Disparity in Forgoing Medical Care Across Race/Ethnicity Groups Among Long-term Adult Survivors of Childhood Cancer

by

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Thesis Abstract

Background: Foregoing medical care is of concern among adult childhood cancer survivors because they are at high-risk for developing a variety of chronic health conditions due to exposures to cancer treatment in childhood.

Objectives: I assessed disparity across race/ethnicity groups in access to care characterized by "foregoing medical care in spite of the needs in the last two years" using 3,275 adult survivors of childhood cancer participating in the St. Jude Lifetime Cohort Study (SJLIFE).

Methods: Using a cross-sectional design, I examined foregoing medical care in the last two years by race/ethnicity and insurance type (private, public and no insurance), using multivariable logistic regression, adjusting for age, gender, cancer diagnosis, treatment modalities, and treatment era, with and without perceived health status and personal income.

Results: Compared to Non-Hispanic (NH) Whites with private health insurance, the adjusted odds ratios (OR) of having foregone care was 0.88 [95% Confidence Interval (CI) 0.68–1.16] for NH Whites with public insurance. For NH Whites with no insurance, the OR was 4.63 [95%CI 3.59–5.98]. Among NH Blacks, for those with private insurance, the OR was 2.02 [95% CI 1.40–2.90] compared to NH Whites with private health insurance. The OR was 1.07 [95%CI 0.69–1.64] for NH Blacks with public insurance, the OR was 8.93 [95%CI 5.69–14.01] compared to NH Whites with private health insurance. Hispanics, on the other hand, showed less foregone care, although not statistically significantly, than NH Whites with private insurance: with HIS private insurance OR=0.28 [95%CI 0.06–1.24]; with HIS public insurance OR=0.98 [95%CI 0.18–5.50]; and with HIS no insurance OR=0.84 [95%CI 0.26–2.68]. While the additional adjustment for income and education attenuated these associations, the pattern of associations remained the same and statistically significant.

Conclusion: These findings showed: 1) NH Blacks forgo medical care approximately two times more frequently than NH whites, unless they have public insurance; 2) under public insurance, there is no difference in foregoing care across the race/ethnicity groups; 3) not having insurance more than quadruples the likelihood of foregoing care among NH Whites and NH Blacks; and 4) Hispanics seem to have means for not foregoing care regardless of their insurance status. Provision of public insurance to all may eliminate these large disparities.

Preface

This thesis is an original work by Lauren A. Lindsey with supervision from Dr. Yutaka Yasui. The identification and design of the research study was done in collaboration with I-Chan Huang, PhD, Tara Brinkman, PhD, Carrie Howell, PhD, Kirsten Ness, PT, PhD, Matthew J. Ehrhardt, MD, MS, Todd M. Gibson, PhD, Nickhill Bhakta, MD, MPH , Melissa Hudson, MD , Les Robison, PhD and St. Jude Children's Research Hospital. This thesis is considered a part of the overall research study under St. Jude Lifetime Cohort (SJLIFE) Study and received ethics approval from the institutional review board. The research was supported by St. Jude Children's Research Hospital through the St. Jude Children's Research Hospital Cancer Center Support Grant No. 5P30CA021765-33 to C. Roberts, the St. Jude Lifetime Cohort Study Grant No. U01 CA195547 to M.M. Hudson and L.L. Robison, and American Lebanese Syrian Associated Charities to all authors.

I was involved in the conception and design of the study, and was responsible for the development of methodology, analysis, and interpretation of the data, as well as drafting and revising the manuscript. Dr. Yutaka Yasui was involved in the conception and design of the study, development of methodology, interpretation of the data, and revision of the manuscript. Dr. I-Chan Huang was involved in development of modified conceptual framework and methodology.

No part of this thesis has been previously published.

Dedication

"I have learned that success is to be measured not so much by the position that one has reached

in life as by the obstacles which he has overcome while trying to succeed."

- Booker Taliaferro Washington

Acknowledgement

I would like to give thanks to God because through him all things are possible. I would also like to thank for my family especially my uncle, Dr. Bryan Keith Lindsey and brother, Ryan Lindsey, MPH whose support and encouragement have assisted me to make it this far. Thanks, and praise are also given to my "Golden Girls" and best friends who were a soundboard for all types of venting during this process. Your love and support have allowed me to make it to the finish line. Your steadfastness during the hard and frustrating times is a true testament to the bonds of friendship and love we share. I would also like to extend immense gratitude for the help and support that I received throughout this degree program to the following persons who have contributed to making this work possible.

