<0.01

4.3 Study Question 3: Association of Factors with Disability

Although two hypotheses were established to address the contextual factors of interest, the variables categorized as personal or environmental were included in the regression models simultaneously. Of note, the employer accommodation variable was eliminated from the regression models after initial data runs and no longer appears as a covariate. Although the variable appeared to influence both types of disabilities initially, the confidence intervals were *very* large. Therefore, the hypotheses are reiterated here yet the results presented will discuss both categories concurrently. All modeling procedures were successful for the breast cancer cohort. Furthermore, all four modeling equations had significant (p<0.01) chi-square values for the models containing the variables compared to a null model. The null model is that which states there is no effect of the independent variables on the dependent variable (133).

The disability models for the prostate cohort were problematic due to small sample sizes. When disability was defined to include activity limitation and participation restriction, a mere dozen were identified to experience either the physical or cognitive outcome. This provided unstable results with very large confidence intervals. Therefore, the multivariate analyses for the prostate cohort are not reported.

4.3.1 Hypothesis 3: Influence of Personal Factors

The third hypothesis sought to assess the following:

- H_3: Personal factors that will place individuals at risk for physical and cognitive disability include minority race, low annual household income, chemotherapy and later staged disease.

4.3.2 Hypothesis 4: Influence of Environmental Factors

The last hypothesis sought to assess the following:

- H_4: Environmental factors (associated with employment) that will place individuals at risk for physical and cognitive disability include blue-collar employment, less sedentary job, and low job satisfaction.

4.3.3 Physical Disability

4.3.3.1 Twelve Month Regression Results

Race, annual household income and treatment were not significantly associated with the presence of disability at $p<0.05$. Moreover, these variables failed to achieve sufficient power (<0.20) to be retained in the final model. The remaining personal factor (disease stage) was found to be significantly associated with the development of disability. As expected, in-situ disease was associated with less physical disability compared to women diagnosed with local disease.

Environmental factors had more impact on physical disability than personal factors when holding variables constant. Shift length and percent of time sitting represented the physical nature of the job. Both variables failed to meet criteria of $p<0.20$ to be retained in the model. The job satisfaction variable also was not included in the final model. However, blue-collar occupation was associated with a higher likelihood of developing physical disability compared to white-collar occupation. Women in a blue-collar occupation were twice as likely as women in white-collar occupations to develop physical disability at twelve months. Another variable that had not been identified a priori for the hypothesis had a significant influence on physical disability. Women without sick leave as a benefit experienced twice the risk of physical disability. Occupation and availability of paid sick leave were correlated with a larger proportion of white-collar workers having paid sick leave available compared to blue-collar workers. Table 32 shows the odds ratios and associated p-values for the variables that remained in the model, i.e. those variables that had p-values <0.20 during the stepwise process.

Table 32: Regression Results for Physical Disability at Twelve Months Among Breast Cancer Cohort (n=279 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Never married	0.3	0.11	0.1 – 1.3
Some college	0.5	0.08	0.2 – 1.1
In-situ disease	0.1	<0.01**	0.0 – 0.4
Environmental			
Blue collar occupation	2.2	<0.05*	1.1 – 4.2
No sick leave	2.1	<0.05*	1.2 – 4.0

*p<0.05, **p<0.01

Reference categories include: married, college degree, locally staged disease, white-collar occupation, and having sick leave

The failure of treatment to influence disability was considered more carefully. Cancer stage and treatment were strongly correlated with women diagnosed at later stages undergoing more aggressive therapy. Therefore, the logistic regression was re-run dropping the cancer stage variable to assess the possible contribution of treatment. This resulted in treatment having a significant association with physical disability at twelve months. Specifically, women undergoing chemotherapy were 3.2 times more likely to experience physical disability compared to women having just surgical therapy as displayed in Table 33.

Table 33: Regression Results for Physical Disability at Twelve Months Among Breast Cancer Cohort – Cancer Stage Eliminated (n=279 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Never married	0.3	0.12	0.01 – 1.4
High school diploma or less	1.8	0.11	0.9 – 3.6
Chemotherapy	3.2	<0.01**	1.4 – 7.3
Environmental			
Blue collar job	1.7	0.13	0.8 - .5
No sick leave	2.0	<0.05*	1.1 – 3.9

*p<0.05, **p<0.01

Reference categories include: married, college diploma, surgery, white collar job and having sick leave

4.3.3.2 Eighteen Month Regression Results

At eighteen months only one variable, sick leave, significantly influenced physical disability. Once again, race, income, physical nature of job and job satisfaction failed to have a significant relationship with physical disability. Occupational classification just missed the cut-off for the stepwise procedure (p=0.2065). Stage did not have an impact at this time and treatment just missed the cut-off to be considered significant. Although not statistically significant, the odds ratio associated with chemotherapy hinted at a three-fold increase in likelihood of physical disability at eighteen months. Marital status remained in the model yet was not significant. At eighteen months, nothing appeared to reduce the probability of developing physical disability. However, not having sick leave was associated with a four-fold increase for the development of physical disability compared to women who had sick leave as a benefit when controlling for the factors in the model. Table 34 presents the odds ratios for the variables remaining in the model with p<0.20.

Table 34: Regression Results for Physical Disability at Eighteen Months Among Breast Cancer Cohort (n=221 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Formerly married	2.3	0.08	0.9 – 5.8
Chemotherapy	2.9	0.05	1.0 – 8.3
Environmental			
No sick leave	4.0	<0.01	1.6 – 10.5

*p<0.05, **p<0.01
Reference categories include: married, only surgical treatment and having sick leave

Despite the inclusion of both cancer stage and treatment in the model for physical disability at eighteen months, the treatment variable was able to come through as a covariate to be retained. This time, the regression was re-run twice. Once after eliminating cancer stage to see if treatment would become more significant. The second run eliminated treatment to see if cancer stage would appear in the model. With cancer stage out of the model, the evaluation of the model estimates and statistics were unchanged. With treatment out of the model, absence of sick leave continued to exert a strong influence on the development of disability. Table 35 displays the outcome of the model revised by eliminating treatment.

Table 35: Regression Results for Physical Disability at Eighteen Months Among Breast Cancer Cohort – Treatment Eliminated (n=222 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Formerly married	2.3	0.08	0.9 – 5.8
Chemotherapy	2.9	0.05	1.0 – 8.3
Environmental			
Blue-collar	1.8	0.20	0.7 – 4.2
No sick leave	3.8	<0.01**	1.4 – 9.9

*p<0.05, **p<0.01
Reference categories include: married, surgery, white-collar and having sick leave

4.3.4 Cognitive Disability

4.3.4.1 Twelve Month Regression Results

As hypothesized, race did significantly impact cognitive disability at twelve months. African-American women were nearly three times as likely to develop cognitive disability compared to women whose race was classified as White/Other. Income, job satisfaction and physical nature of job once again were not retained in the model. Occupational classification did not meet criteria to stay in the cognitive disability model as it had for physical disability. Women with later staged disease were three times more likely to develop cognitive disability at twelve months compared to women with locally staged disease. Marital status, education and vigorous activity were retained in the final model yet not at statistically significant levels. Table 36 displays the results for the modeling process.

Table 36: Regression Results for Cognitive Disability at Twelve Months Among Breast Cancer Cohort (n=277 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
African-American	2.7	<0.05*	1.2 – 6.1
Formerly married	1.8	0.14	0.8 – 4.0
Never married	0.1	0.13	0.0 – 1.8
High school diploma or less	1.9	0.08	0.9 – 4.2
No vigorous activity weekly	0.4	0.07	0.1 – 1.1
Regional/distant/unknown stage	3.0	<0.01**	1.4 – 6.4
Environmental			
No sick leave	2.1	0.05	1.0 – 4.4

*p<0.05, **p<0.01
Reference categories include: White/Other race, married, college diploma, some vigorous activity weekly, locally staged disease and having sick leave

Cognitive disability at twelve months was significantly related to cancer stage when both cancer stage and treatment variables were included in the model. With cancer stage present, treatment was not sufficiently strong enough to be retained. As was done for physical disability, the cognitive disability regressions were re-run after eliminating cancer stage to determine if treatment would remain in the models. At this time, treatment did remain in the model and was associated with a statistically significant relationship with cognitive disability. Women receiving chemotherapy experienced a six fold greater likelihood of developing a cognitive disability compared to women receiving surgery when controlling for other variables. The results from the revised model are presented in Table 37.

