ABSTRACT

Title of Dissertation:	RACIAL AND ETHNIC DIFFERENCES IN ACCESSING TIMELY CANCER SCREENING AND TREATMENT SERVICES: A QUANTITATIVE ANALYSIS
	Christopher J. King, Doctor of Philosophy, 2013
Dissertation directed by:	Professor Stephen B. Thomas Professor Jie Chen Department of Health Services Administration

This research is organized into three integrated studies that explored differences in screening and treatment services across the cancer care continuum by race and ethnicity. The Andersen Behavioral Model of Health Services Use and the Five Dimensions of Access were used as conceptual frameworks. In the first study (Chapter 2), data from the Medical Expenditure Panel Survey were used to examine breast and cervical cancer screening rates before and during the Great Recession (2007-2009). The interaction terms of recession and race and ethnicity were controlled to examine whether minorities exhibited different utilization patterns under economic shock compared to Whites.

In Chapter 3, data from the National Health Interview Survey (NHIS) from 2006-2010 were used to identify adult cancer survivors and adults without a history of cancer. Multivariate logistic regressions were applied to examine the prevalence of cost, organizational and transportation barriers between survivors and the general population. The likelihood of experiencing barriers was explored by race and ethnicity.

In Chapter 4, differences in the likelihood of experiencing access barriers among survivors by race and ethnicity was explored. Data were merged from the 2000-2011 (NHIS) to identify adult cancer survivors who reported cost, organizational and transportation barriers. Logistic regressions were applied to determine the likelihood of reporting each type of barrier, while controlling for demographic and socioeconomic variables. The Fairlie decomposition technique was applied to identify contributing factors that explained differences in accessing care based by race and ethnicity.

Overall, results of the investigations demonstrate that: (1) breast and cervical screening rates declined most among White women during the recession period, while rates increased among Hispanic women during the same period; (2) minority cancer survivors were significantly more likely to experience access-to-care barriers than Whites; and (3) insurance, comorbidity, perceived health and nativity were leading factors that contributed to racial and ethnic differences in timely receipt of cancer screening and treatment services. As provisions of the Affordable Care Act take effect, findings provide insight into practices, policies, and future research that will help achieve Healthy People 2020 screening objectives and reduce racial and ethnic disparities in accessing timely cancer care.

RACIAL AND ETHNIC DIFFERENCES IN ACCESSING TIMELY CANCER
SCREENING AND TREATMENT SERVICES: A QUANTITATIVE ANALYSIS

by

Christopher J. King

Dissertation submitted to the Faculty of the Graduate School of the
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Doctor of Philosophy
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Dissertation Committee:

Professor Stephen B. Thomas, Co-Chair
Professor Jie Chen, Co-Chair
Professor Cheryl Holt
Professor Mary A. Garza
Professor Lori Simon-Rusinowitz

DEDICATION

I dedicate my research to the millions of cancer survivors across the globe.

ACKNOWLEDGEMENTS

First, I would like to give thanks for my Lord and Savior, who has bestowed upon me a life that is filled with curiosity, joy, ambition, and an intrinsic desire to make the world a better place. I also give thanks for the wonderful people who have been positioned in my life – from birth to this very special moment.

To my employers, Greater Baden Medical Services, Inc. and MedStar Health – thank you for investing in my education. Rest assured, my future agenda around translational research will continue to advance the health and wellbeing of the American people, regardless of race, ethnicity and socioeconomic status. I also thank my most recent supervisors, Sally Leonhard and Diane Caslow for allowing me to pursue this degree while working simultaneously. I could not have done this without their generosity.

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constructive feedback throughout this process has sharpened my research skills, positioning me for more meaningful practice and scholarship.

To my friends, I appreciate your patience, realizing that I have not been available to participate in events and all the fun things friends do. While I recognize it was frustrating at times, you continued to support my ambition. You brought me dinner when I was stuck at the computer during the holidays, you listened to me during times of discouragement, and you proofread my work and provided feedback that challenged my thinking. For all these gifts, I thank you and treasure you.

To my family, you have given me the nuts and bolts of what it takes to succeed. During the past six years, there were many storms and the weather blew me in many directions but I stayed true to the key principles that you drilled in me since birth: live a life of integrity, work hard, love hard, be kind, smile, stay humble, and put others first. To my late Grandfather, Mr. Walter E. Thomas, you gave me countless pep talks when I was a child and young adult, "You have a good head on your shoulders and you can do anything you put your mind to. Say your prayers and have a relationship with God and you will be blessed." Those words continue to resonate and govern the choices I make. To the matriarch of my family, Mrs. Naomi Thomas, through your own life, you have sown greatness in me. You have consistently demonstrated the importance of having faith, the art of forgiveness, and the value of patience. To my beautiful mother, Ms. Hazel A. King, I am so blessed to have inherited so many wonderful traits from you. There is no doubt that my optimism, generous spirit, and love for ALL people came directly from you. Ma, thank you for being my number one cheerleader and I am so honored to be your son. I love you.

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LIST OF ABBREVIATIONS

ACA   Affordable Care Act

AHQR   Agency for Healthcare Quality and Research

AOR   Adjusted Odds Ratio

CDC   Centers for Disease Control

CLAS   Culturally and Linguistically Appropriate Services

DHHS   Department of Health and Human Services

IOM   Institute of Medicine

MEPS   Medical Expenditure Panel Survey

MSA   Metropolitan Statistical Area

NBCCEDP   National Breast and Cervical Cancer Early Detection Program

NCCS   National Coalition for Cancer Survivorship

NCI   National Cancer Institute

NHIS   National Health Interview Survey

OR   Odds Ratio

PPACA   Patient Protection and Affordable Care Act

USPSTF   United States Preventive Services Task Force

CHAPTER 1:

INTRODUCTION

As of January 2012, there were approximately 13.7 million cancer survivors in the United States. The number is expected to increase to by 24% (18 million) within the next ten years.[1] A number of factors are contributing to the expected growth. An aging population is increasing the number of persons at risk and advancements in surgical, clinical and pharmacological therapies are improving survival rates.[2] Education and awareness initiatives, coupled with policies and practices that promote early detection have also been efficacious.[2] Collectively, these efforts are allowing persons with a history of cancer to live longer and healthier lives.

While many survivors have benefited from such progress, minorities continue to be disproportionately impacted. For example, for all cancer sites combined, the incidence rate is 6% lower for African American women compared to White women; however, the mortality rate is 16% higher in African American women.[1] Incidence and mortality rates are 15% and 33% higher, respectively, in African American men compared to White men.[1] Compared with Whites, the 5-year relative survival rate is lower in African Americans for nearly every cancer site.[1]

These disparities are magnified when analyzed by certain cancer types. For example, White women are more like to develop breast cancer; however, African American women are more likely to die from breast cancer, even when the stage of diagnosis is controlled.[3–5] The mortality rate is 50% higher for African Americans diagnosed with colorectal cancer compared with Whites; and mortality rates in cancers associated with infectious agents (e.g. lung, liver, bile, gallbladder) are up to twice those of non-Hispanic Whites.[6,7]

The factors that contribute to racial and ethnic disparities in health outcomes and medical treatment are multifactorial and they have been key topics in a number of national reports. For example, the Institute of Medicine's landmark reports, *The Unequal Burden of Cancer* (1999) captured the unequal burden of cancer in communities of color and *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (2002), highlighted the complex, deeply-rooted individual and system-level factors that contribute to poor health outcomes in minority populations.[8,9] Both reports assert that disparities are driven by a complex set of social, economic, cultural, and health system factors and findings have subsequently influenced policy, practice and research focused on closing the gap in racial and ethnic health disparities.

While there has been progress in closing racial and ethnic gaps in health, when compared to Whites, minorities with some of the most common forms of cancer continue to be plagued with higher rates of disability and premature death.[10–13] Due to unique medical and social needs of the cancer survivor, receipt of timely access-to-care is critical for promoting quality of life and longevity.[9,14,15] Using the cancer care continuum as a framework, this research investigates racial and ethnic differences in timely receipt of cancer screening and treatment services.[2,9,15]

The Cancer Care Continuum

Figure 1.1 displays the cancer care continuum. Timely receipt of care at each stage affects quality of life and overall life expectancy. Early screening promotes early detection, resulting in treatment or intervention prior to advanced disease progression.[9,11,14,16] Due to the effects of cancer treatment, in addition to the need for surveillance for recurrence, survivors need access to a comprehensive network of post-

treatment services.[9] Delaying or forgoing care at any stage of the survivorship continuum can lead to undetected recurrence, mismanagement of side effects from treatment, and mental health issues such as social isolation or poor mental health.[15–18]

Figure 1.1 The Cancer Care Continuum

Screening → Diagnosis → Treatment → Post Treatment / Quality of Life
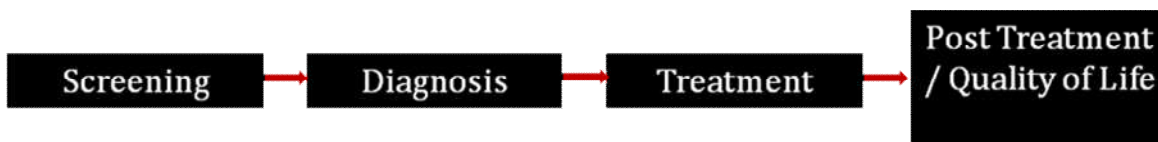
Adapted from the Institute of Medicine[9]

The first study explores the first stage of the continuum *(screening)* by examining differences in breast and cervical screening rates by race and ethnicity before and during the Great Recession. The second and third studies focus on *diagnosis, treatment, and post treatment* by exploring timely access to care among cancer survivors. According to the National Coalition for Cancer Survivorship, an individual is considered a cancer survivor from the time of diagnosis throughout the balance of his or her lifetime.[15] Due to the nature of the disease and its physical and mental impact on the body over the course of a lifetime, cancer survivors are commonly documented in health services literature as a vulnerable population.[1,3,11] Unique medical needs include routine surveillance for primary or secondary malignancies, monitoring chronic effects, and treatment for co-morbidities.[14] Survivors are also more likely to experience sexual dysfunction, infertility, cosmetic changes, and impaired cognition. Compared to the general population, cancer survivors are more likely to report lower perceived health status, psychological distress, poorer mental health, greater role impairment due to emotional problems, and poorer social well-being.[14,19–22] Increased likelihood of these conditions warrant a greater level of engagement with healthcare providers and the healthcare system.

3

Conceptual Framework

The Andersen Model of Behavioral Health Services Use guided the selection of independent variables for all outcome measures. The model assumes that a complex set of conditions determine 1) whether or not individuals use health services; and 2) the volume or frequency in which those services are consumed.[23,24] Recognized as a conceptual model that identifies factors that facilitate utilization of health services, the Andersen Model focuses on three factors: predisposing, enabling factors, and need. Predisposing factors include demographic, social characteristics or individual beliefs about health services. Gender, age, marital status, education, income, US region, language and nativity are selected as predisposing factors. Enabling factors include access to prerequisite resources and the availability of health services in the local community. Insurance and usual source of care are incorporated as enabling factors. Need refers to an individual's perceived severity of illness and subsequently, the need for accessing health services. Perceived health status and comorbidities are included as need factors.

Five Dimensions of Access

Figure 1.2 displays Penchansky and Thomas's Five Dimensions of Access. Described as the concept of "fit" between the patient's needs and the system's ability to meet those needs, the Penchansky and Thomas framework goes beyond the traditional concepts of cost and

Figure 1.2 Five Dimensions of Access[25]

availability.[25] Due to the need for frequent medical visits and specialty care services, access-to-care barriers are especially relevant for cancer survivors. Availability is defined as the relationship between need and physical availability.[25] Accessibility is defined as the relationship between the location of supply and the location of clients, taking account of client transportation resources, travel time, distance and cost.[25] Accommodation refers to the state in which supply services are organized and able to meet client specific needs.[25] Accommodation barriers have received national attention and initiatives are underway to address those barriers. For example, the accommodation dimension is aligned with "Superb Access to Care," the first domain of the Institute of Medicine's six domains of quality.[26] Established to promote patient centered care and the establishment of a medical home, or usual source of care, the Institute of Medicine describes the following as "superb access to care:" ease of making an appointment, ability of patients to select the day and time of their appointment, short wait times, and office hours that make primary care readily accessible on nights, weekends, and holidays. Affordability is expressed as the relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance.[25] While medical providers may be geographically available, acceptable, and accommodating, consistent utilization is contingent upon the consumer's ability to afford the services offered. Acceptability is defined as the relationship of clients' service expectations compared to what is actually delivered.[25]

As part of this research, three outcome variables that are linked to four dimensions are examined: Affordability is captured by forgoing or delaying care due to costs. Accommodation is captured by delaying care due to organizational barriers (i.e.,

cannot get through on phone, wait too long, could not get an appointment soon enough, office not open). Delaying care due to transportation is examined to determined accessibility and availability barriers. Due to survey limitations, barriers associated with acceptability were not explored.