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The School of Public Health at the University of Alberta, which has become my home, and I would like to thank Karen Goodman, Roman Pabayo, Faith Davis, Adam Golvan, and other professors involved in the courses I've taken. I am eternally grateful for your commitment, encouragement, interest, guidance, and support throughout this process. Many thanks.

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List of Symbols & Abbreviations

ALL	Acute Lymphoblastic Leukemia
ACA	Affordable Care Act
AHRQ	Agency for Healthcare Research and Quality
ACT	After Completion of Therapy Clinic
CCS	Childhood Cancer Survivors
CCSS	Childhood Cancer Survivor Study
CI	Confidence Interval
CNS	Central Nervous System
ED	Emergency Department
HPSA	Health Professional Shortage Areas
HIS	Hispanics
MUA	Medically Underserved Areas
MUP	Medically Underserved Population
NHW	Non-Hispanic Whites
NHB	Non-Hispanic Blacks
SEER	Surveillance, Epidemiology, and End Results
SES	Socioeconomic Status
SJLIFE	St. Jude Lifetime Cohort
SJCRH	St. Jude Children's Research Hospital
US	United States of America

– Chapter 1 – Introduction-

Medical advances in the last fifty years have increased the childhood cancer survival rate from 58% to nearly 90% with more children surviving 5 years or more, creating an ever-growing diverse estimated population of at least 429,000 Childhood Cancer Survivors (CCS) living in the United States (US) in 2016 [1-2]. Despite decreased mortality, CCS remain at high risk for developing treatment-related late effects such as secondary neoplasms, cardiovascular and pulmonary diseases that can develop years after completion of therapy [3-8]. Studies within the Childhood Cancer Survivor Study (CCSS) found that cancer treatments such as radiation, steroids, and chemotherapies increased the risk of metabolic issues and cardiac events [3-7]. Reports from several CCS cohorts have found that late effects are common in CCS, developing more than five years after treatment ends, and can significantly reduce quality of life, while increasing both morbidity and poor health outcomes [4-9]. A study by Bhakta et al. found that many CCS, within the St. Jude Lifetime Cohort (SJLIFE), experienced multiple medical conditions that have a cumulative disease burden nearly two-fold greater than what is observed in the general population [8].

Given that most adult CCS have potential long-life expectancy, having access to care and healthcare utilization is crucial for the early detection treatment of late effects to reduce CCS morbidity and ensure quality of life [3, 6-9]. A study by found that adult CCS in the SJLIFE cohort were eight times more likely to have a severe to fatal chronic condition compared top their siblings [10]. Healthcare utilization among long-term adult CCS is an important issue, as most survivors will develop late effects in their adult life due to their treatment exposures [5, 7, 10]. Despite this need, studies have shown disparities in healthcare accessibility and underutilization among cancer survivors [7-8, 11]. Given the impact that foregoing medical care can have on CCS quality of life,

it is important to evaluate whether there is a racial/ethnic disparity in foregoing medical care among adult CCS.

This study aims to examine whether self-reported forgone medical care in the last two years differs by race/ethnicity and insurance status among survivors in the St. Jude Lifetime Cohort (SJLIFE) cohort. These survivors completed the After Completion of Therapy (ACT) clinic of St. Jude Children's Research Hospital following their cancer care and return to St. Jude every two years for medical evaluation. For the purposes of this thesis, foregoing medical care is both an indicator of access to care and healthcare utilization in the community setting during the two years between visits. The study's hypothesis is that there is disparity in foregoing care across race/ethnicity groups and insurance types. The information obtained from this study will provide insights into factors that influence a survivor's ability to access and utilize healthcare. These findings have important implications for Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU Guidelines), health policies such as the Affordable Care Act (ACA), health insurance, as well as the current US healthcare system. The results of this study will provide evidence for future discussions for improving their access to care for childhood cancer survivors. Additionally, these findings will increase our understanding of race/ethnicity differences seen in healthcare utilization among adult CCS.