Table 37: Regression Results for Cognitive Disability at Twelve Months Among Breast Cancer Cohort – Cancer Stage Eliminated (n=374 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
African-American race	2.7	<0.05*	1.2 – 6.0
Formerly married	1.7	0.15	0.8 – 3.6
Never married	0.2	0.15	0.0 – 1.8
High school diploma or less	1.7	0.14	0.8 – 3.7
No vigorous activity weekly	0.4	0.05	0.2 – 1.0
Chemotherapy	6.4	<0.01**	2.1 – 19.0
Environmental			
No sick leave	1.8	0.10	0.9 – 3.8

*p<0.05, **p<0.01

Reference categories include: White/Other race, married, college diploma, some vigorous activity weekly, surgery, and having sick leave

4.3.4.2 Eighteen Month Regression Results

At eighteen months, race no longer influenced cognitive disability. Annual household income, physical nature of the job, job satisfaction and occupational status failed to achieve sufficient association to even be retained in the modeling process. Treatment was not kept in the model in the face of cancer stage. Women with more extensive disease experienced greater cognitive disability as expected. Lack of sick leave again was found to significantly affect disability. Women who were formerly married were three times more likely to report cognitive disability holding all factors constant compared to married women. Table 38 presents the results.

Table 38: Regression Results for Cognitive Disability at Eighteen Months Among Breast Cancer Cohort (n=221 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Formerly married	3.6	<0.05*	1.4 – 9.7
High school diploma or less	2.2	0.11	0.8 – 5.8
No vigorous activity weekly	0.3	0.10	0.1 – 1.3
Regional/distant/unknown stage	3.0	<0.05*	1.1 – 8.1
Environmental			
No sick leave	4.9	<0.01**	1.7 – 14.1

*p<0.05, **p<0.01

Reference categories include: married, college diploma, some vigorous activity weekly, locally staged disease and having sick leave

Cognitive disability at eighteen months had similar findings whether cancer stage and treatment were included in the regression or just the treatment variable. Once stage was eliminated, treatment was able to remain sufficiently strong to have a statistically significant association with cognitive disability as shown in Table 39.

Table 39: Regression Results for Cognitive Disability at Eighteen Months Among Breast Cancer Cohort – Cancer Stage Eliminated (n=304 observations retained)

Contextual Variable	Odds Ratio	P-value	95% CI
Personal			
Formerly married	2.9	<0.05*	1.1 – 7.7
High school diploma or less	2.1	0.14	0.8 – 5.5
No vigorous activity weekly	0.3	0.07	0.1 – 1.1
Chemotherapy	6.1	<0.05*	1.4 – 28.3
Environmental			
No sick leave	4.3	<0.01**	1.6 – 11.8

*p<0.05, **p<0.01

Reference categories include: married, college diploma, some vigorous activity weekly, surgery, and having sick leave

CHAPTER 5: DISCUSSION

The results of this study indicate that physical and cognitive work-related disabilities occur in women and men subsequent to breast and prostate cancer diagnosis and treatment. Both types of disability are generally greater at twelve months post-diagnosis than eighteen months although the declines are not always statistically significant. Furthermore, this study reinforces the critical importance of an explicit definition of disability. Statistically significant variation was observed in physical and cognitive prevalence estimates within the same population using two common definitions. Prior work on disability associated with cancer has identified a variety of contextual factors that have been shown to significantly impact disability. Results obtained from the logistic regression performed in this study did not always support the findings that have been reported in other literature.

5.1 Study Question 1: Prevalence and Direction of Disability Change

5.1.1 Hypothesis 1: Comparison of Physical and Cognitive Disability

The first hypothesis of this study was to test the direction of disability prevalence changes.

- H_1: Cancer related physical and cognitive disabilities will decrease as the timeframe from diagnosis increases from twelve months after diagnosis to eighteen months after diagnosis.

In order to evaluate the changes in disability, attention must be focused on the components that contribute to this measure. Firstly, matters regarding changes in the composite activity requirement covariates were considered followed by examination of the indicator variables (activity limitation and participation restriction) that were multiplied to obtain disability estimates.

5.1.1.1 Comparison of Physical and Cognitive Activity Requirements

The composite task measures were established as dichotomous measures. The interviews did not have the capacity to ensure the responses provided to each particular task were mutually exclusive of the other tasks. Therefore, no effort was expended to generate a composite variable that would take into account the *cumulative* degree of physical activity required by each participant. The dichotomous variable was selected to minimize "multiple counting" on the outcome of interest although this decision could underestimate the extent of physical activity required in the workplace. As would be expected from the additive nature of the composite measure, the proportion of those who had performed the composite physical task exceeded the proportions carrying out each component task. This occurred because some individuals might not admit to performing a task such as heavy lifting but state they do another physical effort and therefore contribute to the numerator for the composite physical task. Therefore, the prevalence of heavy lifting would not be as substantial as the composite report.

Ultimately, no statistically significant difference between the two time periods was observed in the proportion of respondents performing physical tasks for either cohort. Similarly, the proportion of participants requiring cognitive activity did not change from twelve to eighteen months. This pattern is significant for the subsequent work that will focus on comparing disability prevalence estimates. The fact that the overall demand of physical or cognitive tasks did not vary indicates that resulting observations of documented decreases in disability are not simply due to changes in the work tasks.

Physical and cognitive activities were not rare events for the jobs held by our participants. Cognitive tasks were in much higher demand compared to physical tasks with nearly all participants, 90% or more, acknowledging cognitive activity. Physical activity on the other hand was required by only 60-70%. However, results suggest that physical disability was more prevalent than cognitive disability.

Regardless, disabilities occurring with these tasks significantly affect employment. Focused analyses reveal that persons with physical and cognitive disabilities were statistically significantly less likely to remain employed at twelve and eighteen months compared to those who identified to not have a physical or cognitive disability. Specifically, individuals with physical or cognitive disability were represented to a greater degree among the cohort of individuals who left the workforce at both time points. Of those that continued to work despite a disability, the average workday was significantly less than those without disability.

Since physical disability was more prevalent, additional focus was directed toward occupation characteristics. Specifically, it was expected that blue-collar workers would be more likely to be engaged with physically demanding jobs. The analysis of association between occupation and physical task requirement revealed a statistically significant association between these variables for both cohorts. As expected, the proportion of blue-collar workers having to perform physical tasks at their jobs was statistically significantly greater than the proportion of white-collar workers for the women and men. The results obtained for the analysis of occupation with cognitive task revealed white-collar workers carrying out this type of activity to a greater degree than blue-collar workers.

The physical nature of a job as measured by the reporting of physical tasks was confirmed by analyzing the sedentary aspect of a job. The percentage of time spent sitting during their work day was calculated for each participant. The percentage of time spent sitting was statistically significantly different for participants having to perform physical tasks compared to those who did not as was expected. Women who did not have to perform physical tasks spent 63% of their workday sitting compared to women who did undertake physical tasks and only sat 38% of their workday, (ttest $p<0.01$). Men experienced similar results with those not having physical tasks spending 68% of their day sitting compared to 37% of those performing physical tasks ($p<0.01$).

5.1.1.2 Comparison of Domain 1: Activity Limitation

Work related activity limitations appear to significantly decrease as elapsed time from diagnosis and treatment increases for women treated for breast cancer. Limitations occur more with physical tasks than cognitive tasks in women despite the fact that jobs often require more cognitive skills. The proportion of women complaining of physical limitation at eighteen months was nearly half that reported at twelve months. A smaller proportion, just 1/3 of the women complained of cognitive limitation at twelve months which decreased to 22% at eighteen months.

Men diagnosed with prostate cancer experience different degrees of limitations. Although activity limitations decrease as time from diagnosis increases for men, only the decrease associated with physical limitations was statistically significant. The inability to detect a significant change in cognitive limitations could be due in part to study power issues. As did the women, men enjoyed nearly one-half of the physical limitations at twelve months compared to eighteen months. Cognitive limitations were uncommon compared to physical limitations within the prostate cohort and the decrease observed in these limitations did not achieve statistical significance. The difference in limitations was likely due to the different treatment regimens between men and women. Men were more likely to receive surgical intervention only for their diagnosis.