Chapters 2, 3 and 4

In Chapter 2, *Analyses of Racial and Ethnic Differences in Breast and Cervical Cancer Screening before and during the Great Recession,* a national sample is used to conduct the first study that examines breast and cervical cancer screening rates by race and ethnicity before and during the Great Recession of 2007-2009. Chapter 3, *Healthcare Access Barriers among Cancer Survivors by Race and Ethnicity,* contributes to the literature by examining the prevalence of cost, organizational, and transportation barriers among cancer survivors, compared to the general population. The analysis is augmented by exploring each barrier within the context of the interaction of race/ethnicity and cancer history. In Chapter 4, *Decomposing Differences in Medical Care Access among Cancer Survivors by Race and Ethnicity,* the magnitude of racial and ethnic barriers to care are examined by conducting an 11-year analysis using adult cancer survivors as the population of study. By applying the Fairlie decomposition method, factors that contribute to the disparities are quantified.

CHAPTER 2:

**Analyses of Racial and Ethnic Differences in Breast and Cervical Cancer
Screening Before and During the Great Recession**

INTRODUCTION

Economic recessions have historically had a negative impact on preventive services and overall health services utilization.[27] Most recently, millions of Americans were affected by the Great Recession of 2007-2009. Unemployment, loss of employer-sponsored health insurance, reduced net worth and other social factors that contribute to economic vitality were compromised.[28–30] In December 2007, the national unemployment rate was five percent and by December 2009, the unemployment rate rose to more than nine percent (9.5%).[29] Consequently, 5.8 million Americans loss employer–based health insurance coverage and the uninsured rate rose 2.7%, resulting in an additional 5.6 million uninsured Americans.[31] Furthermore, the unemployment rate of the Great Recession rose fastest, compared to the last six recessions in American history.[29]

There were also noteworthy differences in how the recession affected racial and minority populations. As of December 2009, the unemployment rate for African Americans was 16.2%, 12.8% for Hispanics and 9.0% for Whites.[29] Although the unemployment rate for Whites was the lowest, Whites make up the majority of the population. The job loss resulted in 3 million newly uninsured Whites, 0.6 million newly uninsured African American and 1.1 million newly uninsured Hispanics.[31] Only a few investigations have examined the impact of the Great Recession on health services utilization and consistent with prior recessions in American history, the underlying theme is a reduction in health services utilization among the general population.[27,31–33]

Inarguably, early detection through screening can be lifesaving and due to the proven benefits of early detection for breast and cervical cancer, national screening goals have been determined and included as part of Healthy People 2020.[34] Timely mammography screening can reduce breast cancer mortality rates by 15-30%[35–37] and if detected early, cervical cancer is one of the most curable forms of cancers.[38] However, receipt of timely health services is contingent upon a number of financial and nonfinancial factors, many of which connect to the state of the economy.[27,30,31,39] Due to the importance of early detection, analyses of the impact of the recession on national cancer screening efforts and identification of populations and communities most impacted are needed. Findings can help target those who have forgone or delayed preventive screening services due to varying effects of the recession.

To the best of my knowledge, this is the first comparative analysis of breast and cervical screening rates during the Great Recession. Given the loss of health insurance and/or wealth reduction, I hypothesize that the likelihood of receiving breast and cervical screening decreased significantly during the Great Recession, compared to a precession period. Using age-specific guidelines established by the United States Preventive Services Task Force,[40] this study contributes to the literature by examining trends in breast and cervical cancer screening rates before and during the recession periods. Furthermore, analyses by race and ethnicity provide insight on how specific populations were affected.

Conceptual Framework

There is clear evidence that health service utilization is based on system-level factors, such as insurance status and access to and utilization of a usual source of

care.[11,41–43] Moreover, personal characteristics, such as race/ethnicity, educational attainment, marital status and perceived health status are also well documented in the literature as contributors to health service utilization.[11,42,43] Therefore, Andersen's Behavioral Model of Health Services Use was selected as a guide for this study. The model acknowledges predisposing, enabling, and need factors that influence or predict utilization of healthcare services.[23,24] Predisposing factors describe the natural tendency of individuals to use health services and include demographic variables such as race, ethnicity, age, gender, marital status, and occupation.[23,24] Enabling factors refer to the resources needed for the use of health services and include income, insurance coverage, and geographic location. Need factors refer to health status or illness, which warrants utilization of health services.[15]

METHODS

Data

Data from the consolidated Medical Expenditure Panel Survey (MEPS) were used for the analyses.[44] The MEPS is a longitudinal survey sponsored by the Agency for Healthcare Quality and Research (AHQR). The survey provides information on the utilization of health services by a nationally representative sample of civilian, non-institutionalized persons in the United States. African Americans and Hispanics are oversampled and demographic and socioeconomic indicators of respondents are also provided.[44,45]

Using the United States Preventive Service Task Force (USPSTF) age-appropriate screening recommendations,[40] as well as Healthy People 2020 age-based screening recommendations,[34] the research focuses on breast and cervical screening among White,

Hispanic and African American women. For breast screening, the sample includes those between the ages of 50 and 74. Receipt of mammography within the past two years is the dependent variable. For cervical screening, the sample includes women between the ages of 21 and 65. Women who reported having a hysterectomy are excluded. Receipt of a Pap smear within the past three years is the dependent variable. Screening frequencies between the pre-recession period (2004 and 2005) and the recession period (2007 and 2009) are compared.

Key Independent Variables

A dummy variable is created as an indicator for the economic recession, i.e. it equals to 1 if the survey years are 2009-2010, 0 if survey years are 2004-2005. The interaction terms of race and ethnicity with the recession interaction are controlled to explore if racial and ethnic groups have different utilization patterns during the recession period.

Other Independent Variables

Following the Andersen model, predisposing, enabling and need factors are controlled. Predisposing factors include: marital status (married - reference), education (no high school degree - reference), primary language (English – reference), US Region (Northeast – reference) and nativity (US born – reference). Enabling factors include insurance (uninsured – reference), income (>200 Federal Poverty Level – reference), employment status (employed - reference), usual source of care (no – reference) and urban/non-urban (nonurban – reference). Need factors include perceived health status (excellent – reference) and comorbidities (no comorbidity– reference). Comorbidities include common noncancerous conditions that typically require medical attention within

a 12-month period: coronary artery disease, diabetes, hypertension, high cholesterol, osteoarthritis, depression, and anxiety. A binary variable that equaled 1 is constructed if respondents have any of the conditions and 0 otherwise.

Analysis

Rates of receiving a mammograms and Pap smears for each race and ethnicity before and during the Great Recession are presented. Sample characteristics are summarized according to eligibility for mammogram and/or Pap smear. Multivariate logistic regressions are applied to estimate the likelihood of timely receipt of screening services based on USPSTF recommendations. The interaction of the recession and likelihood of screening by race and ethnicity is also analyzed. Stata 12.0 (Stata Corporation, College Station, Texas) is used for all analyses. Appropriate survey commands are used for all analyses to account for sample weighting and the complex survey design to ensure correct variance estimation.

<div align="center">RESULTS</div>

Breast Cancer Screening

Table 2.1 provides characteristics of the population of women between the ages of 50 and 74 who were eligible for mammogram: White 6936 (64%), African American 2074 (19%), and Hispanic 5333 (17%). On average, White women were more likely to report excellent health (18%) compared to Hispanic (8%) and African American women (8%), and less likely to have a comorbidity (71% among Whites, 73% among Hispanics, and 79% among African Americans). White women were more likely to have private insurance (74%), compared to Hispanics (40%) and African Americans (51%). Approximately half of all races and ethnicity were employed and the majority had a

usual source of care - White 92%, Hispanic 84% and African American (90%). Fifty-four percent (54%) of Hispanics did not speak Spanish as a primary language and 67% of Hispanics were not born in the United States.

Figure 2.1 provides summary statistics of mammography rates before and during the recession periods. There was a slight decrease in the percentage of White women screened (78% before and 76% during the recession). Percentages of African American women who were screened were unchanged at 76% and screening among Hispanic women rose 6 percentage points (71% to 77%).

Figure 2.1 Percent of Women with a Mammogram Before and During the Great Recession

	2004-2005	2009-2010
White	0.78	0.76
Hispanic	0.71	0.77
African American	0.76	0.76

Based on age-appropriate recommendations established by the United States Preventive Services Task Force: Women ages 50-74

Table 2.2 displays multivariate results, controlling for the recession indicator, race/ethnicity and other covariates. Overall, compared to the pre-recession period, women were significantly less likely to receive a mammogram during the recession

period (OR .82 p<0.001). African American women were more likely to have a mammogram compared to White women (OR 1.31 p<.01). The interaction term between Hispanics and the economic recession was significant (OR 1.39, p=.05), which indicates that mammography screening among Whites was lower than Hispanics during the recession period. Furthermore, findings show an increase in screening among Latinas during the recession period, compared to the prerecession period. The interaction term between African American women was not significant, which indicated that screening patterns were unchanged among African American women during the recession, compared to White women.

In addition, multivariate regression results show that married women were more likely to have a mammogram than unmarried women (OR 1.36 p<.001). The likelihood of receiving a timely mammogram was significantly lower for women who did not speak English as a primary language compared to those who did (OR .55 p<0.001). Women without a high school degree (reference) were less likely to be screened than those with degrees. Need factors are examined by perceived health and comorbidities. In general, women with higher perceptions of health status were more likely to be screened than those with lower perceptions of their health status and those with comorbidities were more likely to be screening than those without comorbidities (OR 1.74 p<0.001).

The likelihood of screening was greatest among those with incomes more than 200 percent of the federal poverty level (reference). Access to private insurance, public insurance, and a usual source of care were the most significant enabling factors. Compared to uninsured women (reference), those with private insurance were almost three times more likely to be screened (OR 2.97 p<0.001) and those with public

insurance were 2.5 times more likely to be screened (OR 2.50 p<0.001). Residents of the Northeast Region (reference) of the country were most likely to be screened than those in other regions. The Midwest and South fared worse (OR .73 p<0.001; OR .73 p<0.001, respectively).

Cervical Cancer Screening

There were 19,957 women between the ages of 21 and 65: White 10,845 (54%), Hispanic 5333 (27%) and African American 3779 (19%) (Table 2.1). The majority of White women perceived their health as very good or excellent (61%), compared to 44% of Latinas and 46% of African American women. Forty-five percent (45%) of African American women reported a comorbid condition, compared to 44% of Whites and 36% of Hispanics. Hispanics were least likely to have private insurance (41%), compared to 54% of African Americans and 77% of Whites. The majority of all populations were employed (White – 78%, Hispanic – 65% and African American – 74%) and Hispanics were less likely to have a usual source of care (31%). Fifty-three percent (53%) of Hispanics did not speak English as a primary language and 63% of Hispanics were not born in the United States.

Figure 2.2 provides summary statistics of Pap Smear rates before and during the recession periods. There was a slight decrease in the percentage of White women screened (88% before and 85% during the recession). Percentages of African American women who were screened were unchanged at 89% and screening among Hispanic women rose three percentage points (84% to 87%).

Figure 2.2 Percent of Women with a Pap Smear Before and During the Great Recession

100%	2004-2005	2009-2010
■ White	0.88	0.85
■ Hispanic	0.84	0.87
■ African American	0.89	0.89

Based on age-appropriate recommendations established by the United States Preventive Services Task Force: Women ages 21-65

According to the multivariate regressions (Table 2.2), overall, compared to the prerecession period, women were less likely to obtain a Pap smear during the recession period (OR .79 p<.001). However, African American women were more likely to have a Pap smear than White women (OR 1.78 p<.001). Compared to the prerecession period, Hispanic women were more likely to be screened during the recession period (OR 1.56 p<.001). The percentage of White women with a timely Pap Smear dropped three percentage points during the recession; 88% before; 85% during (Figure 2.2). However, percentage rates for Hispanics increased from 84% prior to the recession to 87% during the recession. Rates for African Americans remained unchanged at 89%.

According to multivariate regressions for the two time periods (Table 2.2), married women were more likely to be screened than women who were not married (OR 1.75 p<.001). Those with a college degree were most likely to be screened (OR 2.08 p<.001), followed by those with an advanced degree (OR 1.64 p<.001) compared to those without a degree (reference). Consistent with trends in breast screening, women with

higher perceptions of health status were more likely to be screened than women with lower perceptions of health status (p<.05). However, screening rates were higher for those with comorbidities (OR 1.33 p<.001) compared to those with comorbidities.

Access to insurance, employment, and a usual source of care were the most significant enabling factors. Compared to uninsured women (reference), those with private insurance and public insurance were more than two times more likely to be screened (OR 2.17 p<.001; OR 2.15 p<001). Unemployed women were less likely to be screened than employed women (OR .72 p<.001) and women with a usual source of care were more than two times more likely to be screened than those without a usual source of care (OR 2.08 p<.001). Although there were no statistically significant findings by region, women in urban areas were more likely to be screened than women in non-urban areas (OR 1.20 p<.05).

During the recession period, women were less likely to obtain a Pap smear compared to the prerecession period (OR .79 p<.001). Compared to White women (reference), African American women were more likely to receive a pap smear (OR 1.78 p<.001). Hispanic women were more likely to receive a timely Pap smear during the recession period, compared to the prerecession period (OR 1.56 p<.001).