– Chapter 2 – Literature Review

Epidemiology of Childhood Cancer

Cancer is a common term used to describe the uncontrolled growth of cells that does not obey the normal biological mechanisms and interactions of living organisms. Cancer is the number one cause of disease-related-death among children regardless of age, race, and socio-economic status [1-2]. The most common types of childhood cancer are Leukemia, Lymphoma, Brain and central nervous system (CNS) tumors, and renal tumors [1-2]. While the epidemiology and etiologic factors of childhood cancer are not well established, known risk factors include chronic infections, high birth weight, ionizing radiation, male sex, and genetic factors [1-2].

Although a diagnosis of cancer is rare in children, the incidence rates in the US have increased over time from about 13 children per 100,000 in 1975 to over 17 children per 100,000 in 2019 [1-2]. In 2018, it was estimated that almost 16,000 children are diagnosed with cancer, and 1,190 children die from the disease in the US [1-2]. The total incidence of childhood cancer has been shown to vary by race and ethnicity: the Surveillance, Epidemiology, and End Results (SEER) Program reported that, between 2012 and 2016, the incidence was the highest among Non-Hispanic White (NHWs) children with 195 cases per million, followed by 174 per million cases among Alaska Native and Indigenous Americans children. Childhood cancer incidence is shown to be lower in both Asian American and Pacific Islander children with an incidence rate of 168 cases per million and an incidence rate of 165 per million among Hispanic (HIS) children. Non-Hispanic Black (NHBs) children have the lowest incidence rate at 146 cases per million [1-2]. While the incidence of childhood cancer has increased, the survival rate has increased to nearly

90%. Thanks to major medical advances in the last fifty years, more children are surviving 5 years or more following treatment with the highest rates among NHWs [2-6].

Childhood Cancer Survivorship as a Public Health Issue

An increase in the childhood cancer survival rate has contributed to the increase in the overall population of childhood cancer survivors (CCS) estimated to be 429,000 in the United States in 2015, and expected to grow to 500,000 by 2020 [2,9]. With the increase in survival, treatment-related late effects such as secondary neoplasms, cardiovascular diseases, and pulmonary diseases, can develop and be observable years after completion of therapy [3-6]. Due to treatment related late effects, adult CCS are more likely to experience poorer health status, more severe chronic conditions, reduced quality of life and have difficulties obtaining employment and insurance compared to their siblings [5] or the general population [8-9]. Studies involving CCS have shown that perceived health status and a chronic disease with a Common Terminology Criteria for Adverse Events (CTCAE) grade of 3–4 were associated with an increased need of healthcare utilization in adult CCS [8].

Studies examining long-term CCS have reported differences in health outcomes when comparing NHWs, NHBs, and HISs [7, 11-12]. Liu et al. observed that while total chronic health conditions were comparable across NHWs, NHBs, and HISs in the Childhood Cancer Survivor Study (CCSS) cohort, NHBs were more likely to report hypertension and severe cardiovascular conditions from 2000 to 2009 [7]. It was also reported that NHBs and HISs had a higher prevalence of obesity and were at a higher risk for diabetes. However, with adjustments for socioeconomic factors including insurance status, differences in all-cause mortality and some chronic conditions were attenuated, because large percentages of NHBs and HISs CCS in the study were uninsured

[11]. Bhatia et al. reported that NHB and HIS survivors in the CCSS, who were diagnosed from 1970 to1999, experienced a largely comparable overall morbidity burden as compared to NHW survivors [11]. Healthcare accessibility and health insurance coverage are frequently cited as reasons for racial and ethnic health disparities in the general population [13-18] and among adult CCS [19-25]. Given that the ever-growing population of long-term adult CCS includes diverse racial/ethnic minority groups, there is a crucial need to evaluate whether access and utilization of healthcare differs by race/ethnicity among long-term cancer survivors.