The fact that women had higher proportions of physical limitations was somewhat expected because more were required to perform physical tasks compared to men. However, the cognitive job demands for both cohorts were equal yet the women experienced greater limitations in performing these tasks than the men. This may reflect the "chemo-brain" phenomenon that others have acknowledged. A statistically significant association between cognitive limitation and chemotherapy at twelve and eighteen months ($p<0.01$) was documented with chemotherapy patients complaining more about cognitive limitations.

Finally, attention was turned just to those individuals who had paired data available for the twelve and eighteen month task and limitation measures. This subgroup of women also experienced statistically significant decreases in physical and cognitive activity limitation. The results for the men with paired data were unchanged. The physical limitation variable changed significantly over time while the cognitive limitation variable did not.

5.1.1.2.1 Supplemental Activity Requirement Comparisons – Physical Task

The results of this study indicated activity limitations decreased over time even when the relative proportion of individuals reporting the task did not. Several explanations for this pattern exist. One explanation relates to the fact that all participants were asked to answer questions regarding activity and limitation regardless of their employment status at the time of the interview. It is possible that recall bias associated with leaving the workforce may have altered perceptions from twelve to eighteen months. However, analyses of activity requirement and activity limitations did not vary significantly by employment category (employed, not employed, retired/disabled/unable to work) or change in employment category (leaving/joining the workforce vs. no change). Similar results were obtained for the physical and cognitive tasks and limitations.

Therefore, another option was that sub-groups of respondents were being lost preferentially. Figures 7 and 8 depict the proportion of breast and prostate respondents, respectively, that performed each task at the various categories. The breast cohort did have a statistically significant ($p<0.01$) change in the relative proportions responding they had to stoop *all of the time* or *some of the* *time*. However, since both these categories would be collapsed together for the physical task composite variable, the overall impact of this shift was trivial. No statistically significant changes were noted in the relative proportion of prostate cohort respondents reporting each physical task time commitment option.

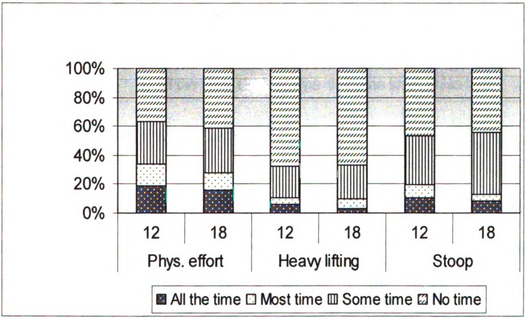


Figure 7: Breast Physical Tasks

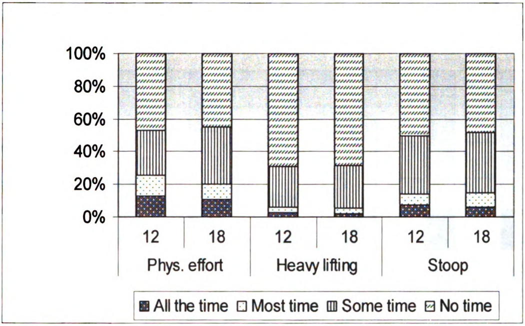


Figure 8: Prostate Physical Tasks

The next step was to compare the individuals reporting on the individual tasks making up the composite cognitive task variable. The breast cohort did experience some differences in the analysis task. Similar to the stooping requirement, the significant difference occurred among respondents reporting the all of the time and most of the time categories. Since both these categories contribute equally to the composite variable, the overall impact on the composite measure would not be critical. The prostate cohort again experienced no statistically significant difference in the relative proportion of individuals reporting each time commitment. Figures 9 and 10 display the relative proportions of each response for the breast and prostate cohort, respectively.

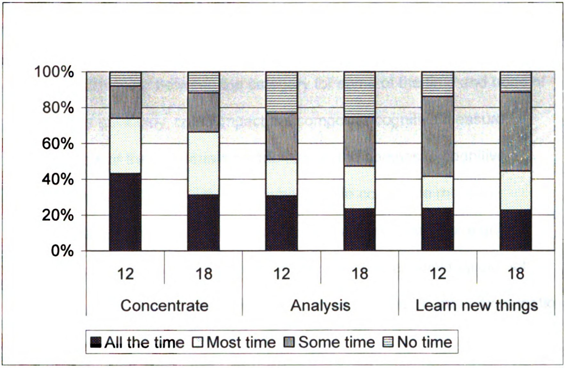


Figure 9: Breast Cognitive Tasks

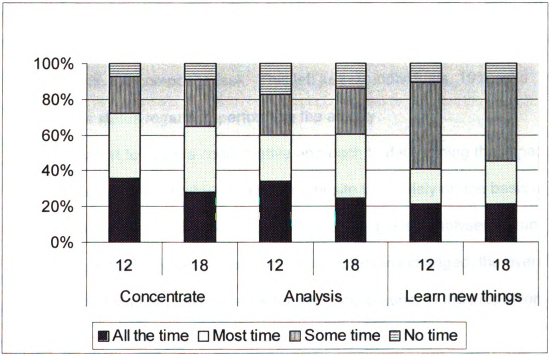


Figure 10: Prostate Cognitive Tasks

However, the change in reporting categories among the breast cohort for the concentrate task was statistically significant ($p<0.01$) and did involve respondents changing between the category for some of the time and none of the time. This obviously, could impact the composite cognitive measure.

A review of the individuals contributing to the composite cognitive measure identified 32 total individuals who had the composite measure determined solely due to the concentration task at either twelve or eighteen months. Recall that this would occur in the event that the individual did not perform analysis or learning new things as part of their job. Further examination of these individuals showed that the majority, n=20 (62.5%), had no change in their performing the task and no change in reported activity limitation of the task between twelve months and eighteen months. Six individuals, 19%, reported no change in conducting the activity but rather just a change in the activity limitation associated with the composite task. This left just six individuals, 19%, who changed their status regarding performing the activity.

In an effort to apply a conservative approach to determining the impact of these individuals who contributed to the composite task solely on the basis of their concentration task, all 32 were omitted and unadjusted analyses re-run. Although the actual p-values of some of the comparisons changed, the overall interpretation of statistical significance for the comparisons: 1) the proportion of the composite cognitive task requirement, 2) the proportion of the cognitive task limitation and 3) the proportion of participation restriction at the $p<0.01$ or $p<0.05$ levels were unchanged. The ultimate interpretation of the change in cognitive disability remained statistically significant but achieved greater levels of significance, i.e. moved from $p<0.05$ to $p<0.01$. Since the presence of these individuals appears to have no effect on the components of disability and dilutes rather than establishes significance of overall disability findings, the more conservative approach selected was to retain them in order to maximize the number of respondents available for the multivariate analyses.

5.1.1.2.2 Activity Limitations Compared to National Estimates

We see that the individuals in this study had less overall limitation when evaluating activity limitation against the 50+% national estimate provided by Ness and colleagues (2006) (1). At twelve months, the breast cohort approached this limitation proportion for physical activities only. As mentioned above, the limitation among the men was much less than this at both twelve and eighteen months. This disparity may be a result of the participants enrolled in this study versus the general U.S. population. However, it could be an example of the difficulty in comparing estimates without clear definitions of the outcomes provided. The general pattern of greater physical disability (as defined by limitation) compared to cognitive limitation reported in the literature was supported by the findings of this study. Despite the greater number of participants having to carry out cognitive tasks for their job, fewer experienced limitations in these activities compared to the physical tasks.

5.1.1.3 Comparison of Domain 2: Participation Restriction

A smaller percentage of the breast cancer cohort, less than 20%, documented any participation restriction with their work in contrast to the larger proportions experiencing activity limitations. This prevalence did not change markedly from twelve to eighteen months. Similarly, less than ten percent of men reported participation restriction at twelve months. The small decrease to 7% at eighteen months did not reach statistical significance at $p<0.05$. The participation restriction experienced by the individuals in this study was less than the 30% national estimate obtained by Ness (2006) despite these participants being much closer to their diagnosis.

In contrast to the activity limitation covariates, the participation restriction variable was constructed from other data. Measures such as weekly hours worked, working full or part-time, and reductions in salary from baseline to twelve and eighteen months were used to generate the restriction variable. The benefit of these questions was that response options to these made it possible to identify occurrences that were related to the cancer diagnosis and treatment. However, it is likely that additional participation restriction may exist within these groups yet the surveys lacked specific questions that could tease out this concept more fully. This may explain the discrepancy between these findings and Ness' results.