Table 2.1   Demographic Characteristics of Sample Based on USPSTF Age-Appropriate Recommendations

	Women Ages 50-74 (Mammogram)			Women Ages 21-65 (Pap Smear)		
	White	Hispanic	African American	White	Hispanic	African American
	N=6936(%)	N=1884(%)	N=2074(%)	N=10845(%)	N=5333(%)	N=3779(%)
Age (years)	60	59	59	41	38	39
Marital Status						
Married	4230(61)	998(53)	728(32)	6398(59)	2880(54)	1020(27)
Not Married	2706(39)	886(47)	1346(68)	4447(41)	2453(46)	2759(73)
Perceived Health						
Excellent	1248(18)	151(08)	167(8)	2711(25)	907(17)	680(18)
Very Good	2289(33)	375(21)	477(23)	3904(36)	1440(27)	1058(28)
Good	2081(30)	659(35)	746(36)	3037(28)	1973(37)	1285(34)
Fair	902(13)	527(28)	498(24)	868(08)	853(16)	605(16)
Poor	416(06)	151(08)	186(9)	325(03)	160(03)	151(04)
Comorbidity						
Yes	4924(71)	1375(73)	1638(79)	4772(44)	1920(36)	1700(45)
No	2012(29)	509(27)	436(21)	6073(56)	3413(64)	2073(55)
Education						
No degree	1040(15)	1168(62)	663(32)	1193(11)	2560(48)	831(22)
High school degree	3606(52)	471(25)	954(46)	4989(46)	1919(36)	2003(53)
College degree	1040(15)	113(06)	166(08)	2386(22)	427(08)	454(12)
Advanced degree	1317(18)	131(07)	290(14)	2277(21)	427(08)	491(13)
Income						
> 200% FPL	693(10)	414(22)	539(26)	1410(13)	1547(29)	1171(31)
< 100% FPL	1040(15)	527(28)	539(26)	1735(16)	1653(31)	983(26)
100-200% FPL	5202(75)	942(50)	996(48)	7700(71)	2133(40)	1625(43)
Insurance						
Uninsured	486(07)	452(24)	249(12)	1193(11)	1866(35)	605(16)
Private	5132(74)	754(40)	1058(51)	8351(77)	2186(41)	2040(54)
Public	1317(19)	678(36)	767(37)	1301(12)	1281(24)	1134(30)
Usual Source of Care						
Yes	6381(92)	1583(84)	1867(90)	9001(83)	3680(69)	2948(78)
No	555(8)	301(16)	207(10)	1844(17)	1653(31)	831(22)
Employment						
No	3121(45)	1037(55)	1058(51)	2386(22)	1866(35)	983(26)
Yes	3815(55)	847(45)	1016(49)	8459(78)	3467(65)	2796(74)

Primary Language						
English	6936(100)	867(46)	2074(100)	10845(100)	2506(47)	3779(100)
Other	-	1017(54)	-	-	2827(53)	-
Urban/Non-urban						
Urban	5271(76)	1714(91)	1784(86)	8676(80)	4853(91)	3288(87)
Non-urban	1665(24)	170(9)	290(14)	2169(20)	480(9)	491(13)
US Region						
Northeast	1249(18)	301(16)	332(16)	1952(18)	693(13)	642(17)
Midwest	1803(26)	94(5)	332(16)	3037(28)	427(8)	681(18)
South	2497(36)	717(38)	1224(59)	3579(33)	1813(34)	2154(57)
West	1387(20)	772(41)	186(09)	2277(21)	2400(45)	302(8)
Nativity						
US born	6752(96)	622(33)	1950(94)	10411(96)	1973(37)	3477(92)
Non US born	184(4)	1262(67)	124(6)	434(4)	3360(63)	302(8)

Notes: Source : Medical Expenditure Panel Survey 2004/2005 and 2009/2010

Table 2.2:   Interaction of Recession and Screening by Race and Ethnicity and Results of Multivariate Analyses after Controlling for the Recession

	Pap Smear		Mammogram	
	OR	p-value	OR	p-value
Key Independent Variables				
Before recession (year =2004, 2005)	ref		ref	
Recession indicator (year =2009, 2010)	0.79	0.00	0.82	0.00
White	ref		ref	
African American	1.78	0.00	1.31	0.01
Hispanic	1.11	0.35	0.94	0.68
Interaction: African American & Recession	1.12	0.41	1.10	0.50
Interaction: Hispanic & Recession	1.56	0.00	1.39	0.05
Other Covariates				
Age	0.98	0.00	1.00	0.69
Marital Status				
Not Married	Ref		ref	
Married	1.75	0.00	1.36	0.00
Perceived Health				

Excellent	ref		ref	
Very good	0.85	0.04	0.90	0.29
Good	0.73	0.00	0.71	0.00
Fair	0.63	0.00	0.59	0.00
Poor	0.43	0.00	0.46	0.00
Comorbidity				
No	ref		ref	
Yes	1.33	0.00	1.74	0.00
Education				
No degree	ref		ref	
High school degree	1.12	0.11	1.36	0.00
College degree	2.08	0.00	1.78	0.00
Advanced degree	1.64	0.00	1.73	0.00
Income				
>200% FPL	ref		ref	
<100% FPL	1.06	0.54	0.73	0.00
100- 200% FPL	1.01	0.92	0.72	0.00
Insurance				
Uninsured	ref		ref	
Private	2.17	0.00	2.97	0.00
Public	2.15	0.00	2.50	0.00
Usual Source of Care				
No	ref		ref	
Yes	2.08	0.00	2.58	0.00
Employment				
Employed	ref		ref	
Unemployed	0.72	0.00	0.92	0.25
Primary Language				
English	ref		ref	
Other	0.82	0.09	0.55	0.00
Urban/Non-urban				
Non-urban	ref		ref	
Urban	1.20	0.01	1.03	0.72
US Region				
Northeast	ref		ref	
Midwest	0.94	0.47	0.73	0.00
South	0.99	0.86	0.73	0.00
West	1.04	0.68	0.78	0.01

Nativity

US born	ref		ref	0.68
Non US born	0.94	0.59	1.05	0.68

Notes: Source: Medical Expenditure Panel Survey 2004/2005 and 2009/2010
Women 50-74(n=10,894); Women 21-65(n=19,957)

DISCUSSION

This study contributes to the literature by examining racial and ethnic trends in breast and cervical cancer screening rates before and during the Great Recession. Findings also provide insight into how the recession period may have impacted Healthy People 2020 breast and cervical cancer screening goals. Furthermore, comparative findings provide insight on specific populations and geographic locations that should be targeted for local and national screening efforts. Social and demographic factors associated with screening were incorporated in the analyses to capture the magnitude of predisposing, enabling and need factors that are associated with health services utilization.

Consistent with findings from prior studies on the impact of preventive health services utilization during recession periods,[27,33,39] screening rates for breast and cervical cancer screenings dropped during the Great Recession. Since it is estimated that three million Whites loss insurance coverage during the recession,[31] it is not surprising that White women contributed most to reduction. The decline has resulted in a negative impact on the Healthy People 2020 objective, which identifies 81% as the national target for breast screening and 93% as the national target for cervical screening.[34] Due to the likelihood of advanced-stage diagnosis, the implications can be serious and costly.[4,5,46,47] Efforts are needed to re-engage this population in education and screening services to reduce risks and promote early detection.

Screening rates among Hispanics were higher during the recession period than before the recession period. A six-percent percentage increase for breast screening and a three-percent increase in cervical screening during the recession period, compared to the pre-recession period, is moving Latinas closer to national targets. This is especially noteworthy since Latinas have been historically diagnosed with the both cancers at more advanced stages than Whites.[48,49] Screening efforts funded by the National Breast and Cervical Cancer Early Detection Programs have made a significant contribution to the overall numbers of women screened. Latinas, in particular have benefitted - approximately 312,000 Latinas were screened for cervical cancer and 267,000 were screened for breast cancer during 2006 through 2011.[50] In addition, philanthropies, such as the Avon Foundation and the Susan B. Komen Foundation have made significant contributions in heightening awareness and expanding access to breast screening – particularly among communities of color.[51,52] Improved screening among Latinas may also be the result of local and national partnerships that offer evidence-based, culturally-tailored outreach and preventive services, specifically among safety-net provider groups.[53]

Consistent with prior research findings, insurance and usual source of care were the strongest predictors of screening.[42,54,55] It should also be noted that the gap in likelihood of screening between those with private insurance and public insurance is fairly small, suggesting that public and private providers are achieving a fairly consistent level of performance. Based on socio-economic data, African American screening rates may have remained unchanged between the two periods for two possible reasons: 1) although African Americans were adversely impacted by the recession, their income

reductions were not as dramatic as Whites[31] and 2) compared to Whites, higher proportions of African Americans have lower incomes; those populations may have already been covered by Medicaid or other forms of public insurance.[31,56]

In 2002, Fiscella and colleagues found that poor English fluency is a contributor to healthcare access disparities by ethnicity, even when controlling for insurance.[57] Results of this study corroborate those findings, since there was a significant association between primary language and likelihood of timely screening. Screening among women 50 and older who did not speak English as a primary language was significantly lower than those who spoke English as a primary language. Therefore, culturally and linguistically tailored outreach services for these populations may be helpful. In addition, subsequent research that explores social or cultural dynamics that may impact decision making for these populations is needed.

Consistent with US regions most impacted by unemployment and uninsurance during the recession, breast screening in the Midwest and South was lowest, followed by the West.[30,31] The region with the largest percentage increase in the number of newly uninsured persons was the Midwest and increased in uninsured populations were highest in the South and West.[31] The Northeast region fared better, mainly because of more widespread public insurance programs with high eligibility thresholds.[31] Since women in urban communities were more likely to be screened for cervical cancer, special efforts are needed to screen residents of rural communities in the South, Midwest and West who have elected to forgo screening due to factors associated with the recession.

There are many provisions of the Patient Protection and Affordable Care that will have a positive impact on screening rates; however, expanded Medicaid coverage, health

insurance exchanges, and no cost sharing requirements for breast and cervical screening are expected to make a favorable impact.[58] As the provisions are phased in through 2019, there are opportunities to educate those who are most likely to benefit. Widespread local and national efforts are needed to ensure that those who have been affected by the recession understand the law and how can benefit them.

Limitations: This study had several limitations. First, the analyses were cross-sectional and do not explore causality between events that occurred during the recession period and decreased screening rates. Second, the MEPS questionnaire relies on patient recall and thus survey answers may have recall bias. Third, although I controlled for the demographic and socioeconomic status of the respondents, variables, such as physician-patient relationship or cultural preference, were omitted due to the data limitation. These omitted variables may directly or indirectly influence the rates of receiving cancer screening tests. Fourth, although I controlled the geographic measures such as metropolitan statistical area (MSA) status and US Census regions, future research should focus on the state variation during the economic recession. Due to five and ten year recommendations for sigmoidoscopy and colonoscopy, respectively, data are not currently available to assess the impact of the recession on colorectal screening. Future research is needed as data become available.

CONCLUSION

The findings in this study corroborate an abundance of literature that underscores the important role of insurance and usual source of care in accessing preventive screening services. Since screenings for women with public insurance remained relatively high and unchanged during the recession, the case for expanding insurance coverage and a usual

source of care is further strengthened. While the provisions of the ACA will support these opportunities, collaborative efforts between health services providers, local and federal government, not-for-profit stakeholders and private industry are needed. These partnerships can help ensure that those most impacted by the recession are able to re-enter the system of care and receive timely and appropriate preventive health services.

CHAPTER 3:

Healthcare Access Barriers among Cancer Survivors by Race and Ethnicity

INTRODUCTION

Cancer is one of the most prevalent chronic diseases affecting millions of Americans. According to the National Coalition for Cancer Survivorship (NCCS), a cancer survivor is anyone who has received a cancer diagnosis at some during his or her lifetime, including those who are in remission or cancer free.[15]   In 2002, there were approximately nine million cancer survivors and the number of survivors increased substantially to 13.7 million in 2012, more than 150% of the prevalence rate 10 years ago.[1,14] The increase in cancer survivorship is attributable to an aging population, as well as national efforts to promote early detection. Advancements in technology, clinical treatment and pharmacological therapies are also helping survivors live longer and healthier lives.[1,2]

Despite these accomplishments, survivors still require access to a spectrum of medical and support services throughout the duration of their lives. Timely access to services that address the mental and physical effects of treatment can be lifesaving.[17,59] Unique medical needs include routine surveillance for primary or secondary malignancies, monitoring for chronic effects, and treatment for co-morbidities, such as depression.[17] Survivors are also more likely to experience sexual dysfunction, infertility, cosmetic changes, and impaired cognition.[17] Compared with persons with no history of cancer, cancer survivors are more likely to be in fair or poor health and have functional limitations.[14] These findings corroborate the importance of access and utilization of primary care and support services.[17]

Racial and ethnic disparities in treatment and access to care among cancer survivors are well-documented in health services research.[1,8,10,11,59,60] For example, a number of researchers have found that approximately 30-50% of minority women do not receive timely follow-up care after an abnormal breast screening.[4,5,46,61] Ward and colleagues (2004) found that Whites were more likely than other racial/ethnic groups to receive timely and aggressive treatment for colorectal cancer.[10] These differences in access to care contribute to poor health status and disparities in mortality by race and ethnicity.[11]

System-level factors such as transportation, organizational characteristics and costs are also documented in the health services literature as predictors of medical treatment and support service utilization.[62–64] Guidry and colleagues (1998) found that African American survivors were more likely than Hispanic and White survivors to: 1) report they lost medical coverage after diagnosis, 2) be denied medical coverage after diagnosis, 3) be denied coverage after changing jobs, and 4) reach their insurance spending limits.[62] The researchers also found African American and Hispanic survivors more likely to report transportation difficulties than Whites.[65]

There are also organizational characteristics that result in delaying or forgoing medical care. Examples include limited hours of operation, long wait times, inability to get through on the phone, and inability to obtain a timely appointment.[66–68] Kullgren and colleagues (2011) found that 17.5 percent of U.S. adults delayed care due to organizational barriers.[69] However, there is limited research on the impact of organizational characteristics on delaying or forgoing medical care, specifically as it relates to cancer survivors and racial and ethnic populations.[62]

A number of studies have examined access-to-care barriers related to cost.[23,66,68] For example, Weaver and colleagues (2010) found that cancer survivors were more likely to delay care due to cost when compared to the general population.[64] Sabatino and colleagues (2006) found that uninsured survivors and survivors on public insurance were more likely to delay care due to cost.[63] This study contributes to the body of literature by going beyond costs and examining the impact of organizational and transportation barriers among cancer survivors, using the general population as a comparison group. This deeper analysis of the interaction of cancer survivorship by race and ethnicity and the frequency of barriers provides additional insight into the relationship between race/ethnicity, access-to-care and survivorship.