Foregoing Medical Care among Cancer Survivors

Financial hardship due to medical cost has become common in the US general population with more than half of the US households surveyed from 2015 to 2017 reporting problems with healthcare affordability and delaying or foregoing medical care because of cost [13-15]. Studies by Mortensen and Chen showed that HISs had significantly lower physician visits compared to NHWs during the recession of 2007 to 2009 [26]. Also, Travers et al. showed that NHBs were more likely than NHWs to forgo medical care during the post-recession from 2006-2013 [27]. Access to care is especially important for adult childhood cancer survivors, as nearly all adult CCS could develop chronic medical conditions or suffer from severe conditions related to past cancer treatment [9,25]. Assessing forgone care is important because it indicates a gap between perceived need and actual utilization of healthcare services and is an especially important measure for adult CCS given their need for medical care. Several articles have used delaying or foregoing medical care due to cost as an indicator of access to care because it is a direct measure of financial barriers to medical care [29- 34]. Studies conducted by Weaver et al. found that survivors with lower socioeconomic status (SES) and younger than 65 were more likely to delay or forgo medical care

due to cost [29]. According to Kent et al. (2013), cancer survivors who reported any degree of cancer-related financial problems were more likely to delay or forego medical care [30]. Additionally, several reports describe observed associations between delaying or foregoing medical care and health status, income, insurance, and race/ethnicity [26-28, 30]. A study by Chen et al. (2016) found that those who reported foregoing medical care were less likely to report having excellent or very good health status, signifying the negative effect that self-reported forging medical care has on perceived health status [30].

Research has also found that adult cancer survivors who reported financial hardship were more likely to report delaying or foregoing medical care. Several studies by Guy et al. found that cancer survivors had significantly higher out of pocket medical costs, compared to individuals without a cancer history. These studies also found that survivors with low income and public insurance had higher rates of foregoing medical care compared to people with high income and private insurance [32-35]. A study by Whitney et al. found differences in delay or foregoing medical care among adult cancer survivors compared to adults without a history of cancer even after adjusting for predictors for foregoing medical care including, insurance, adult and identified younger age, being a racial/ ethnic minority, and having lower income [36]. Additionally, a report by Kent el al. found that racial/ethnic minority adult cancer survivors were more likely to report experiencing financial hardship and were more likely to report foregoing medical care, compared to NHW survivors [30]. While foregoing medical care has been well documented among cancer survivors, research has begun to investigate foregoing medical care among adult CCS. Recently, A report by Huang et al. described that more than half of adult CCS reported feeling worried about paying for medical care and medication, and that one third of survivors had forgone medical care in the last two years [37].

Barriers to healthcare access and utilization

Access to healthcare is essential in treating both the physical and emotional burden of cancer treatments that can reduce quality of life [2-7]. Health insurance coverage is an important contributing factor to healthcare access and utilization across all racial and ethnic groups [38-42, 45-46]. Moreover, healthcare accessibility as well as health insurance is vital for adult CCS, as nearly all report chronic health conditions and treatment-related late effects that require long-term follow-up care [42-45, 46]. Several studies have reported that, among adult CCS, low participation in follow-up care was associated with health insurance status, specifically the lack of insurance, across all racial and ethnic groups [42-46]. Studies by Oeffinger et al., Nathan et al., and Klosky et al. consistently observed that low follow-up care participation was associated with lack of health insurance status across all racial and ethnic groups among adult CCS. However, healthcare utilization and insurance status differed by race and ethnicity [42-45]. Oeffinger et al. observed that adult CCS who were NH Blacks, male, older, uninsured, lived further away from hospital, and reported no future health concern, were less likely to obtain medical care [42]. Klosky et al. reported that CCS who were NHBs and/or HIS were nearly two times more likely to be non-attenders compared to NHWs for long-term follow-up clinic visits at SJCRH. The study also found that patients without health insurance were 2.4 times more likely to be non-attenders than patients with private insurance after adjusting for socioeconomic factors [43]. Nathan et al. noted that survivors who were NHB, uninsured, and older were less likely to receive risk-based survivorship care [44].

While several reports have shown that private insurance reduced likelihood of delaying or foregoing medical care [38-45], very recently, Zheng et.al. reported that among privately insured cancer survivors, those who had high-deductible health insurance plans were more likely to forgo medical care for financial reasons compared to private insured survivors with low-deductible health insurance plans. This finding indicated that the type of private insurance coverage maybe a barrier to access to care among privately insured cancer survivors [46]. As both insurance status and low healthcare utilization, these factors could also explain the racial/ethnic differences observed among CCS. While research has shown that barriers to access to care have resulted in lower healthcare utilization, increased morbidity, worsening health status as cited above, few studies have studied foregoing medical care among minority adult CCS who participate in Childhood cancer survivor cohorts. Given that participants in these cohorts like SJLIFE receive education on the importance of follow-up care and treatment-related late effects, there is a crucial need to examine whether a racial/ethnic disparity exists in the SJLIFE cohort.