When evaluating activity limitation and participation restriction as the necessary components of disability, these data indicate participation restriction seems to be the more difficult criteria to fill. With few exceptions, the prevalence of activity limitation for each task (including the composite measures) exceeded the proportion of women documenting participation restriction regardless of time. A similar relationship between these domains was noted for the tasks (specific and composite) within the male cohort. Due to the nature of the survey questions and the need to create indicator variables for participation restriction, the validity of activity limitation data is likely superior to participation restriction.

5.1.2 Comparison of Physical Disability

Physical disability prevalence among the cohort of women statistically significantly decreased from 13% at twelve months to 7% at eighteen months, $p<0.05$. A positive confirmation for the sub-sample of women that had paired data available documented statistically significant decreases in physical ($p<0.01$) disability from twelve to eighteen months. Thus, the women in this study enjoyed decreasing disability as time elapsed since their diagnosis and treatment. One interpretation of this relationship may be that although they appeared to endure greater levels of disability initially, their conditions were more transient in nature.

Men also experienced a decrease in physical disability from twelve to eighteen months yet this finding was not statistically significant. When restricted to the paired samples, the decrease remained not statistically significant. This could suggest then, that although men appear to experience less disability secondary to their disease process, the conditions may represent more permanent conditions compared to those that women experience.

It should be noted that disability occurred in a smaller proportion of individuals than either activity limitation or participation restriction as expected. For these purposes, disability was constructed based on two domains, activity limitation and participation restriction, as recommended by the ICF model. While the model actually requires a third domain, the health condition measure, this was considered inherent in both cohorts as a result of their cancer diagnosis.

Regarding the disability outcome, it was not surprising that women experienced greater disability related to their cancer diagnosis and treatment compared to men. Women experienced greater prevalence of each disability component (e.g. activity limitation and participation restriction) compared to the men so it is expected that they would incur greater burden of the combined measure. Also, women underwent more aggressive treatment regimens than did men leading to greater adverse outcomes. These patterns confirmed that documented by census data regarding increased disability in females compared to males after fifteen years of age.

5.1.3 Comparison of Cognitive Disability

The decline in cognitive disability from 9% at twelve months to 5% at eighteen months was also statistically significant within the breast cancer cohort ($p<0.05$). Again, the sub-sample of women with paired data also experienced a statistically significant decrease in cognitive ($p<0.05$) disability.

Cognitive disability also declined in men from twelve to eighteen months. However, this was not a statistically significant change. When restricted to the paired sample, the decrease remained not statistically significant.

As noted with the physical disability outcome, the experience of the women may indicate a transient condition that improves over time. However, these data do not contain information over a longer duration that could address the possibility of complete recovery. It may be that some low level of disability is a permanent condition.

The men however, did not show any improvements in physical or cognitive disabilities. The small prevalence estimates may represent a baseline disability that is present as a permanent condition. Or, it may be that complete recovery is possible but the men were not followed for a sufficient length of time to measure this. Yet another consideration is that the study lacked the power to detect a decrease in disability.

5.1.4 Factors Associated with Changing Disability from Twelve to Eighteen Months

The results indicate that for most participants, disability status was a relatively stable condition from twelve to eighteen months post-diagnosis. Among the breast cancer cohort experiencing a change in disability, just slightly more documented an improvement compared to no change for both physical and cognitive types of disabilities. A similar pattern was noted for the men. A promising observation among the women is that those reporting disability worsened represented less than twenty percent of those having a change. A higher proportion of men reported physical disability worsened yet none claimed of worsening cognitive disability.

Small cell sizes prohibited regression modeling although ordered logistic regression was considered to evaluate the disability change over time as a categorical variable with three levels. Therefore, some unadjusted analyses were performed to evaluate if associations were present. Changes in physical disability over time had no associations with cancer stage, treatment, income, race, physical demands of job and occupation. The only variable to have an association was baseline health status ($p<0.05$) among the women. A greater proportion (43%) of individuals who worsened over time claimed to have only a fair/poor perceived health status compared to those reporting a good or very good/excellent health status. This suggests that women who have compromised health at the time of a cancer diagnosis may be at risk for ongoing physical disability. This relationship would support that published in the scientific literature.

Since the physical disability measure was referenced to the work environment, the lack of association between changes in disability and occupational status was somewhat surprising. However, when evaluating disability change against employment status change between twelve and eighteen months, women did experience a significant association. Women who reported a worsening of their disability status were more likely to have left the workforce compared to women who reported their disability status had improved.

Changes in cognitive disability over time in the breast cancer cohort were associated with cancer stage and age at diagnosis. As expected, those who worsened over time were more likely to be diagnosed with regional disease (80%). These associations reinforce the importance of early screening and detection. Individuals able to receive treatment before cancer has spread are then less likely to have their disability status exacerbated over time. Again, occupational status was not associated with cognitive disability change. However, unlike physical disability change, the change in cognitive disability was not related to employment change between twelve and eighteen months.

No significant associations were observed between men who changed their physical or cognitive disability status over time and the variables listed above. It is probable the study did not have sufficient power to test these relationships.

5.2 Study Question 2: Variation in Reported Prevalence Due to Disability Definition

5.2.1 Hypothesis 2: Comparison of Disability Prevalence

- H_2: Cancer related physical and cognitive disabilities will be more prevalent at twelve and eighteen months using an activity limitation definition of disability compared to an ICF definition requiring activity limitation and participation restriction.

These analyses show the importance of a clear definition for disability. When framed only by activity limitation, prevalence estimates of physical and cognitive disability were significantly greater than estimates generated by a framework of activity limitation with participation restriction when measured on the same subjects. The differences between approximations were on the order of three to four-fold, and were all statistically significant at $p<0.01$. The variability reported within the same study sample shows how difficult it might be to compare disability rates among these participants to other groups in the literature.

One concern with the activity limitation definition of disability is the tendency to emphasize the pathologic disruption of the individual over the capability of performing a social role. An individual may be unable to stand upright to perform surgery in the conventional manner. However, this does not necessarily mean the individual is incapable of being a surgeon. Peter A. Galpin, MD, FACS, successfully worked with a wheelchair manufacturer to design an instrument that could support his body so that he could operate at the same level as the rest of a surgical team. Therefore, although he experienced an activity limitation in that he is a paraplegic and cannot walk, he pursued environmental assistance that allows him to operate within the confines of this limitation. This individual would likely be considered disabled by the activity limitation definition but not necessarily by the ICF definition including participation restriction.

Continued debate and discussion regarding a suitable disability definition and model is necessary by the communities focused on "disability". Perhaps the ICF definition is too restrictive while the activity limitation does not sufficiently discriminate the concept of disability as the negative interaction between someone and their contextual factors. In the absence of a well-defined and widely accepted definition, disability prevalence estimates will likely vary even within similar conditions and under similar environments. Furthermore, informing policy, legislation or social campaigns and trying to evaluate their effectiveness will be difficult at best without a clear focus on the condition and what it represents.

5.3 Study Question 3: Association of Factors with Disability

These study questions sought to identify the relationship between contextual factors with the presence of disability using logistic regression. Robust standard errors were used to provide estimates in case the models were not well specified. Because of small numbers, modeling was unsuccessful on the prostate cohort.

5.3.1 Hypothesis 3: Influence of Personal Factors

The third hypothesis was interested in evaluating the association between disability and personal characteristics.

- H_3: Personal factors that will place individuals at risk for physical and cognitive disability include minority race, low annual household income, chemotherapy and later staged disease.

5.3.2 Hypothesis 4: Influence of Environmental Factors

The last hypothesis was interested in evaluating the association between disability and environmental (employment) characteristics.

- H_4: Environmental factors (associated with employment) that will place individuals at risk for physical and cognitive disability include blue-collar employment, less sedentary job, and low job satisfaction.

5.3.3 Physical Disability

5.3.3.1 Twelve Month Regression Results

Both personal and environmental contextual factors influenced the final model for physical disability at twelve months yet neither race nor income specifically appeared to influence the presence of physical disability. The environmental variables that did significantly influence physical disability included blue-collar occupation and lack of sick leave.

Women with in-situ disease were less likely to experience physical disability compared to women with local disease. This relationship was anticipated; more extensive disease would generally require more aggressive treatment.