Conceptual Framework

Access to health services is a critical component of disease prevention and disease management. While affordability and geographic access to health services are most commonly identified in the literature as barriers to care, there are organizational barriers that impede access and utilization of timely care.[66–68] Awareness of and attention to those dynamics is especially noteworthy in developing and designing health services to meet the needs of cancer survivors.

This study examines barriers to medical care among cancer survivors by using Penchansky and Thomas's Dimensions of Access as a conceptual framework.[25] According to the framework, access is a concept that represents the degree of "fit" between the client and the healthcare system. Affordability is based on the relationship of prices or fees and the clients' perception of value. Accommodation addresses the state in which supply services are organized and able to meet client specific needs.

Accessibility captures the relationship between location of supply and location of clients.[25]

The purpose of this study is to examine the prevalence of three common access-to-care barriers and determine whether cancer history and race/ethnicity are associated with the likelihood of reporting barriers. Analyses include an examination of similarities and differences between cancer survivors and the general population and the reasons for forgoing medical care based on costs (Affordability), transportation (Accessibility), and organizational characteristics (Accommodation). Moreover, each barrier is explored within the context of the interaction of race/ethnicity and cancer history.

METHODS

Data from the 2006-2010 National Health Interview Survey (NHIS) are merged and analyzed to achieve a sufficient sample size. The NHIS is based on approximately 35,500 households or 87,500 persons in the noninstitutionalized civilian population.[70] The survey is designed to track the incidence and prevalence of illness, accidental injuries, the prevalence of chronic conditions and impairments, the extent of disability, and the utilization of healthcare services. The NHIS survey design includes clustering, stratification, and multistage sampling. A different sample population is identified each year, and African Americans and Hispanics are over sampled.[70]

Cancer survivors are defined as persons age 18-64 who report "ever having" any of the five most common forms of cancer in the United States: breast, cervical, colon, prostate, and melanoma (n=2,281). Adults without cancer are defined as persons age 18-64 who report not having any form of the five forms of cancer, nor any other form of

cancer (n=243,925). Forgoing or delaying medical care within the past 12 months is the dependent variable.

Independent variables included sex, race/ethnicity, primary language, age, insurance, income, marital status, level of education, perceived health status, co-morbidities, usual source of care and geographic region. Insurance coverage is categorized as: no insurance, private insurance, and public insurance (Medicaid, state insurance health programs, military plans, or Medicare). Co-morbidities include eleven noncancerous conditions that typically require medical attention within the past 12 months: coronary artery disease, stroke, liver conditions, diabetes, heart conditions, hypertension, weak or failing kidneys, arthritis, ulcer, asthma, and bronchitis. Persons with one or more of these conditions are compared to those with no co-morbidities.

Barriers to Care

Barriers to care are classified into three broad categories: cost, organizational, and transportation. Responses for all questions are dichotomous. The following variables are collapsed into the cost category: delayed medical care due to cost, needed but could not afford medical care, needed but could not afford prescription(s), and needed but could not afford mental health. Organizational barriers are based on delivery system limitations. Due to low response rates, I collapse four variables into one category: could not get an appointment, office not open, could not get through on phone, and long wait in doctor's office. Only one question in the survey addresses transportation – "delayed care due to transportation."

Data Analysis

Stata 11.0 (Stata Corporation, College Station, Texas) is used for all analyses. The NHIS is based on a number of sampling strategies, including oversampling of

racial/ethnic populations, stratification, and clustering. Thus, Stata 11.0 survey commands are used for the analyses to account for sample weighting and the complex survey design to ensure correct variance estimation.

RESULTS

Cancer Survivors. There were 2,281 adults age 18-64 with a history of one or more of the five forms of cancer: breast (n=790), cervical (n=679), colon (n=201), prostate (n=256) and melanoma (n=355). Approximately 77% (n=1772) were women and 23% (n=509) were men (Table 3.1; 3.4). Nearly 81% were White, 9.2% African American, 5.7% Hispanic and 4.2% other races. The majority of respondents reported a usual source of care and spoke English as a primary language (91% and 99%, respectively). Seventy-five percent of persons with a history of cancer were ages 45-64. Approximately 67% reported educational levels less than a bachelor's degree; 67% had private insurance. The majority of cancer survivors (62.9%) reported at least one or more of the 11 co-morbidities (Table 3.1).

General Population. There were 243,925 persons with no history of cancer in the sample; 49.7% were male and 50.3% female. Sixty-six percent were White, 12.3% African American, 15.1% Hispanic and 6.7% other races. The majority of respondents (67.6%) reported no usual source of care and 95.7% spoke English as a primary language. Nearly 71% reported educational levels less than a bachelor's degree; 67.2% had a private insurance. Only 14.7% reported one or more of the 11 co-morbidities (Table 3.1).

Table 3.1: Demographic Characteristics of Adults With and Without a History of Cancer

Characteristics	Cancer Survivors (n=2,281)*		Adults without Cancer (n=243,925)	
	n	WT% (95% CI)	n	WT% (95% CI)
Sex				
Male	509	22.8 (21.1,24.6)	118,006	49.7 (49.5,49.9)
Female	1,772	77.2 (75.4,78.9)	125,919	50.3 (50.1,50.5)
Race/Ethnicity				
White	1,646	80.9 (79.1,82.5)	127,965	66.0 (65.3,66.7)
African American	292	9.2 (8.0,10.6)	36,201	12.3 (11.8,12.8)
Hispanic	222	5.7 (4.9,6.7)	58,350	15.1 (14.5,15.6)
Other	121	4.2 (3.4,5.1)	21,409	6.7 (6.4,7.0)
Primary Language				
English	2,242	99.1 (98.7,99.4)	226,153	95.7 (95.5,96.0)
Spanish/other	35	0.8 (0.5,1.1)	15,999	3.8 (3.5,4.0)
Other	4	0.1 (0.001, 0.3)	1,773	0.5 (0.5,0.6)
Age				
18-24	70	3.5 (3.0,4.4)	37,936	15.7 (15.3,16.1)
25-34	186	7.7 (6.6,9.0)	53,487	21.6 (21.3,22.0)
35-44	317	13.7 (12.2, 15.3)	56,093	22.2 (22.0,22.5)
45-54	665	28.4 (26.5,30.5)	55,829	23.2 (22.9,23.5)
55-64	1,043	46.7 (44.4,49.0)	40,580	17.2 (16.9,17.5)
Insurance Status				
No Insurance	280	11,9 (10.4,13.6)	55,895	20.0 (19.6,20.4)
Private Insurance	1,493	67.0 (64.8,69.2)	152,935	67.2 (66.6,67.8)
Public Insurance	508	21.1 (19.3,23.0)	35,095	12.8 (12.5,13.2)
Income Level				
$0-24,999	1,131	59.7 (57.2,62.2)	101,625	55.6 (55.1,56.0)
$25,000-54,999	481	27.1 (24.9,29.5)	50,435	30.2 (29.8,30.6)
$55,000-74,999	135	7.1 (5.9,8.4)	13,405	8.4 (8.1,8.6)
$75,000 and above	117	6.1 (5.0,7.5)	9,709	5.9 (5.6,6.1)
Marital Status				
Never Married	337	15.1 (13.6,16.8)	71,318	29.4 (28.9,29.9)
Married	1,086	47.8 (45.2,50.3)	136,221	56.4 (55.8,57.0)
Widowed/Separated/Divorced	855	37.1 (34.8,39.5)	34,421	14.2 (13.9,14.4)
Highest Education				
Less than High School	52	2.2 (1.6,3.0)	12,425	5.2 (5.0,5.4)
High School Diploma/GED	609	30.1 (28.0,32.3)	66,443	30.9 (30.4,31.4)
Some College	730	34.9 (32.7,37.2)	70,233	33.7 (33.3,34.1)
Bachelors and above	649	32.8 (30.4,35.3)	60,157	30.3 (30.0,30.9)
Perceived Health Status				
Poor	208	8.2 (7.1,9.5)	5,522	2.2 (2.1,2.3)
Fair	394	16.6 (15.0,18.4)	19,448	7.4 (7.3,7.6)
Good	691	30.5 (28.6,32.6)	64,630	25.3 (25.0,25.6)
Very Good	659	29.8 (27.8,31.9)	77,418	32.7 (32.4,33.0)
Excellent	326	14.9 (13.4,16.4)	76,422	32.4 (32.0,32.8)
Co-morbidity				
No Co-morbidity	846	37.8 (35.5,39.9)	209,664	85.3 (85.1,85.5)
1 or more co-morbidities	1,435	62.3 (60.1,64.6)	34,261	14.7 (14.5,14.9)
Usual Source of Care				

No	214	9.3 (8.0,10.7)	168,448	67.6 (67.2,67.9)
Yes	2,067	90.7 (87.3,92.0)	75,479	32.4 (32.1,32.8)
Geographical Region				
Northeast	400	19.7 (17.2,22.4)	40,599	17.8 (17.2,18.5)
North Central/Midwest	538	24.3 (22.3,26.4)	48,659	22.7 (21.7,23.7)
South	840	35.8 (33.2,38.6)	89,401	36.4 (35.4,37.5)
West	503	20.2 (18.2,22.3)	65,266	23.0 (22.2,23.9)

WT% indicates weighted percentage; 95% Confidence Interval
*Breast, cervical, prostate, colon cancer, melanoma

Access to Care Barriers among Survivors, the General Population and Racial/Ethnic Minorities

Overall, 31% of cancer survivors reported at least one of the three barriers compared to 15% of the general population (P<.05). Eighteen percent (18%) of survivors reported cost as a barrier, compared to 11% of the general population; 14% of survivors reported organizational barriers compared to 4% of the general population, and 3% reported transportation barriers, compared to <1% of the general population (p<.05).

As presented in Table 3.2, cost was more likely to be considered as a barrier by African American and Hispanic survivors (24.6%, 24.3%, respectively) compared to Whites and other race survivors. However, the frequency of cost as a barrier in the general population was fairly consistent among Whites (11.8%), African Americans (11.6%), and Hispanics (11.9%). Twenty-one percent (21%) of African American cancer survivors reported organizational barriers compared to 16.3% of other races, 14.3% of Hispanics and 13.9% of Whites. More Hispanic cancer survivors reported transportation barriers (7.9%) compared to other races (4.7%), African Americans (4.1%), and Whites (3.1%) (Table 3.2).

Table 3.2 Summary Statistics: Barriers to Medical Care among Adults by Race/Ethnicity

Barriers	n	Cancer Survivors WT% (95% CI)	n	Adults without Cancer WT% (95% CI)
Cost Barriers				
White	292	17.7 (15.8,19.8)	14,836	11.8 (11.5,12.1)
African American	50	24.6 (17.7,33.2)	6,609	11.6 (11.1,12.0)
Hispanic	68	24.3 (19.6,29.7)	4,285	11.9 (11.4,12.3)
Other	20	17.2 (10.7,26.5)	1,609	8.3 (7.8,8.9)
Organizational Barriers*				
White	231	13.9 (12.3,15.8)	5,195	4.2 (4.0,4.3)
African American	48	21.0 (15.3,28.1)	2,350	4.0 (3.8,4.3)
Hispanic	44	14.3 (10.5,19.2)	1,759	4.9 (4.6,5.2)
Other	19	16.3 (9.8,26.0)	900	4.4 (4.0,4.7)
Transportation Barriers				
White	52	3.1 (2.3,4.1)	762	0.6 (0.5,0.7)
African American	8	4.1 (1.7,9.8)	534	0.9 (0.8,1.0)
Hispanic	23	7.9 (5.2,11.7)	603	1.6 (1.5,1.8)
Other	4	4.7 (1.5,14.1)	160	0.9 (0.7,1.1)
No Barriers				
White	1,168	71.2 (68.8,73,5)	109,040	85.0 (84.6,85.3)
African American	138	61.8 (53.8,69.2)	49,806	85.2 (84.7,85.7)
Hispanic	186	64.0 (58.2,69.3)	30,434	84.2 (83.7,84.6)
Other	85	70.8 (60.3,79.5)	19,005	87.9 (87.2,88.5)

WT% indicates weigthed percentage; 95% Confidence Interval
*Couldn't get appointment soon enough, waited too long to see the doctor, clinic/doctor's office wasn't open, couldn't get through on the phone

Logistic regression results are presented in Table 3.3. In the unadjusted model, adults with a history of cancer were more likely to report cost as a barrier (OR 1.76 $p<.001$). The interaction between cancer survivors and African Americans and Hispanics who reported costs as barriers was statistically significant in the adjusted model (OR 1.55 $p<.05$; OR 2.30 $p<.05$, respectively).