Conceptual Framework of Healthcare Utilization

Several theories and models have been used to examine health care utilization patterns, with the Andersen Healthcare Utilization Model being the most popular. The model measures access to medical care by evaluating the actual use of health services against the need of service due to illness to assess individual health behavior among diverse populations [47-50]. The model identifies factors that enable healthcare utilization based on three factors: predisposing, enabling, and need factors. Figure 1 depicts the ways these factors relate to the use of health services according to Andersen's model. Predisposing factors are characteristics that predispose individuals to use or forgo medical care such as age and gender. Enabling factors are personal or family

resources that support healthcare utilization such as health insurance and income. Need factors are related to individuals' need for accessing and utilizing healthcare based on their health status or severity of illness such as perceived health status or chronic conditions [47-50]. Understanding the impact that race/ethnicity and insurance status have on forgone medical care may provide insights on how to tackle and improve healthcare utilization among adult CCS.
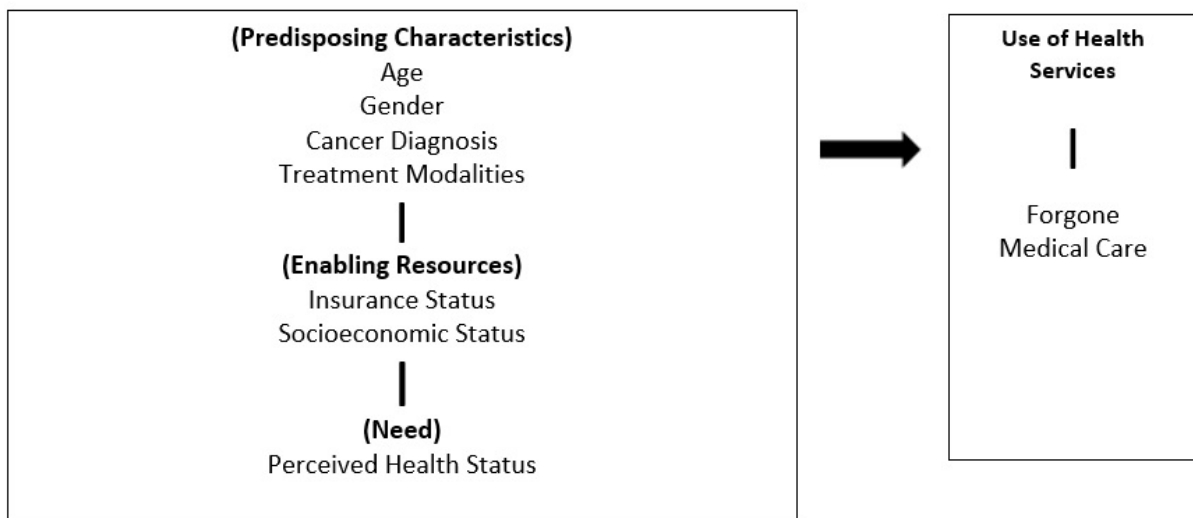
Figure 1: The Andersen Model of Healthcare Utilization Adapted from Andersen, R. M. [47].

– **Chapter 3** –

Disparity in foregoing medical care across race/ethnicity groups among adult survivors of childhood cancer study