The interaction of stage and treatment however was of concern. Of note, the women in the in-situ group underwent significantly less chemotherapy for treatment than women in the local stage group ($p<0.01$). Therefore, early detection is critical not only to enhanced survival but appears to be associated with decreased likelihood of physical disability as well. Although treatment had been included as a variable in all the modeling processes, it only was retained in the final model for the long-term physical disability. Because of the correlation between stage and treatment, the models were re-run without cancer stage. Subsequently, treatment did have an impact on physical disability as expected. Chemotherapy was significantly associated with increased risk of physical disability at twelve months and just missed the cut-off for increasing risk at eighteen months.

Women in blue-collar occupations were at twice the risk for physical disability compared to women employed in white-collar occupations. Similarly, women without a sick leave benefit were at greater risk of physical disability than women who had sick leave.

Several variables selected to represent the physicality of a job were included in the modeling process. These variables were the duration of a working shift (in hours) and the percent of that shift spent seated. Neither variable was sufficiently influential on physical disability to be retained in the models during the stepwise process. The variable related to job satisfaction also failed to remain in the model.

However, it is possible that the influence of a more physical job was incorporated within other variables such as occupation type. Occupational status was shown to influence the likelihood of physical disability at twelve months. Women who were classified as having blue-collar occupations had significantly less time during their work shift spent seated compared to women in white-collar occupations. Similarly, women in blue-collar occupations were at increased risk for physical disability. Although the physical demands of the job were not retained in the final models, women in blue-collar jobs were shown to have more physically demanding jobs than those in white-collar jobs. This may explain why they experienced greater physical disability. The increased likelihood may also be due to the more stringent scheduling that blue-collar jobs may require. Women in white-collar professions may enjoy more flexibility with scheduling. Therefore, although they may be experiencing the same adverse effects, i.e. fatigue, they might be able to modify their work hours to lessen the impact of participation restriction.

A similar argument may be made for the lack of sick leave being associated with increased likelihood of physical disability. If women are not able to take time off from work to recuperate from the cancer treatments, their physical capacity will be compromised. Women suffering from fatigue or pain are less likely to approach physical activity with the same zeal as if they did not have these conditions. This in turn, may adversely affect their job performance with respect to physical demands.

The continued persistence of paid sick leave as a significant influential variable in disability is intriguing. Paid sick leave is generally associated with positions that would be considered white-collar or high-paying and these variables were included in the modeling procedures. However, paid sick leave may be associated with blue-collar positions if the individuals enjoy union membership that has bargained for this particular benefit. Among the participants in the breast cohort who were classified as blue-collar workers, only 1/3 reported they belonged to a union. However, when comparing the sick leave benefit of blue-collar workers who were in a union versus those who were not union members, a statistically significant association was observed with nearly 90% of union members having sick leave while only 40% of non-union members had sick leave. When the model was re-run after including the union variable, the sick leave variable had been replaced by the union variable as a significant predictor. As expected, those who were union members had less risk of physical disability at twelve months compared to those who were not union members (OR=0.29, 95% CI: 0.11 – 0.71, $p<0.01$).

5.3.3.2 Eighteen Month Regression Results

Prolonged physical disability, i.e. that present at eighteen months, was associated with lack of sick leave. Women without sick leave appeared to have nearly four times the risk for long term physical disability compared to women with sick leave as a benefit. The associations of sick leave at twelve and eighteen months suggest that the impact on physical disability increases over time. Prolonged adverse effects are significant when individuals do not have the optimum time away to recover fully. Of note, women without sick leave were employed in more physically demanding jobs with 39% of their time sitting compared to 49% for women with sick leave (ttest $p<0.01$). The influence of union membership was evaluated in light of the strong association noted between sick leave and long term physical disability. At eighteen months, union membership did not affect the relationship between sick leave and physical disability and was not significant itself.

5.3.4 Cognitive Disability

5.3.4.1 Twelve Month Regression Results

Personal variables were significantly associated with the presence of cognitive disability at twelve months. In contrast to physical disability, race was a statistically significant predictor of cognitive disability with African-American women having nearly three times the risk of white/other women for cognitive disability. This pattern supports what has been described in disability literature.

This association may be due to the increased representation of African-American in the subgroup of women diagnosed at later stages.

Cancer stage also impacted cognitive disability at twelve months for women with breast cancer. Women diagnosed with regional/distant or unknown disease were three times more likely to have cognitive disability compared to women with local disease. This relationship evolved as expected. Women with more invasive disease had more extensive treatment regimens and presumably more untoward effects. In this sample, the proportion of women with local disease undergoing chemotherapy regimens was less than the proportion of women with widespread disease.

Paid sick leave was not significantly associated with cognitive disability and just missed the formal cut-off value. Therefore, the model was re-run adding the union variable into the model to examine what impact this would have. Similar to what was observed for physical disability, union membership was protective against cognitive disability (OR=0.26, 95% CI: 0.1 – 0.8, $p<0.05$) and the sick leave variable was no longer retained in the model.

5.3.4.2 Eighteen Month Regression Results

At eighteen months, extensive disease continued to be associated with an increased risk for cognitive disability. Along with this, lack of sick leave again became significantly associated with increasing risk of cognitive disability. This suggests the importance of sufficient time for recovery from cancer treatments. Women able to take advantage of paid sick leave experienced not only less long-term physical disability but also less long-term cognitive disability. Union membership did not impact the relationship observed between sick leave and long-term cognitive disability.

Marital status became an important variable for long-term cognitive disability. Women who were separated, divorced or widowed were over three times more likely to suffer cognitive disability compared to women who were married during their cancer episode. This may reflect a lack of social support from which to draw among women who were formerly married. Alternatively, this may be in part due to available resources. Married women might not rely solely on their own employment for financial or health care coverage. Therefore, formerly married women may be less willing to risk job loss and continue working without adequate recovery periods.

The association between chemotherapy and cognitive disability was apparent when cancer stage was removed from the model. In fact, treatment exerted the greatest influence on cognitive disability in the short and long-term among the independent variables. This supports the notion of a "chemo-brain" phenomenon about which some patients complain. These observed relationships also support what has been described in the literature regarding impaired cognitive function subsequent to chemotherapy. Since dosing was not included as part of data collection, a dose-response evaluation could not be conducted.

5.4 Limitations Associated with Project

5.4.1 Overview

Several limitations of this study must be acknowledged. The primary issue arises from using an existing data set to answer different study questions. A sampling scheme powered to answer these questions was not carried out. Based on the disability estimates obtained from this sample and the available participants, the power estimates ranged from 66% down to 13%. All the available respondents remaining in the subject pool at twelve and eighteen months were included in these analyses yet the disability definition required the presence of both activity limitation and participation restriction which resulted in small numbers having the outcomes of interest.

Furthermore, issues related to framing of interview questions must be recognized. Since this study was not the primary purpose of the funded study, the most direct manner of obtaining data related to participation restriction and disability was not available. Instead, indicator variables were necessary to represent these domains. Activity limitation questions were not without their own problems. No examples of activity were provided to subjects and no measurement of capacity for physical activity was available.

Another limitation is the geographic restriction of these results. The scope of this study is work-related disability as reported by individuals residing in Wayne, Oakland and Macomb counties. Individuals residing in rural areas may experience disability in varying amounts and patterns.

In addition to the issue of the limitation of the catchment area for participants, there are also concerns about the representativeness of these respondents to the larger population that may be diagnosed with breast or prostate cancer. Despite the advantages of this particular registry system, the cases recruited to the study were largely White and of higher income levels. The employment eligibility and telephone criteria may have resulted in differential participation.

While a great deal of baseline data was available for the multivariate analyses, some of the employment measures were only first addressed at the twelve-month interview. This calls into question whether these employment variables were independent variables or dependent variables in light of the disability outcome.

Lastly, with the exception of SEER provided stage and treatment information, all data regarding job tasks, limitations and participation restriction were based solely on self-report. Verification of data provided against medical or employment records was not possible.

5.4.2 Study Participants

By design, the participants in this study were at least 30 years old and were employed at the time of diagnosis. The men were significantly older than the women, 55 years vs. 50 years ($p<0.01$). Since disability has been shown to increase as age increases, this might indicate that the men would experience greater disability than the women. However, national disability statistics also claim that women suffer more disability than men beyond fifteen years of age which would then argue for increasing disability prevalence among the female cohort in this study.