Compared to the general population, adults with a history of cancer were more likely to report organizational barriers in unadjusted and adjusted models (OR 3.81 CI 3.35-4.34; OR 1.19, 1.01-1.39) (Table 2.3). Hispanics and persons from other races were more likely than Whites and African Americans to report organizational barriers in the adjusted model (OR 1.20 $p<.01$; 1.07 $p<.05$). In unadjusted models, African American

cancer survivors were more likely than White survivors to report organizational barriers (OR 1.70 p<.05). However, in adjusted models there were no significant interactions between race and cancer survivors in relation to organizational barriers.

Adults with a history of cancer were almost five times more likely to report transportation as a barrier, compared to the general population (OR 4.75 p<.001) in unadjusted models. However, this association became non-significant in adjusted models. There were also noteworthy disparities in transportation barriers by race/ethnicity regardless of cancer survivorship. In the adjusted model, African Americans and other races in the general population were more likely to report transportation barriers than Whites (OR 1.36 p<.001; 1.64 p<.001). Hispanics were more likely to report transportation barriers in the unadjusted model only (OR 2.60 p<.001). There were no statistically significant findings in the interaction between cancer survivors and race/ethnicity in relation to transportation barriers (Table 3.3).

Table 3.3 Barriers to Medical Care among Adults by Race/Ethnicity and Cancer Survivorship

	Unadjusted Model			Adjusted Model†		
	OR	95% CI	p-value	OR	95% CI	p-value
Race/Ethnicity						
White	1.00			1.00		
African American	0.96	0.92-1.02	.21	0.66	0.62-0.70	<.001
Hispanic	1.00	0.96-1.05	.93	0.63	0.59-0.68	<.001
Other	.68	0.63-0.73	<.001	0.59	0.54-0.65	<.001
Cancer History						
No	1.00			1.00		
Yes	1.16	1.56-2.00	<.001	1.12	0.97-1.29	.14
Interaction – Cancer Survivors						
White	1.00			1.00		
African American	1.55	1.00-2.42	.05	1.55	1.05-2.28	.03
Hispanic	1.48	1.09-2.01	.01	2.23	1.28-4.15	.01
Other	1.42	0.82-2.46	.21	1.16	0.57-2.37	.68
ORGANIZATIONAL BARRIERS*						
Race/Ethnicity						
White	1.00			1.00		
African American	0.96	0.88-.099	.03	0.91	0.84-0.99	.04
Hispanic	1.13	1.06-1.21	.001	1.20	1.10-1.32	<.001
Other	1.02	0.94-1.11	.62	1.18	1.07-1.30	.001
Cancer History						
No	1.00			1.00		
Yes	3.81	3.35-4.34	<.001	1.19	1.01-1.39	.04
Interaction – Cancer Survivors						
White	1.00			1.00		
African American	1.70	1.12-2.57	.01	1.00	0.63-1.58	.99
Hispanic	0.89	.61-1.29	.53	1.43	0.81-2.51	.22
Other	1.15	0.63-2.11	.65	0.74	0.36-1.54	.42
TRANSPORTATION BARRIERS						
Race/Ethnicity						
White	1.00			1.00		
African American	1.40	1.22-1.60	<.001	1.36	1.16-1.61	<.001
Hispanic	2.60	2.29-2.86	<.001	1.11	0.91-1.36	.30
Other	1.36	1.11-1.67	.003	1.64	1.29-2.10	<.001
Cancer History						
No	1.00			1.00		
Yes	4.75	3.73-6.06	<.001	1.25	0.92-1.71	.16
Interaction – Cancer Survivors						
White	1.00			1.00		
African American	0.90	0.34-2.35	.83	0.90	0.45-1.80	.77
Hispanic	0.99	0.58-1.67	.96	0.83	0.26-2.61	.75
Other	1.10	0.32-3.78	.88	0.22	0.04-1.09	.06

OR indicates odds ratio; CI, Confidence Interval

*Couldn't get appointment soon enough, waited too long to see the doctor, clinic/doctor's office wasn't open, couldn't get through on the phone[+]

†Adjusted for sex, race/ethnicity, age, language, insurance status, income level, marital status, perceived health status, co-morbidity, usual source of care, geographical region

Significant differences in types of barriers by cancer type were identified. Among all cancer types, persons with cervical cancer were more likely to report cost and transportation barriers and those with prostate cancer were least likely to report cost barriers and transportation barriers. There were no statistically significant associations between organizational barriers and cancer type (Table 3.4).

Table 3.4 Barriers to Medical Care among Cancer Survivors by Cancer Site (weighted)

Site	Weighted Percentage (95% CI)			
	Cost	Organizational Barriers	Transportation	No Barriers
Breast (n=790)	16.0 (13.4,19.0)	14.6 (12.1,17.4)	2.4 (1.4,3.9)	72.7 (69.4,75.7)
Cervical (n=679)	28. (24.3,32.1)	17.2 (14.4,20.4)	5.7 (3.9,8.2)	58.2 (53.9,62.3)
Colon (n=201)	12.8 (8.7,18.4)	14.3 (9.8,20.3)	5.0 (2.8,8.8)	74.6 (67.6,80.5)
Prostate (n=256)	9.0 (5.9,13.5)	9.6 (6.4,14.2)	1.5 (0.6,3.9)	83.4 (78.1,87.6)
Melanoma (n=355)	17.0 (13.1,21.7)	12.8 (9.4,17.3)	3.4 (1.8,6.4)	74.4 (69.0,79.1)
Chi-Square test with 4 df	P<.001	P=.07	P=.01	p<.001

CI indicates Confidence Interval; 95% Confidence Interval

DISCUSSION

By applying the dimensions of access, I explored the impact of access barriers on delaying or forgoing medical care.[25] Findings in health services literature suggest that costs, organizational characteristics, and transportation are critical components to the facilitation of timely medical care.[3,62,65,67,71,72] I found the presence of these barriers to be magnified among cancer survivors. For example, survivors were more likely to report barriers to medical care than the general population (30% vs. 15%). This is a serious concern because of the projected growth in the number of cancer survivors in the United States, coupled with the need for survivors to undergo routine preventive care and follow-up services that promote quality of life and reduce risks of recurrence.[1,11,17]

Moreover, since the presence of co-morbidities results in an increased need for medical visits[14], the prevalence of these barriers is especially noteworthy, given that 62.3% of survivors reported one or more co-morbidities.

Cost Barriers - Affordability

Innovative surgical techniques and advanced clinical therapies are improving survival rates for many types of cancers.[73] These accomplishments have contributed to escalating costs of treating the most common cancers; and consequently, many of those costs are shared by the patient.[74] The need for more frequent medical visits among survivors also increases the likelihood for more co-payments and out-of-pocket expenses.[17,64] In this study, 88.1% of cancer survivors had either public or private insurance and 90.7% of survivors reported a usual source of care; therefore, consistent with prior studies, the impact of cost in delaying or forgoing care transcends insurance status and usual source of care.[62–64]

In addition to escalating costs, there may be other uncalculated explanations for survivors reporting cost as a barrier. Unfortunately, such costs cannot be ascertained based on the NHIS survey questionnaire. The NHIS question asks participants, *"Did you delay medical care within the past 12 months because of cost?"* Based on the respondent's perception, this question may be interpreted as: 1) direct costs associated with treatment *(e.g. I cannot afford the co-payment or I cannot afford out of pocket expenses for uncovered services);* or 2) the prohibitive cost of services that may facilitate utilization of health services *(e.g. I cannot afford to get there or I cannot afford to take off work)* commonly referred to in the literature as intangible costs.[75]

Within these contexts, survivors may have been more likely to report cost barriers than the general population due to some of the possible reasons: 1) the need for more

frequent medical visits, requiring additional out-of-pocket or cost-sharing expenses;[47,62,64] 2) interruption of insurance coverage continuity;[62,76] 3) additional costs associated with transportation services or child care expenses to comply with treatment a regimen;[65,76] and 4) competing financial obligations associated with meeting day-to-day basic needs, especially among persons with low-incomes.[77]

The difference between cost barriers reported by African Americans and Hispanics compared to Whites is especially noteworthy. African Americans and Hispanics were more likely than Whites to report costs as barriers in the adjusted interaction model. This may be the effect of greater acuity or more complex medical conditions, requiring more medical visits.[11,12,75] A greater burden of intangible costs for these populations may be an explanation for this phenomenon. For example, persons from communities of color may experience more travel expenses for accessing primary or specialty care services because those services may not be available in their neighborhoods.[65,78] Future studies that tease out the impact of direct and intangible cost barriers by racial and ethnic survivors are needed.

Psychological, socio-cultural or spiritual issues may also impact attitudes and perceived treatment of cancer treatment modalities.[79,80] These perceptions may influence how minorities perceive value and overall affordability of health services costs.[81] These considerations are especially important since a number of researchers have found that minorities are more likely to receive poorer quality health services, when compared to Whites.[8,81–83] Within this context, additional research is needed to examine survivors' purchasing priorities or purchasing attitudes.

Organizational Barriers- Accommodation

Penchansky and Thomas describe accommodation as the state in which health services are operationally delivered in relation to meeting the client's needs.[25] In this study, I assess this dimension based on: 1) inability to obtain a medical appointment within a desired timeframe; 2) long wait time; 3) inconvenient hours of operation; and 4) inability to get through on the phone. Overall, 14% of survivors reported accommodation barriers, compared to 4% of the general population. Survivors were also more likely to report these types of barriers in the adjusted model. This may be, in part, due to the need for more medical visits or more frequent interactions with the healthcare system, resulting in greater likelihood for encountering barriers.[14,64]

However, since Hispanics and persons from other races were more likely to report organizational barriers in the adjusted model, there may be cultural or linguistic dynamics that contribute to these barriers.[3] For example, a number of investigations cite language barriers, acculturation issues, employment limitations, discrimination, distrust, and racism as culpable factors.[8,84,85] Due to low response rates, I was not able to conduct an analysis of each of the four accommodation questions; therefore, a deeper investigation of each question is an opportunity for further exploration. This will be especially important since more than 32 million persons are projected to obtain insurance coverage by 2019.[86]

Accommodation barriers have received national attention and major initiatives are underway. For example, funding from the Patient Protection and Affordable Care Act has been earmarked to test the efficacy of innovative access-to-care practice models.[87] Furthermore, accommodation concepts are aligned with "Superb Access to Care," the first domain of the Institute of Medicine's six domains of quality.[26] Established to

promote patient-centered care and the establishment of a medical home, or usual source of care, the Institute of Medicine describes the following as "superb access to care:" ease of making an appointment, ability of patients to select the day and time of their appointment, short wait times, and office hours that make primary care readily accessible on nights, weekends, and holidays.[26]

Due to the importance of survivors' obtaining routine and ongoing care, cancer care providers may improve patient care and align with national objectives by testing new options and integrating access-to-care best practices in their operational modalities. Examples may include extending office hours, offering same day appointments, and employing community health workers or patient navigators. Prior studies suggest these strategies to be effective in increasing access and promoting continuity of care.[71,72,85] Moreover, these efforts may be especially beneficial for low-wage earners who may not have the flexibility to take off work during traditional work hours.[3,77]

Transportation Barriers - Accessibility

Cancer is a unique chronic disease condition, requiring highly specialized care and frequent medical visits.[1] Therefore, reliable transportation is a critical component to patient compliance with medical appointments. While there were no significant differences between cancer survivors and the general population in terms of transportation barriers, noteworthy racial and ethnic disparities associated with transportation barriers did exist, regardless of cancer survivorship.

African Americans and other races were more likely to report transportation barriers than Whites. A plethora of research suggests that communities of color are more likely to be medically underserved and the availability of specialized cancer care services may be geographically inaccessible for residents of these communities.[8,65,78]

Efforts to provide more convenient geographic access to cancer care services in medically underserved communities, coupled with initiatives to promote door-to-door transportation services for persons with cancer may help reduce the number of survivors who delay or forgo care due to transportation. Assessing survivors' transportation needs should be a routine component of patient management. Medical providers can support these needs by developing partnerships with volunteer agencies and community resources that offer or facilitate transportation services.[65]

Limitations

There are several limitations to highlight. First, the NHIS questionnaire relies on patient recall and thus survey answers may have recall bias. Second, co-morbidities are restricted to only eleven health conditions. Third, due to low response rate, I collapse four organizational barriers into one category. Fourth, the NHIS does not collect information about survivors' cancer stage, current treatment, or cancer recurrence so the acuity levels of survivors in the sample could not be controlled in the analyses. Finally, since the dataset includes respondents from years 2006-2010, historical effects are not considered which may compromise external validity.

CONCLUSION

This study contributes to the body of literature by highlighting similarities and differences in access-to-care barriers between cancer survivors and the general population. Moreover, findings provide deeper insight into the prevalence of barriers in both populations by race/ethnicity. National surveys, such as the NHIS and Medical Expenditure Panel Survey, should be expanded to include questions that address survivor attitudes and perceptions by race/ethnicity, specifically as they relate to comprehensive access-to-care barriers. As national efforts continue to ensure access to

medical homes for all Americans, access to a medical home is a small component of the continuity of care continuum. Simultaneous and coordinated efforts to implement more culturally-tailored investigations of costs, organizational and transportation barriers will shape policy, improve delivery system designs, and ultimately promote health equity.

CHAPTER 4:

**Decomposing Differences in Medical Care Access among Cancer Survivors
by Race and Ethnicity**

INTRODUCTION

The number of cancer survivors increased by 50% in the last decade, from nine million in 2002 to 13.7 million in 2012.[1,14] The incidence of cancer in 2012 alone reached 1.6 million people and the number is projected to increase 45% by 2030 (1.6 million to 2.3 million); racial and ethnic minorities are expected to represent 28% of the cases.[88] The gravity of these statistics cannot be overlooked, realizing that racial and ethnic disparities in treatment, outcome, and mortality continue to exist.[8,10–13] This is especially important since Hispanics are the fastest growing segment of the American population and minorities are projected to represent the majority of the population by 2050.[89]

Compared to the general population, cancer survivors are more likely to report lower perceived health status, psychological distress, poorer mental health, greater role impairment due to emotional problems and poorer social well-being.[14,19–22] Unique medical needs include routine surveillance for primary or secondary malignancies, monitoring chronic effects, and treatment for morbidities.[17] In order to effectively address these needs and promote quality of life, a greater level of engagement with healthcare providers and the healthcare system is warranted.

Timely receipt of these services is paramount; however, compared to the general population, cancer survivors are more likely to delay care because of financial and nonfinancial barriers.[63,90–92] For example, out-of-pocket costs have been documented as a contributing factor to survivors delaying or forgoing medical care.[93] The average

annual amount of out-of-pocket expenses for newly diagnosed adult survivors is estimated at $2,159 – more than three times the average amount the general population spends on out-of-pocket expenses.[93] These expenses can be prohibitive, especially for persons with lower socioeconomic statuses and minorities, who are more like to be uninsured or have public insurance.[8,63,94,95]

The structural design of the delivery care system also influences the likelihood of receipt of care. Examples include but are not limited to organizational factors, such as office hours, time to obtain an appointment, and wait time.[69] This is a particularly important issue, since persons with Medicaid and other forms of public insurance are more likely to have a difficult time accessing providers or securing timely appointments.[8,96,97] Since minorities represent 68% of persons with Medicaid in the United States, they are especially susceptible to these challenges.[56]

Access to transportation services also influences receipt of timely medical care. A number of investigations have found racial/ethnic disparities in the ability to access transportation services for medical treatment.[65,92,98,99] For example, Guidry and colleagues found that Hispanic survivors consistently reported barriers such as distance, access to an automobile, and the availability of someone to drive them to the doctor as major problems.[65] Hispanic and African American respondents also identified the need to travel farther distances for chemotherapy and radiotherapy. [65]

National legislation, such as the Patient Protection and Affordable Care Act, is expected to help increase access-to-care and promote continuity of care for cancer survivors.[100] As components of the legislation are phased in through 2019, it is important to consider the growing numbers of minorities, coupled with greater cancer incidence

projections over the next 20 years. Within this context, more recent, comprehensive, and nationally representative investigations are needed to examine access-to-care barriers across racial and ethnic populations. Furthermore, deeper analyses aimed at uncovering contributing factors to access-to-care disparities by race/ethnicity will shape policy and practice that will: 1) improve survivors' quality of life, 2) help close the gap in treatment and mortality disparities; and 3) strengthen national healthcare reform efforts.

I address this opportunity by using the Andersen Behavioral Health Model and Penchansky and Thomas's Dimensions of Access as a conceptual framework. First, I examine the likelihood of cost, organizational, and transportation barriers that contribute to delaying or forgoing medical care or treatment for Whites, African Americans and Hispanics. Then I decompose factors to uncover predisposing, enabling, and need factors associated with access-to-care disparities.

While a number of investigations have examined access barriers among cancer survivors,[62,63,92,94,95] this 11-year analysis contributes to the literature by: 1) examining the magnitude of the disparity by race and ethnicity; 2) going beyond cost and examining the magnitude of organizational and transportation barriers; and 3) decomposing social and demographic factors that contribute to the disparities. Findings provide insight that will support more culturally-tailored interventions and services aimed at increasing the percentage of minority cancer survivors who receive timely access to healthcare services.

Conceptual Framework

Andersen Behavioral Health Services Model - Recognized as a conceptual model that identifies factors that facilitate utilization of health services, the Andersen Model of Behavioral Health Services Use focuses on three dynamics: predisposing factors, enabling factors, and need factors.[23] Predisposing factors include demographic, social characteristics or individual beliefs about health services. Enabling factors include access to prerequisite resources and the availability of health services in the local community. Need refers to an individual's perceived severity of illness and subsequently, the need for accessing health services.[23]

Access to Care –Described as the concept of "fit" between the patient's needs and the system's ability to meet those needs, Penchansky and Thomas's five Dimensions of Access go beyond the traditional concepts of cost and availability.[25] Availability is defined as the relationship between need and physical availability. Accessibility captures the relationship between location of supply and location of clients. Accommodation refers to the state in which supply services are organized and able to meet client specific needs. Affordability is based on the relationship of prices or fees and the clients' perception of value. Acceptability is defined as the relationship of clients' service expectations compared to what is actually delivered.[25,69] In this study, I examine three outcome variables that are linked to four dimensions: Affordability, Accommodation, Accessibility and Availability. Dependent variables are examined by race/ethnicity in the context of barriers to medical care and treatment. Due to survey limitations, outcome measures that explore Acceptability barriers are not explored.

METHODS

Data from the 2000-2011 National Health Interview Survey (NHIS) were merged and analyzed to achieve a sufficient sample size. The NHIS is based on approximately 35,500 households or 87,500 persons in the noninstitutionalized civilian population in the United States.[70] The survey is designed to track the incidence and prevalence of illness, accidental injuries, the prevalence of chronic conditions and impairments, the extent of disability, and the utilization of healthcare services. The NHIS survey design includes clustering, stratification, and multistage sampling. A different sample population is identified each year. African Americans and Hispanics are over sampled.[70]

Cancer survivors are defined as persons age 18-64 who reported "ever having" any form of cancer.[101] Due to sample size limitations, racial/ethnic groups are restricted to White, African American and Hispanic. Those who reported origins of Latino or Hispanic descent are categorized as Hispanic. The final sample size included 9,941 Whites, 1,141 African Americans, and 1,033 Hispanics.

Outcome variables

Binary variables are constructed for each of the survey questions. Three dependent variables are explored and some questions in the survey are collapsed to achieve a sufficient sample size.

1) Delay or forgo medical care or treatment because of cost (Affordability). This variable includes four different questions in the NHIS survey: a) did not obtain medications because of cost; b) did not obtain care because of cost; c) delayed care because of cost; and d) did not obtain mental health because of cost.

2) Delay medical care because of organizational barriers (Accommodation). This variable includes four different questions in the survey: a) delay care because doctor's office not open; b) delayed care because could not get through on the phone; c) delay care because the wait is too long in the doctor's office; and d) delay care because could not get an appointment soon enough.

3) Delay medical care because of lack of transportation (Accessibility).

Independent Variables

Predisposing factors include: sex, age, marital status, education, income, region, language of interview, which served as a proxy for native language, and nativity. Enabling factors include insurance, transportation, and source of care. Need factors include perceived health status and comorbidities. Insurance coverage is categorized as: no insurance, private insurance, and public insurance. Co-morbidities include 11 noncancerous conditions that typically require medical attention within the past 12 months: coronary artery disease, stroke, liver conditions, diabetes, heart conditions, hypertension, weak or failing kidneys, arthritis, ulcer, asthma, and bronchitis. A binary variable that equals 1 if respondents had any of the conditions and 0 otherwise is constructed.

Data Analysis

The likelihood of experiencing unmet health needs by race and ethnicity during the last decade is summarized. Multivariate logistic regressions are applied to estimate the likelihood of delaying or forgoing medical care or treatment because of cost, organizational, and transportation barriers. Race and ethnicity, and other covariates are controlled in the regressions. Year indicators are controlled to measure aggregated market changes over the 11-year period.

The Fairlie decomposition method (nonlinear analysis), an adaptation of the Oaxaca-Blinder method (linear analysis) is applied.[102] Using the method, the mean differential for each dependent variable between Whites (reference) and African Americans and Hispanics is decomposed. In order to obtain robust standard errors, bootstrapping is conducted at 100 times simulation. The output of the model expresses

the predicted probability for each race/ethnic group in reporting barriers. After controlling for all covariates, the output also allows me to calculate a total explained percentage, which represents how much of the observed characteristics are explained by the model. Statistically significant independent variables that contribute to the disparities are presented.

Stata 12.0 (Stata Corporation, College Station, Texas) is used for all analyses. The NHIS is based on a number of sampling strategies, including oversampling of racial/ethnic populations, stratification, and clustering. Stata 12.0 survey commands are used for all analyses to account for sample weighting and the complex survey design for correct variance estimation.

RESULTS

Table 4.1 provides characteristics of the sample population. There were 12,125 adults who reported ever having at least one or more forms of cancer: White – 9,951 (82.0%); African American – 1,143 (9.4%); Hispanic – 1,033 (8.5%). Out of the 12,125, the majority of were women (67.2%) and 72.7% of all survivors were between the ages of 45-64. The majority of White respondents were married (44.0%); 47.0% of African Americans and 41.2% of Hispanics were widowed, divorced or separated. The majority of survivors across all groups self-reported a perceived health status as good, very good, or excellent: White – 77.0%; African American – 58.1%; Hispanic – 65.8%. African Americans had more comorbidities (73.0%) than Whites (56.9%) and Hispanics (58.0%). Sixty percent (60.3%) of all respondents attained education beyond high school. The majority of White (58.0%), African American (68.0%) and Hispanics (66.8%) reported annual incomes below $24,999. More than 90% of survivors reported a

usual source of care. Compared to Whites, private insurance for African Americans and Hispanics was 15.1 and 14.3 percentage points lower, respectively. The interview was conducted in Spanish with 24.5% of Hispanics. Almost half (48.7%) of Hispanics in the sample were not US born. Compared to Whites, African Americans and Hispanics were more likely to report cost, organizational, and transportation barriers (p<.05). There was a 30.5 percentage point gap between Hispanics and Whites who reported cost barriers, 53.7% vs. 23.2%, respectively. The percentage of African Americans (7.7%) who reported transportation barriers was higher than Whites (2.8) and Hispanics (5.1%) (p<.05).

Table 4.1 Demographic Characteristics of Adults with a History of Cancer

	Whites n(%)	African Americans n(%)	Hispanics n(%)
Outcome Variables			
Delay/forgo due to cost barriers	*2320(23.2)*	*360(31.5)**	*362(53.7)**
Delay due to organizational barriers	*1333(13.3)*	*192(16.8)**	*200(19.3)**
Delay due to transportation barriers	*274(2.8)*	*87(7.7)**	*52(5.1)**
Sex			
Male	3414(34.8)	328(28.8)	232(23.9)
Female	6537(65.2)	813(71.2)	801(76.1)
Age			
18-24	262(2.9)	35(3.7)	46(4.4)
25-34	779(7.7)	107(9.8)	135(12.2)
35-44	1558(15.1)	168(15.9)	244(23.1)
45-54	2938(29.3)	340(29.0)	299(29.2)
55-64	4432(45.0)	493(41.6)	312(31.1)
Marital Status			
Never married	1308(16.6)	308(31.0)	179(19.7)
Married	3429(44.0)	215(22.0)	332(39.1)
Widowed/divorced/separated	3266(39.4)	508(47.0)	382(41.2)
Perceived Health Status			
Poor	788(7.9)	166(13.0)	130(11.7)
Fair	1525(15.3)	340(28.9)	248(22.5)
Good	2863(28.6)	355(32.3)	341(34.2)
Very good	2836(28.8)	196(18.4)	200(20.8)
Excellent	1921(19.6)	82(7.4)	112(10.8)
Comorbidity			
No	4273(43.1)	304(27.0)	453(42.0)
Yes	5678(56.9)	837(73.0)	580(58.0)
Education			
No degree	933(9.3)	256(22.6)	345(29.6)
High school	2646(26.3)	317(28.6)	250(23.6)
College or more	6335(64.4)	550(48.8)	436(46.8)
Income			
<$24,999	4636(58.0)	685(68.0)	621(66.8)
$25,000-$54,999	2209(28.2)	202(21.2)	188(21.9)

$55,000-$74,999	686(8.6)	44(4.8)	30(3.5)
>$75,000	422(5.2)	55(6.0)	68(7.8)
Usual Source of Care			
Yes	9190(92.1)	1055(92.3)	904(87.5)
No	771(7.9)	86(7.7)	129(12.5)
Insurance			
Uninsured	1018(10.2)	177(16.0)	235(21.5)
Public	4354(39.9)	585(49.2)	471(42.9)
Private	4579(49.9)	379(34.8)	327(35.6)
US Region			
West	1684(18.2)	148(13.6)	165(17.8)
Northeast	2541(25.5)	260(23.6)	88(9.3)
North Central/Midwest	3574(36.2)	621(55.1)	381(37.1)
South	2152(20.1)	112(7.7)	399(35.8)
Interview Language			
English	9910(99.9)	1137(100)	742(75.5)
Spanish or other	7(<.01)	-	289(24.5)
Nativity			
US Born	9654(97.0)	1092(95.7)	526(52.3)
Non US born	293(2.9)	49(4.3)	500(48.7)