Comparisons of employment-related factors between men and women are not always valid and a key feature of this study was the focus on disability with respect to physical or cognitive work activities. Therefore, attempting to compare the disability estimates in the women with those in the men may be inappropriate. Consequently, this study is unsuitable for assessing comparisons in disability based on gender.

As mentioned earlier, one of the rationales for selecting the MDCSS as a recruitment pool was the large inclusion of African-Americans because of its geographic location. Unfortunately, the LMOS was unable to recruit African-Americans to the same degree. Consequently, the proportion of minority participants in the disability study was less than 25%. Preferential enrollment of white individuals may have occurred because of other participation requirements that simultaneously selected for a higher socioeconomic status group, e.g. having a telephone or being employed.

The participants were relatively well educated and a good proportion had high-income levels prior to their diagnosis. Even twelve months after their diagnosis, more than half of the men still enjoyed a household income level greater than $75,000 annually. Changes in income level were not statistically significant for the men between baseline and twelve months. However, the women did experience a statistically significant shift between from the high to the moderate level income during this time.

The race, income and education distributions observed in the study sample suggest persons enjoying higher socioeconomic status were included. Therefore, the disability prevalence estimates might not accurately reflect what may be expected from these particular cancer conditions in a randomly selected cohort. However, physical and cognitive work activities were believed to correlate with socioeconomic condition so estimates of disability associated with each category may provide some insight to the experience of individuals of different socioeconomic status. Physical tasks were speculated to be associated with manual labor (i.e. lower socioeconomic status) while cognitive tasks were considered to be associated with higher socioeconomic conditions. An unadjusted look at the relationship between occupation and requirement for physical activity documented a statistically significant relationship with more blue-collar workers performing physical tasks compared to white-collar workers regardless of male or female.

Since fitness level has been associated with disability in other studies, we were interested in describing measures of usual physical capacity for these cohorts. Fitness level may affect disability by contributing to an individual's resilience to health insults. Conflicting information regarding fitness levels of the participants were obtained. No more than twenty percent of either cohort participated in regular activity at least three times per week at baseline regardless of intensity. This suggests that the participants were more sedentary. However, more than 2/3 of both groups declared they worked up a sweat either sometimes or always. This result could be interpreted to mean that respondents did some form of vigorous activity and perhaps were not as sedentary as originally believed.

One reason for this discrepancy might be the lack of objective time frame in the sweat question. Alternatively, respondents may have inferred the regular activity questions to be asking about recreational activity in nature while the sweat question may have included activities that would not be considered recreational, such as yard work or physical labor. Because of these conflicting results, the ability to interpret the baseline tolerance for physical activity was questioned. Subsequent analyses failed to implicate a significant association of activity with physical disability yet the variable was retained at a non-significant level in the modeling equations for cognitive disability. The direction of influence suggested women not engaging in vigorous activity had lower probability of developing cognitive disability compared to women who did work up a sweat.

Since the goal of the study was to evaluate disability in previously healthy breast and prostate cancer patients, some measures of pre-existing medical conditions were important to include. Individuals with multiple medical conditions may experience less tolerance for the untoward effects of treatment compared to persons with none or just a few. This may result in a greater likelihood of subsequent disability. Several variables, including count of comorbid conditions and perceived health status were taken as proxies of health. Results indicated that both the breast and prostate cohorts enrolled in the study were relatively healthy. Less than ten percent of each reported having three or more comorbid conditions and over 70% claimed to have excellent or very good health status.

The disability estimates may then be underestimated in this population relative to the general population.

5.4.3 Evaluation of Selection Bias

Because of the limited recruitment of minorities, a formal evaluation of the potential selection bias that may have occurred in this source study population was conducted in Bradley, et al's 2005 methods paper (119). This analysis was performed by comparing demographic and clinical elements on enrolled participants to all the potentially eligible subjects identified in the MDCSS. In addition, census data on variables at the block group level were obtained for all potential subjects. Refer to Appendices C and D for details of the Selection Bias Examination reported in that article.

These comparisons revealed that potential subjects who refused to be screened for eligibility were somewhat older than the enrolled participants by approximately two years for both cohorts. Also, the proportion of African-American subjects were statistically significantly ($p<0.01$) greater in the "unable to contact" subgroup compared to the enrolled populations for breast and prostate cancer patients. More African-Americans were also included in the "eligible but refused" group among the prostate cases. Similarly, the "unable to contact" and "ineligible" breast and prostate groups had statistically significantly (at least $p<0.05$) higher proportions of individuals with unknown cancer stage. This was hypothesized to reflect individuals who may have not had their cancer staged because of advanced disease at diagnosis, thus these individuals may have been in poorer health (119). Since the outcome of interest is disability, the omission of potentially sicker individuals would result in underestimating the overall prevalence.

5.4.4 Disease Aspects of Cohorts

Over seventy percent of both cohorts were diagnosed early, in-situ or local stage, in their disease process. Early diagnosis has been associated with improved survivability thanks to aggressive treatment. This could impact disability in two directions. If disability is associated with later staged cancer that ultimately suffers greater mortality, the overall prevalence of longer-term cancer-related disability in the population could remain low. However, if the aggressive treatment causes some disability, the improved survival of persons with early disease may result in increasing disability prevalence. Cancer stage and treatment were strongly correlated in this study.

Data regarding cancer treatment were obtained from two data sources. The SEER data set provided information on stage and treatment. The participants also provided data regarding treatment. Limitations with SEER and patient reporting have been documented and the degree to which each data source was inaccurate for these participants cannot be defined with these data. As a result, the decision was made to accept all reports of treatment regardless of source.

The breast cohort's experience reveals the aggressive nature of treatment provided even for early stage disease. Sixty-six percent of women with local disease received chemotherapy compared to only four percent of women with in-situ disease. The more extensive the treatment regimen, the more plausible it is disability may result. In contrast, treatment of choice for the men was largely surgical intervention without adjuvant therapy. Over 60% of the men received just surgery. In fact, the proportion of men not receiving treatment of any form exceeded the proportion undergoing chemotherapy.

5.4.5 Employment Aspects of Cohorts

Most, 2/3 of total participants, were employed in white-collar occupations. This is not unexpected in light of the income levels that were reported among the respondents. This may impact the disability prevalence estimates and therefore these findings may not be representative of the entire employed population that may be diagnosed with cancer. The mean shift lengths at baseline were 8 and 8.8 hours for the breast and prostate cohort, respectively, with nearly half the shift being sedentary. The greater proportion of workers with these characteristics (white collar, sedentary work) may result in greater cognitive disability and less physical disability being reported in these cohorts.

More than 80% of both cohorts reported they had a supportive employer who accommodated their illness. Thankfully, this stands in contrast to discrimination experiences that persons with cancer historically faced. The support of their employer may have had an influence over respondent loyalty since a minority (less than 40%) of individuals stated they would be interested in a new job if they could be guaranteed similar benefits. At least 80% expressed dedication to their work in the form of acknowledging being a perfectionist about work or being personally involved in their work. Half of the breast and prostate cancer individuals stated satisfaction in their life came from their job yet job satisfaction ratings did not vary by employment status change.

The dedication individuals' feel towards their work may impact disability in both directions. Individuals who are dedicated to their job and obtain life satisfaction from their work may minimize potential disability in order to maintain the connection. Alternatively, those who are perfectionists may be more aware of the limitations imposed by their disease and treatment and the inability to carry on in their normal fashion resulting in higher reports of limitations.

CHAPTER 6: CONCLUSIONS

6.1 Implications & Recommendations

These results suggest options for further investigation. The first research question was interested in the level of physical and cognitive disability with work tasks in these participants. Disability estimates were less than national averages yet the comparability of the involved populations and results are questionable. The individuals in this study were more likely to enjoy higher socioeconomic status than the general population; this provides one rationale for the discrepancy.

Evaluated only within the confines of the experience of the enrolled individuals, physical disability appears to be more widespread than cognitive disability for both men and women. This relationship occurs in spite of the fact that physical tasks are not as prominent in the work setting.

Women appear to experience greater disability with their work tasks at both time frames than men experience with their own jobs. However, women enjoy a statistically significant decline in reported physical and cognitive disability from twelve to eighteen months. Therefore, the study was successful at rejecting the null hypothesis that no difference would exist between the time frames for the women. The men's experience appears to be more stable and this pattern likely reflects differences in the treatment protocols between breast and prostate cancer. However, it may also be that this pattern could be an artifact of small cell size. The null hypothesis of a decrease in prevalence could not be rejected based on these data for the men.