*Note: n=12.125 –categories may not equal due to missing values; * = p<.05 using independent t-tests; Data Source: National Health Interview Survey, 2000-201*

Figure 4.1 % of Cancer Survivors who Delayed Care Due to All Barriers Combined

11-year average - White 32.5%; African American 39.4%; Hispanic 42.0%
African American and Hispanic = p-value <.05
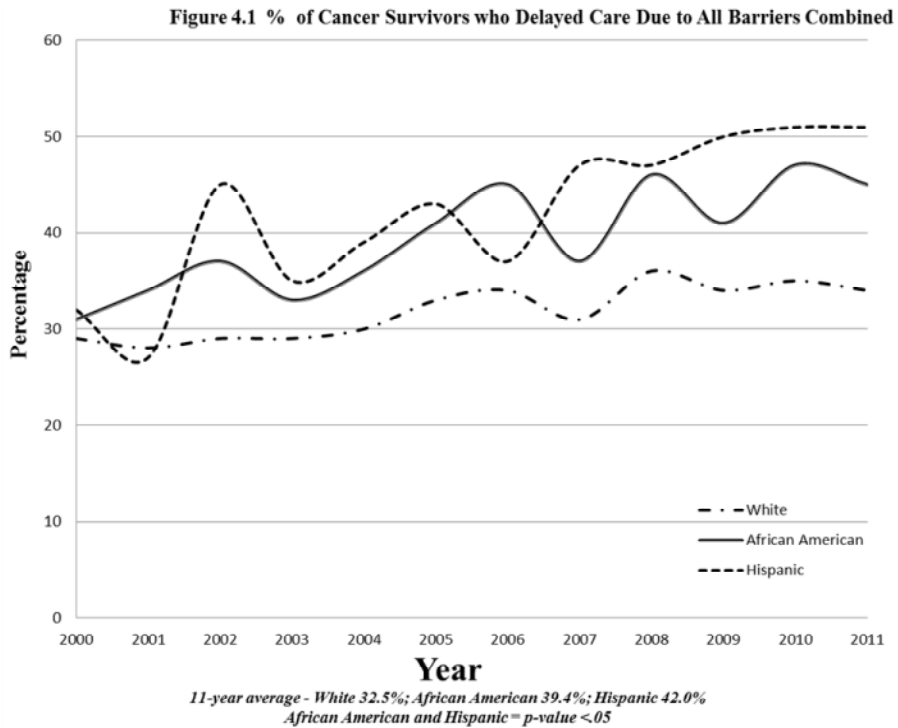
To determine the overall percentage of survivors by race and ethnicity who did not receive timely care due to all of the barriers combined, three outcome measures are collapsed into one dummy variable. Trends were assessed by plotting percentages by race and ethnicity over the 11-year period (Figure 4.1). Findings illustrate a modest increase in the percentages of minority survivors who reported barriers over the 11-year period. The 11-year percent average of those who did not receive timely care due those barriers was highest among Hispanics (42.0%) followed by African Americans (39.4%) and Whites (32.5%).

Multivariate Regression and Decomposition Results

Table 4.2 displays the adjusted model of cancer survivors who did not receive timely care due to cost, organizational and transportation barriers. Adjusted odds ratios for each independent variable by race and ethnicity are presented and reported at a 95% confidence interval. The model controls for all independent variables, including year.

Cost Barriers

There were no statistically significant findings in cost barriers between Whites and minorities (Table 4.2). Compared to those between the ages of 18-24, survivors between the ages of 55-64 were least likely to delay care because of cost (OR 45; p <.001). Widowed, divorced or separated survivors were also more likely to report cost barriers (OR 1.48 p<.001) compared to those who were never married (reference). There was also a negative correlation between perceived health status and likelihood to delay care or treatment because of cost – the better the perceived health, the less likely to delay or forgo. Survivors with comorbidities and no usual source of care were also more likely to delay or forgo health services due to cost (OR 1.41, OR 2.55; p<.001, respectively).

Compared to those who were uninsured, survivors with private and public insurance were less likely to delay (OR .27 p<.001; OR .38 p<.001 respectively). Residents of the Western region were least likely to delay care because of cost compared to residents of other regions. There were also significant findings in the likelihood for survivors to delay care due to cost in years 2004-2005 (consecutively) compared to 2000 (reference)

Table 4.3 presents the results of the decomposition model. The top panel presents the results of the predicted likelihood of delaying/forgoing any care for each race/ethnicity group, the differences in the predicted likelihood and the percentages of the disparities can be explained by the model. The bottom panel lists individual factors associated the disparities. These decomposition estimations controlled for all explanatory variables. For brevity purposes, variables that are significantly associated with racial and ethnic disparities in healthcare access are reported.

The predicted probability of delaying care or treatment due to cost was .29 for Whites, .35 for African Americans and .40 for Hispanics. The observed differences in cost barriers explain 99% of disparities in African Americans and 34% of disparities in Hispanics when compared to Whites. Insurance and perceived health were significant explanatory variables associated with cost disparities among African Americans and Hispanics. Comorbidity was an explanatory variable that was unique for African Americans and age, nativity and year were significant factors for Hispanics.

Organizational Barriers

Hispanics were more likely to delay care due to organizational barriers (OR 1.38 p<.05) than Whites (reference) (Table 4.2). There were also negative correlations between the survivors' age and likelihood to delay because of organizational barriers –

the younger the survivor, the greater the likelihood to delay. Consistent with cost barriers, the better the perceived health, the less likely to delay or forgo because of organizational barriers. Persons with comorbidities (OR 1.48 p<.001) and public insurance (OR 1.40 p<.001) were also more likely to delay care due to organizational issues. Survivors who reside in the South (OR 1.46 p<.001) were also more likely to report organizational barriers, compared to those who reside in the west (reference). Year 2011 was the only year in which survivors were more likely to delay due to organizational barriers (OR 1.44 p<.05); 2000 (reference).

The predicted probability of delaying care due to organizational barriers was .14 for Whites, .18 for African Americans and .22 for Hispanics. The decomposition model explained 53% of the observed differences in the African American population. Private insurance and perceived health status were key factors associated with the disparity in African Americans. While the model explained 13% of the organizational access disparities in Hispanics, there were no significant findings.

Transportation Barriers

Compared to Whites, African Americans were more likely to delay care due to transportation (OR 1.54 p<.001) (Table 4.2). Widowed, separated or divorced survivors were more likely to delay due to transportation than those were never married (OR 1.39 p<.05). Consistent with cost and organizational barriers, I found a negative correlation between perceived health status and likelihood to delay because of transportation - the better the perceived health, the less likely to delay or forgo because of transportation. Survivors with comorbidities (OR 1.63 p<.001) and public insurance (OR 1.87 p<.001) were also more likely to experience transportation barriers while those with private

insurance were least likely (OR .35 p<.001). Year 2009 was the only year in which survivors were more likely to experience transportation barriers (OR 2.12 p<.05) compared to 2000 (reference).

The predicted probability of delaying care due to transportation was .03 for Whites, .09 for African Americans and .06 for Hispanics (Table 4.3). The transportation decomposition model explained 58% of the observed differences in African Americans and 82% of the observed differences in Hispanics. Perceived health was the only factor associated with the disparity between Whites and African Americans. The model could not explain significant contributing factors to transportation access disparities in the Hispanic population.

Table 4.2 Adjusted Model: Cancer Survivors who Delay or Forgo Medical Care due to Cost, Organizational and Transportation Barriers

	Cost Barriers OR (95% CI)	P-value	Organizational Barriers OR (95% CI)	P-value	Transportation Barriers OR (95% CI)	P-value
Race/Ethnicity						
White	1.00 (ref)		1.00(ref)		1.00(ref)	
African American	0.92	0.34	1.01	0.83	1.54	0.00
Hispanic	1.24	0.06	1.38	0.01	1.45	0.19
Age						
18-24	1.00(ref)		1.00(ref)		1.00(ref)	
25-34	1.23	0.19	0.84	0.42	0.45	0.02
35-44	1.00	0.06	0.70	0.05	0.54	0.05
45-54	0.79	0.14	0.55	0.00	0.35	0.00
55-64	0.45	0.00	0.46	0.00	0.28	0.00
Marital Status						
Never married	1.00(ref)		1.00(ref)		1.00(ref)	
Married	0.67	0.00	0.89	0.30	0.71	0.13
Widowed/divorced/ separated	1.48	0.00	0.94	0.54	1.39	0.05
Perceived Health						
Poor	1.00(ref)		1.00(ref)		1.00(ref)	
Fair	0.69	0.00	0.88	0.28	0.69	0.02

Good	0.45	0.00	0.75	0.01	0.22	0.00
Very Good	0.27	0.00	0.57	0.00	0.16	0.00
Excellent	0.16	0.00	0.41	0.00	0.13	0.00

Comorbidity

No	1.00(ref)		1.00(ref)		1.00(ref)	
Yes	1.41	0.00	1.48	0.00	1.63	0.00

Education

No degree	1.00(ref)		1.00(ref)		1.00(ref)	
High School/GED	1.03	0.69	1.05	0.62	0.84	0.29
Some College or more	1.06	0.73	1.30	0.01	0.76	0.09

Usual Source of Care

Yes	1.00(ref)		1.00(ref)		1.00(ref)	
No	2.55	0.00	0.92	0.50	1.10	0.68

Insurance

No insurance	1.00(ref)		1.00(ref)		1.00(ref)	
Public insurance	0.38	0.00	1.40	0.00	1.87	0.00
Private insurance	0.27	0.00	.94	.51	0.35	0.00

Language

English	1.00(ref)		1.00(ref)		1.00(ref)	
Spanish or other	0.81	0.34	0.71	0.16	0.51	0.18

US Region

West	1.00(ref)		1.00(ref)		1.00(ref)	
Northeast	1.23	0.02	1.17	0.16	0.96	0.85
North/Central/Midwest	1.23	0.01	1.13	0.23	0.91	0.62
South	1.41	0.00	1.46	0.00	1.15	0.50

Nativity

US Born	1.00(ref)		1.00(ref)		1.00(ref)	
Non US Born	0.89	0.47	1.08	0.64	0.67	0.46

Years

2000	1.00(ref)		1.00(ref)		1.00(ref)	
2001	1.02	0.90	1.14	0.50	1.38	0.34
2002	0.94	0.73	1.21	0.34	1.06	0.86
2003	1.10	0.55	0.87	0.52	1.10	0.78
2004	2.45	0.00	1.16	0.42	1.34	0.39
2005	2.83	0.00	1.24	0.24	1.59	0.16
2006	3.36	0.00	1.28	0.21	1.39	0.36
2007	2.54	0.00	1.11	0.57	0.82	0.62

2008	3.05	0.00	1.35	0.11	1.07	0.85
2009	2.92	0.00	1.43	0.05	2.12	0.03
2010	3.37	0.00	1.27	0.19	1.72	0.09
2011	2.95	0.00	1.44	0.04	1.72	0.09

Notes: Data Source: National Health Interview Survey 2000-2011; Adults ages 18-64; OR = Odds Ratio

Table 4.3: Decomposition Results for Barriers to Care by Race/Ethnicity

	Cost Barriers		Organizational Barriers		Transportation Barriers	
	White(ref) Predicted Value = .29		*White (ref) Predicted Value=.14*		*White (ref) Predicted Value = .03*	
	African Americans	Hispanics	African Americans	Hispanics	African Americans	Hispanics
Predicted Value	.35	.40	.18	.22	.09	.06
Total Difference	.06	.12	.03	.07	.05	.02
Explained by Model	0.06= (99%)	0.12= (34%)	0.03= (53%)	0.07= (13%)	0.05= (58%)	0.02= (82%)
Significant Individual Factors						
Age	-	.01	-	-	-	-
Public Insurance	-.03	-.03	-	-	-	-
Private Insurance	.03	.04	-.02	-	-	-
Perceived Health	.03	.01	.02	-	.02	-
Comorbidity	.01	-	-	-	-	-
Nativity	-	.03	-	-	-	-
Year	-	.01	-	-	-	-

Notes: Data source - National Health Interview Survey 2001-2011. Non-significant results are excluded for each decomposition. All regression models include year fixed effects. Positive/negative coefficients indicate the share of explanatory variables that are positively/negatively associated with forgoing or delaying care. The share of observed characteristics is the ratio of total explained over total differences. Unobserved heterogeneity accounts for the remaining share.

DISCUSSION

By using the Dimensions of Access as a framework, this study contributes to the literature by dissecting three access-to-care dimensions and examining disparities in explanatory variables between White and minority cancer survivors. Findings show that affordability (cost barriers), accommodation (organizational barriers), and availability/accessibility (transportation barriers) negatively impact survivors' ability to obtain timely medical care and treatment. Furthermore, compared to Whites, the predicted probability of encountering those barriers was consistently greater for African American and Hispanic survivors.