These findings hint that physical demands may be more problematic than cognitive and therefore, a reasonable primary target for accommodation or rehabilitation efforts. Unfortunately, this study lacked the detail regarding the degree to which activity was limited. Additionally, no information was available regarding the nature of accommodation or rehabilitative services to which these women had access. Perhaps the decreases observed reflect the availability of these services. Or, perhaps these occurred despite having no accommodation or rehabilitation services. If the latter is the case, this offers some hope that a baseline long-term disability could be reduced to nearly zero with appropriate supports. Variables of this sort would be important to include in subsequent studies.

The second study question focused on exploring the potential difference in disability estimates within the same population using two common disability definitions. Many authors report disability without explicitly defining the term and this presents obstacles to comparing published rates. One common reference for disability is some measure of activity limitation. This definition tends to minimize the importance of participating in a social role. The ICF definition includes both activity limitation and participation restriction as necessary domains for disability.

As anticipated, the disability prevalence estimates using activity limitation were significantly greater than the prevalence estimates using the ICF definition. The variation was on the order of three to four-fold. These results rejected the null hypothesis that no difference in prevalence estimates would be obtained from the two definitions. Differences of this magnitude indicate prevalence comparisons between studies could be suspect. However, the manner in which participation restriction was computed in this study may play a role in these discrepancies as well.

Lastly, the third study question sought to evaluate the influence of suspected contextual factors on the presence of disability. The contextual factors were categorized as personal or environmental. The environmental factors were all employment-related variables.

Contrary to expectations, income level was not associated with disability. Race played a lesser role than expected. African-American women only were nearly three times more likely to experience cognitive disability compared to Caucasian/Other women holding variables such as income or education constant. Marital status played a role in cognitive disability at eighteen months. Women who were formerly married were over two times as likely to have cognitive disability compared to married women. This may reflect a lack of support structure in dealing with the disease.

Cancer stage and treatment had the strongest impact of the personal factors with both physical and cognitive disability. Women diagnosed with earlier staged disease experienced less disability than those diagnosed later. Also, those receiving chemotherapy experienced more disability than those undergoing surgery. Stage and treatment were correlated and both wouldn't remain in the models together. This emphasizes the importance of early detection. Screening is essential to early diagnosis where the treatments may be less severe.

Environmental factors had an impact on work-related disability as expected. However, the degree of physical activity at a job and overall job satisfaction did not seem to influence disability. Occupational category was only influential for physical disability with blue-collar workers having more disability than white-collar workers. Blue-collar workers had more physical jobs than white-collar workers so it is likely the physical demands did play a role. The availability of sick leave was consistently related to physical and cognitive disability. Women who did not have a sick leave benefit were more likely to suffer. Legislation such as FMLA provide workers some assurance of maintaining a job should they be off work for a medical condition yet no mandate exists for having this be paid time off. Women who do not have sick leave may not be able to afford lost wages associated with time off. Therefore, they have no option but to compromise their health to continue to work.

Increasing attention to disability coupled with the increased detection of cancer in a working population provided motivation for this study. The results and limitations associated with this study identify elements that future work should address. While the results obtained here support relationships documented in existing literature (e.g. more physical disability, impact of stage and treatment), other well-established associations (e.g. age, income level or fitness capacity), were not observed. This argues for the need to replicate this work with a focus on these research questions and with sufficient enrollment for robust analyses.

6.2 Summary

The findings of this study may not be representative of the disability experience that all employed persons with a cancer diagnosis may face. There is evidence that the cohorts recruited for this study were mostly white and from a higher income bracket. Furthermore, the disability prevalence estimates vary within the same sample depending on the domain(s) used to establish disability. Significant work is yet to be done to completely describe the disability experience of cancer patients, the outcome of which may be used to suggest interventions to ameliorate disability. This work is offered as the first step in establishing a baseline disability framed by a comprehensive theoretical model.

These results provide evidence as to the importance of defining disability clearly when disability is an outcome of interest. The disability prevalence estimates reported here were much lower than those published elsewhere. Readers must use caution when evaluating disability estimates and making comparisons. The outcome should be clearly defined by the author. This study used the definition of disability according to the ICF theoretical framework and incorporated elements of activity limitation along with participation restriction.

These data showed that disability is a concern for employed breast and prostate cancer patients at least within eighteen months after diagnosis. Physical disabilities were more prevalent than cognitive disabilities for women and men and occurred at a lower level than national disability estimates. Also, women enjoyed significant decreases in prevalence while men did not. It is reasonable to suspect that women may suffer more disability due to the more aggressive treatment regimens they undergo yet the affects may not necessarily be permanent conditions. On the other hand, the stable estimates for men might suggest that their distress is indeed permanent. Over time, a permanent condition could be more problematic for the population of prostate cancer survivors.

Based on these data, we were unable to test the determinants of disability in the prostate cohort. The problems encountered serve as testament to the problems encountered in using secondary data sources. The available sample was simply not sufficient for the very low prevalence estimates that appear to afflict the population.

One goal of this study was to identify variables that were significantly associated with disability and might be amenable to intervention. Personal factors such as income or age were not significant in these participants. However, African-American women were at higher risk for cognitive disability. Much more important to the outcome of disability was cancer stage and treatment. Since treatment is reflective of cancer stage, the importance of screening and early detection must be stressed. Women diagnosed with in-situ disease had significantly less disability. Regarding variables such as race, income level or education, it is important to provide educational materials promoting screening and early detection using culturally competent methods.

The most significant environmental factor for influencing presence of disability was the absence of paid sick leave as a benefit. Adequate recovery time is necessary to adjust to the affects of cancer treatments. Individuals who cannot afford to take this time and work through treatment may experience longer lasting impacts. These results suggest legislation like FMLA do not go far enough in protecting workers when they are diagnosed with a serious illness. Employers may wish to consider the cost of paid sick leave versus the costs associated with lower productivity to re-evaluate their benefit packages.

Important elements related to disability were not included in this study since it relied on existing data. Future studies should include mechanisms to track the nature and intensity of limitations and restrictions. The dichotomous measures used here are suitable for pilot investigations but complete analyses of disability should strive for more discriminating data. It would also be necessary to include information on the types of accommodations and/or rehabilitation services patients use during their recovery period. Once these are accurately described, the focus could turn to developing methods to reduce the associated disability.

APPENDICES

Appendix A: Work Related Activity Limitation Questions

Question	Eligible Responses
Physical Tasks	
My job requires lots of physical effort	All or almost all of the time Most of the time Some of the time None or almost none of the time
My job requires lifting heavy loads.	All or almost all of the time Most of the time Some of the time None or almost none of the time
My job requires stooping, kneeling, or crouching	All or almost all of the time Most of the time Some of the time None or almost none of the time
My job requires me to keep up with the pace set by others	All or almost all of the time Most of the time Some of the time None or almost none of the time
Cognitive Tasks	
My job requires intense concentration or attention.	All or almost all of the time Most of the time Some of the time None or almost none of the time
My job requires me to analyze data or information.	All or almost all of the time Most of the time Some of the time None or almost none of the time
My job requires that I learn new things.	All or almost all of the time Most of the time Some of the time None or almost none of the time
Asked After Each Task if All/Most/Some response	
Has cancer or its treatment limited or interfered with your ability to do this part of your job?	Yes No

Appendix B: Participation Restriction Questions

Question	Eligible Responses
What is the main reason you (the patient) do not work?	Own illness/cancer
Was this decrease (in hours) related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above
Some people work part-time because they cannot find full-time work or because business is poor. Others work part-time because of family obligations or other personal reasons. What is your MAIN reason for working part-time?	Health/medical limitations due to cancer and/or its treatment
Was this decrease (in hourly earnings for main job) related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above
Was this decrease (in total earnings for main job) related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above

Appendix B: Participation Restriction Questions (continued)

Question	Eligible Responses
Was this decrease (in hourly earnings for other jobs) related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above
Was this decrease (in total earnings for other jobs) related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above
Was the reason you stopped working related to your cancer?	Yes - due to treatment Yes - due to cancer symptoms Yes - due to other reasons Yes - due to treatment and symptoms Yes - due to treatment and other reasons Yes - due to symptoms and other reasons Yes - due to all of the above