Insurance was an enabling factor that contributed to disparities in preventing or delaying care due to cost in African Americans and Hispanics. The negative public insurance coefficients suggest that African Americans and Hispanics are not as likely to experience cost barriers when they have access to public insurance. Furthermore, the disparity in delaying care due to cost can be explained by minorities having disproportionate access to private insurance when compared to Whites.

Through Medicaid expansion and health insurance exchanges, the provisions of the Patient Protection and Affordable Care Act (PPACA) will help close the gap in delaying care or treatment due to costs.[100,103] However, findings suggest that increasing access to public and insurance alone will only partially address the disparity. Enabling factors, such as transportation and organizational barriers play a key role.[65,71] According to the adjusted model, minority survivors with public insurance were more likely to delay care due to transportation barriers and African American survivors, in general, were more likely to experience transportation challenges. A number of investigations

provide insight into the causes of this phenomena: 1) Communities of color are more likely to be medically underserved, requiring patients to travel farther distances for primary care, specialty care, prescriptions and support services.[78,104,105] 2) Primary care physicians may be less likely to accept patients with Medicaid or other forms of public insurance, requiring them to travel farther distances.[106–109] 3) Minorities are also more likely to seek racially and linguistically concordant medical providers.[8,83,110–112] These preferences, coupled with national shortages of minority providers, may contribute to increased travel time and associated expenses.[8,83,113] Policies and patient management practices that acknowledge the relevance of these factors in facilitating care should be supported and implemented.

Lewin-Epstein (1991) describes a usual source of care as the patient's entry point into a complex and bureaucratic healthcare system that promotes continuity and links patients to specialty care and other support services.[114] These findings corroborate the relationship between a usual source of care and reporting cost as a barrier. Survivors without a usual source of care were 2.5 times more likely to report cost as a barrier. Therefore, there are opportunities to close the gap in cost barriers by implementing comprehensive efforts to increase the number of survivors with a usual source of care.

In the wake of national efforts to increase access to a usual source of care, timely receipt of care will rely upon convenient and more responsive access to medical providers. Ease of obtaining an appointment soon, hours of operation, wait times and other patient-centered factors are relevant factors for increasing access-to-care for minority populations.[115] Deficiencies in these areas can cause consumers to lose access to a usual source of care provider, resulting in exacerbation of medical conditions.[68]

Compared to Whites, Hispanic survivors were more likely delay care due to organizational barriers. Findings also suggest nativity as a contributing factor to cost related barriers between White and Hispanics. Unobserved factors, such immigration status, complex or confusing health policies or procedures, and limited orientation to a system of care also contribute to organizational access barriers.[8,84,85,115]

One strategy that has been effective in breaking down many of these barriers has been the inclusion of patient navigators as members of the cancer care team. Patient navigators serve as patient advocates whose duties include but are not limited to: helping patients secure timely medical appointments, promoting effective communicate with providers, troubleshooting and resolving psychosocial barriers that impede care, and completing entitlement applications.[84,85,116] Cancer care providers should take advantage of patient navigator demonstration projects funded by the Department of Health and Human Services as part of the Patient Protection and Affordable Care Act.[117] Providers may also consider employing navigators or developing linkages with organizations that employ navigators. These efforts will improve access to timely and appropriate care, help retain persons in care, and ultimately reduce or eliminate racial and ethnic cancer mortality disparities.

It is clear that the current capacity of the nation's healthcare system cannot support the 32 million Americans expected to benefit from expanded coverage; 13 million of whom are projected to be Medicaid beneficiaries.[118] Again, these projections are especially relevant since persons with Medicaid were more likely to encounter organizational barriers even when other predisposing, enabling and need factors are controlled. While the ACA does include funding initiatives that address these issues,

there are opportunities for surveillance and future research to examine how minority cancer survivors and those with Medicaid fare during and post ACA implementation.

Perceived need is explored by including perceived health and comorbidity in the decomposition model. Perceived health was a significant explanatory variable in the cost model for African American and Hispanic survivors. The difference is likely due to poorer health status associated with higher acuity and comorbidities that may have been exacerbated by underinsurance, resulting in the absence of preventive care.[10,12,13,94] Cormorbidity was attributable to the disparity in Hispanics. Again, this may be the result of a higher population of Hispanics with complex or exacerbated cancerous conditions caused by delaying or forgoing care over time.[8,59]

Based on the 11-year analysis, consecutive annual trends in the likelihood of survivors to delay care or treatment from years 2004-2011 were found. This finding is noteworthy since adjusted odds ratios range from 2.45(p<.001) to 3.37(p<.001) compared to 2000 (reference). Since this time period overlaps with the Great Recession of 2007-2009[30], findings corroborate prior investigations that have found a downward trend in health services utilization across racial and ethnic populations during the recession.[31,33] Furthermore, African American survivors in the North/Central/Midwest, Northeast, and Southern regions of the United States and Hispanics in the South may have been especially burdened by the recession.

As a result of these findings, thousands of survivors delayed or forwent medical care. Comprehensive efforts that are culturally and linguistically appropriate should be underway to help survivors understand the ACA, their respective entitlements, as well as various modalities for enrollment and accessing services. These types of initiatives will

be instrumental for re-orienting survivors to the healthcare system and promoting continuity of subsequent care.

Limitations

There are several limitations to highlight. First, the NHIS questionnaire relies on patient recall and thus survey answers may have recall bias. Second, co-morbidities were restricted to only eleven health conditions. Third, in order to achieve a sufficient sample size, anyone who reported one or more forms of cancer were collapsed into one dataset. Therefore, access-to-care barriers could not be analyzed by cancer type. Fourth, the NHIS did not collect respondent's type of community during the time period (i.e. rural, metropolitan, suburban); therefore, transportation barrier by type of community could not be analyzed. Fifth, due to low response rates, four unique questions were categorized into *"delaying or forgoing medical care or treatment because of cost"* and four unique questions were categorized as *"delaying medical care due to organizational barriers."* Therefore, trends in responses by the eight individual questions could not be assessed. Sixth, the NHIS questions do not specifically ask if delayed care was directly related to cancer care services; therefore, it cannot be assumed that reported delays were directly associated with cancer treatment or services that facilitate treatment. Finally, the NHIS does not collect information about survivors' cancer stage, current treatment, or cancer recurrence so the acuity levels of survivors in the sample could not be controlled in the analyses.

CONCLUSION

Unraveling the multidimensional components of access-to-care are prerequisites for improving quality of care at all phases of the cancer care continuum. Consequently, a multifaceted approach is necessary for improving cancer survival rates and closing the gap in racial/ethnic health outcome disparities. Research, policies, and operational practices that go beyond insurance are needed to promote timely access to cancer care services. Executing these efforts within the context of the unique needs of minorities, persons with low incomes and Medicaid beneficiaries will help close the disparity gap in access, morbidity and mortality. Furthermore comprehensive efforts are needed to ensure survivors understand the ACA and how they may benefit. Collectively, these efforts will promote health equity and improve quality of life for all cancer survivors.

CHAPTER 5:

CONCLUSION

The purpose of this study was to examine racial and ethnic differences in access to timely cancer screening and treatment services for a growing number of cancer survivors. In light of healthcare reform efforts, the findings of this study provide key considerations for *practice, policy* and *future research.* Collectively, these recommendations, which go beyond the Affordable Care Act, will help: 1) increase the percentages of women screened for breast and cervical cancers; 2) decrease cancer-related mortality by promoting early detection and ensuring timely access to care for survivors; and 3) reduce or eliminate racial and ethnic disparities in cancer treatment and health outcomes.

Practice

Language and nativity, a proxy for acculturation, were identified as characteristics associated with lower screening rates and delayed access to care due to cost. For example, women who did not speak English as a primary language were less likely to receive a mammogram and nativity was one of the leading factors attributed to the disparity in delaying care due to cost between Whites and Hispanics. Furthermore, Hispanics were more likely to delay care due to organizational barriers than Whites. Linguistic barriers, confusing policies or procedures, unavailability of evening or weekend hours, and culturally insensitive practices may be root causes.

Cancer care providers can address these issues by taking proactive measures to create and sustain a system of care that is culturally and linguistically tailored to meet the needs of the populations they serve. Evidence-based practices are needed to help persons

who do not speak English as a primary language and those who are not born in the United States, understand their rights as citizens and consumers. Since immigrants cannot access Medicaid until they have been in the United States for at least five years, cancer care providers can establish linkages with federally qualified health centers and other safety net providers to ensure that survivors have access to critical medical and psychosocial services.

Providing nontraditional access to medical appointments and testing new appointment models may also help reduce access to care disparities. For example, expanding office hours to include nights and weekends, offering same-day access to medical appointments, and ensuring patients can get through on phone the during the first attempt may be effective. Since patients with cancer are likely to miss work due to medical appointments or lose their jobs due to missed work, these new models may also contribute to survivors' ability to sustain employment.

Low-income communities and communities of color are more likely to be medically underserved. These shortages result in survivors traveling longer distances for care. Longer distances may require multiple transportation modalities, resulting in increased costs, especially in urban communities (i.e. car, bus, train, taxi). Although there are provisions in the Affordable Care Act to increase the availability of primary care and specialty care in underserved communities, cancer care cancer providers can take immediate actions to address transportation challenges. For example, assessing a patient's transportation needs can be routine and integrated as part of the patient's overall plan of care. Providers can also develop community-based partnerships with transportation agencies. For example, cancer care providers can collaborate with transportation

providers and develop memoranda of understanding to offer door-to-door transportation services for patients. Developing driver volunteer programs may also be a viable option, particularly for rural communities or for those with compromised immune systems. While these initiatives can help increase access to timely medical care, they can also benefit the medical provider by reducing no-show rates.

During the recession period, breast and cervical screening rates dropped. As the economy rebounds and as components of the ACA are phased in, women who have forgone screening should be targeted and re-engaged in care. Educational and awareness campaigns should emphasize that ACA regulations prohibit insurers from imposing cost sharing requirements on preventive screening measures such as breast, cervical and colorectal screening. Concentrating these efforts in the Midwest, South and West may be most effective in improving national screening rates and achieving Healthy People 2020 screening targets.

Policy

From the ACAs no-cost screening provisions to expanded health insurance coverage, the country is making progress in the area of prevention. However, there are still policy-relevant opportunities. National efforts are needed to create and sustain systems of care that are culturally and linguistically sensitive. For example, the United States Office of Minority Health's Culturally and Linguistically Appropriate Standards can be enforced by the Centers for Medicare and Medicaid to ensure that all providers that receive federal funds or reimbursements have operations that reflect the standards. In addition, organizational and licensing or certification entities can include these standards as criteria for organizational performance expectations and professional competency standards. Collectively, these accomplishments will help cancer care providers engender

more sensitive practices that will help close the gap in racial and ethnic access-to-care disparities.

Since its inception in 1991, the National Breast and Cervical Cancer Early Detection Program, has screened more than 10.4 million women across the country. Furthermore, more recently, culturally-tailored evidence-based practices have been implemented to increase access to this program for a rapidly growing Hispanic population. These efforts may explain why screening rates improved among Hispanic women during the recession period. As a result of its effectiveness, funding appropriations for the program should remain level until cancer screening utilization effects of the ACA can be explored; and due to the reduction in breast and cervical screening during the recession period, the federal government and other national stakeholders should prioritize screening resources to target residents of the South and Midwest.

According to the decomposition model, increasing the number of African Americans and Hispanics with public insurance, will help close the disparity in access-to-care due to cost. While there is a provision in the ACA to incentivize providers to accept those with Medicaid, some providers may still place caps on the number of persons they treat with Medicaid due to the administrative burden. Whether they choose to participate in Medicaid expansion or not, states should develop policies and procedures to reduce the administrative burden imposed on medical providers who see patients with Medicaid. The alleviation of cumbersome procedures will increase access-to-care and have a favorable impact on minority cancer survivors.

Future Research

The results of this study offer opportunities for a variety of future investigations. For example, due to National Health Interview Survey limitations, access barriers that are related to the Acceptability dimension of access could not be explored. Uncovering these barriers will help health services researchers and practitioners better understand unobserved factors that could not be explained by the decomposition model. Therefore, expanding the access to care section of the survey to include questions related to patients' preferences and their providers' ability to meet those preferences will be helpful; for example, "I delayed care because no one could speak my language" or "I delayed care because I was mistreated during my last visit." Delaying care due to child care or because of the inability to take off work should also be explored. Access to this information will help health services researchers develop future studies that will inform practice and policy.

Increasing the number of adults screened for colon cancer between 50 and 75 years old is also a Healthy People 2020 goal; however, due to the USPTF's five and ten year screening intervals for sigmoidoscopy and colonoscopy, respectively, more time needs to elapse before data are available. Therefore, future research is needed to explore trends in colon cancer screening rates by race and ethnicity before and during the Great Recession. Findings will help identify socio-demographic and geographic populations to target for screening and re-engagement in preventive health services.

In order to obtain a sufficient size of survivors in Chapters 3 and 4, I collapsed those with a history of cancer into one population. Therefore, I could not analyze the

likelihood of encountering barriers by cancer type. More research is needed to examine trends in encountering barriers by cancer type.

And finally, more than 32 million Americans are expected to gain health insurance through ACA provisions. This translates into an influx of persons entering a system of care with an already overwhelmed primary and specialty care capacity. Although the ACA includes initiatives to address these shortages, future investigations will be needed to assess the impact of survivors forgoing care due to organizational barriers in this new climate.

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