Appendix C: Selection Bias Review – Enrolled Subjects Compared to Potentially Eligible Subjects

	(1) Subjects enrolled	(2) No physician contact information and physician refusal	(3) Not able to contact	(4) Eligible, refused	(5) Not screened, refused	(6) Ineligible
Breast cancer	**N=496**	**N=159**	**N=169**	**N=87**	**N=163**	**N=241**
Mean age (SD)	50.5 (7.60)	51.9 (7.97)	50.06 (8.77)	50.52 (7.87)	52.17 (8.01)*	55.65 (8.63)**
Race						
White, other, Hispanic	392 (79.0)	113 (71.1)	97 (57.4)**	64 (73.6)	118 (72.4)	157 (65.4)
Black, non-Hispanic	104 (21.0)	34 (21.0)	54 (32.0)**	21 (24.1)	32 (19.6)	67 (27.9)
Stage						
In situ	125 (25.2)	34 (21.4)	49 (29.0)	21 (24.1)	35 (21.5)	61 (25.4)
Local	203 (40.9)	71 (44.6)	51 (30.2)*	33 (37.9)	63 (38.6)	96 (40.0)*
Regional	138 (27.8)	40 (25.2)	42 (24.8)	28 (32.2)	44 (27.0)	65 (27.1)
Distant	13 (2.6)	7 (4.4)	9 (5.3)	3 (3.4)	9 (5.5)	5 (2.1)
Unknown	17 (3.4)	7 (4.4)	18 (10.6)**	2 (2.3)	12 (7.4)*	13 (5.4)*

Notes: SD=standard deviation, shown in parentheses for age. Percentages are shown in parentheses for race and stage. Missing age data in the breast sample: physician refusal (n=7), not able to contact (n=17), refusals (n=1), not screened (n=11), ineligible (n=13). Missing race data in the breast sample: physician refusal (n=11), not able to contact (n=18), refusals (n=2), not screened (n=13), and ineligible (n=13). Enrolled subjects (column 1) were compared to column 2 through column 5 and ineligible subjects accounted for in column 6 were also compared to the "not able to contact" subjects in column 3, (*) denotes statistical significance from enrolled subjects at p<.05 and (**) denotes statistical significance from enrolled subjects at p<.01.

Appendix C: Selection Bias Examination (continued)

	(1) Subjects enrolled	(2) No physician contact information and physician refusal	(3) Not able to contact	(4) Eligible, refused	(5) Not screened, refused	(6) Ineligible
Prostate cancer	**N=294**	**N=92**	**N=174**	**N=92**	**N=120**	**N=223**
Mean age (SD)	56.27 (5.88)	57.1 (8.02)	57.2 (5.52)	57.10 (5.37)	57.6 (4.78)*	59.9 (5.49)**
Race						
White, other	220 (74.8)	51 (55.4)	79 (45.4)**	53 (57.6)*	82 (68.3)	131 (58.7)
Black, non-Hispanic	74 (25.2)	25 (27.2)	54 (31.0)**	31 (33.7)*	23 (19.2)	67 (30.0)
Stage						
In situ	0	0	0	0	1 (0.8)	0
Local	214 (72.8)	65 (70.6)	120 (68.6)	67 (72.8)	93 (77.5)	155 (69.5)
Regional	57 (19.4)	16 (17.4)	19 (10.9)*	20 (21.7)	14 (11.7)	42 (18.8)*
Distant	1 (0.3)	2 (2.2)	3 (1.7)	0	3 (2.5)	6 (2.7)
Unknown	22 (7.5)	9 (9.8)	32 (18.3)**	5 (5.4)	9 (7.5)	20 (9.0)**

Notes: SD=standard deviation, shown in parentheses for age. Percentages are shown in parentheses for race and stage. Missing age data in the prostate sample: physician refusal (n=8), not able to contact (n=26), refusals (n=5), not screened (n=9), ineligible (n=19). Missing race data in the prostate sample: physician refusal (n=16), not able to contact (n=41), refusals (n=8), not screened (n=15), ineligible (n=25). Enrolled subjects (column 1) were compared to column 2 through column 5 and ineligible subjects accounted for in column 6 were also compared to the "not able to contact" subjects in column 3, (*) denotes statistical significance from enrolled subjects at p<.05 and (**) denotes statistical significance from enrolled subjects at p<.01.

Appendix D: Selection Bias Review - Census Comparison of Enrolled to Potentially Eligible

Breast Cancer	**(1) Subjects enrolled**	**(2) Physician refusal, no contact**	**(3) Not able to contact**	**(4) Eligible, refused**	**(5) Not screened, refused**	**(6) Ineligible**
Race/ethnicity (%)						
White, non-black	79.3	74.6	63.3*	75.9	81.9	68.8
African-American	20.7	25.4	36.7**	24.1	18.1	31.2
Marital status (%)						
Married	50.5	49.3	42.8*	49.8	49.9	45.5
Divorce, separated, widowed	25.0	24.9	29.0	25.4	26.2	27.5
Single	24.5	25.7	28.2	24.8	23.8	26.9
Children <18 (%)	44.2	45.1	45.1	43.5	43.4	43.3
Education (female) (%)						
No high school diploma	15.0	14.9	20.5**	15.7	16.1	19.0
High school diploma	29.3	27.4	29.8	29.5	29.9	29.6
Some college	23.7	23.9	22.3	25.0	22.9	23.5
College degree or higher	32.0	33.8	27.4	29.8	31.1	27.9
Employment (%)						
Blue collar	24.4	23.6	29.6	25.9	25.7	28.1
Unemployed or not in the labor force	44.6	44.8	47.9	43.7	44.9	46.7
Below poverty (%)	7.7	8.9	14.3**	8.8	7.9	12.5
Household income (%)						
<$20,000	14.7	15.9	22.5**	14.5	15.5	20.0
>$20,000 and <$75,000	50.5	47.9	49.6	52.8	51.6	51.3
≥$75,000	34.8	36.2	27.9	32.6	32.9	28.8

Notes: The percentage below poverty is at the census tract level. All other percentages are at the block group level. Enrolled subjects were compared to column 2 through column 5 and ineligible subjects were also compared to the "not able to contact" subjects, (*) denotes statistical significance from enrolled subjects at $p<.05$ and (**) denotes statistical significance from enrolled subjects at $p<.01$.

Appendix D: Selection Bias Examination (continued)

Prostate Cancer	Subjects enrolled	Physician refusal, no contact	Not able to contact	Eligible, refused	Not screened, refused	Ineligible
Race/ethnicity (%)						
White, Hispanic, non-black	77.1	75.5	58.7	66.2	78.6	63.3
African-American	22.9	24.5	41.2**	33.8	21.4	36.7
Marital status (%)						
Married	57.7	51.4	46.8*	53.6	55.2	48.1
Divorce, separated, widowed	13.3	18.4	17.0*	15.0	14.0	17.3
Single	29.0	30.1	36.2	31.4	30.8	34.6
Children <18 (%)	44.3	43.3	44.0	43.8	43.8	45.0
Education (%)						
No high school diploma	13.5	18.7	21.0**	17.2	14.9	20.9
High school diploma	22.8	25.6	26.8	25.6	23.4	27.1
Some college	24.7	26.7	21.1*	23.2	22.9	23.4
College degree or higher	39.0	29.0	31.1	33.9	38.7	28.6
Employment (%)						
Blue collar	44.1	52.5	51.8	50.1	46.4	53.6
Unemployed or not in the labor force	30.2	31.8	38.0**	32.3	31.5	36.1*
Below poverty (%)	7.4	10.8*	14.0**	10.1**	8.3	12.6
Household income (%)						
<$20,000	13.7	17.2	20.9**	16.2	15.5*	20.8
≥$20,000 and <$75,000	46.6	51.9	50.2	49.0	46.6	50.2
≥$75,000	39.7	30.8	28.9*	34.8	37.9	29.0

Notes: The percentage below poverty is at the census tract level. All other percentages are at the block group level. Enrolled subjects were compared to column 2 through column 5 and ineligible subjects were also compared to the “not able to contact” subjects, (*) denotes statistical significance from enrolled subjects at p<.05 and (**) denotes statistical significance from enrolled subjects at p<.01.

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