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Abstract

Adult survivors of childhood cancer are at high risk for developing a variety of chronic health conditions due to exposures to cancer treatment in childhood. Healthcare access is, therefore, of particular concern for this population. We assessed disparity across race/ethnicity groups in access to healthcare characterized by "foregoing medical care in the last two years due to cost," using 3,275 adult survivors participating in the St. Jude Lifetime Cohort Study (SJLIFE). Multivariable logistic regression analysis adjusting for age, gender, cancer diagnosis, treatment modalities, treatment era, and perceived health status showed that, compared to Non-Hispanic (NH) Whites with private health insurance, adjusted odds ratios (ORs) of having foregone care were: for NH Whites with public insurance, OR=0.88 (95% Confidence Interval (CI) 0.68–1.16); for NH Whites with no insurance, OR=4.63 (95%CI 3.59–5.98); for NH Blacks with private insurance, OR=2.02 (95%CI 1.40–2.90); for NH Blacks with public insurance, OR=1.07 (95%CI 0.69–1.64); and for NH Blacks with no insurance, OR=8.93 (95%CI 5.69–14.01). Hispanics, on the other hand, showed less foregone care, although not statistically significantly, than NH Whites with private insurance: for Hispanics with private insurance OR=0.28 (95%CI 0.06–1.24); for Hispanics with public insurance OR=0.98 (95%CI 0.18–5.50); and for Hispanics with no insurance OR=0.84 (95%CI 0.26–2.68). These results indicate that, among the SJLIFE cohort from 2015 to 2017, NH Blacks forgo medical care approximately twice more frequently than NH whites, even after adjusting for insurance type, while Hispanics seemed to not forego care regardless of their insurance status. Importantly, there was no disparity in foregoing care under public insurance across the race/ethnicity groups as the rate was similar to that of NH Whites under private insurance. Not having insurance more than quadrupled the likelihood of foregoing care in both NH Whites and NH Blacks in the SJLIFE cohort from 2015 to 2017. These findings suggest that

expansion of public insurance may eliminate these large disparities among childhood cancer survivors.

Introduction

Childhood cancer survivors (CCS) are a high-risk population for a wide range of chronic conditions because of the very treatment for their cancer. Subsequent neoplasms, cardiovascular and pulmonary diseases that develop years after completion of therapy are examples of chronic conditions referred to as "late effects" of cancer therapy [1]. The size of this high-risk population has been increasing due to dramatic improvements in survival over the last several decades: Since 1975, the survival rate for children's cancer has increased from below 30% to nearly 90%, with an estimated population of almost 500,000 adult CCS in the United States (US) in 2019 [2]. Access to care among long-term adult childhood cancer survivors is an important issue as a disproportionate number of survivors often report chronic conditions and treatment-related late effects [10-11].

Foregoing medical care is harmful as it prevents screening and treatment of people with risk factors and/or medical conditions. By foregoing medical care, these risk factors and conditions will go undetected and untreated until a more serious condition develops or a medical emergency occurs [3-4]. In the US general population, racial disparities are known to influence foregoing medical care [5-7]. Reports from the Agency for Healthcare Research and Quality's (AHRQ) on National Healthcare Quality found that nearly one out of four Non-Hispanic Black (NHB) adults and two out of five Hispanics (HIS) adults were uninsured and that these populations were more likely to delay or forgo medical care [5-7]. Additionally, these reports also showed that NHBs and HISs had lower access to care compared to Non-Hispanic Whites (NHWs) because they were less likely to have a usual source for medical care in 2016 [5-7]. Recently, a study by Travers et al. showed that since the great recession of 2007 to 2009, NHBs were more likely to forgo medical care compared to NHWs foregoing [8]. Foregoing medical care is especially harmful for a high-

risk population such as cancer survivors as it prevents proper medical attention and care despite having the need [9- 11].

Foregoing medical care is more frequent among adults with cancer history compared to adults without cancer history [9-11]. Several reports have presented associations between cancer survivors and delaying or foregoing medical care due to cost [10-11]. A study by Weaver et al. found that more than one million US cancer survivors with health insurance reported foregoing needed medical care due to cost, and that NHB and HIS survivors were twice as likely to forgo medical care compared to NHW survivors [10]. Kent et al. also reported that NHB and HIS adults with a history of cancer were twice as likely to forgo medical care compared to NHW adults with a history of cancer. [11]: survivors who reported financial problems due to cancer treatments were more likely to delay or forego medical care; and racial/ethnic minority survivors of cancer were more likely to report experiencing financial hardship and more likely to report foregoing medical care compared to NHW survivors. Recently, there has been more focused research on foregoing medical care among adult CCS specifically, which is warranted because many CCS report financial problems, unemployment, and low incomes [12-14]. Huang et al. reported that more than half of adult CCS reported feeling anxiety about affording medical care and medications, and one-third had forgone medical care in the last two years [14]. Given that most adult CCS could have potential for long-life expectancy, foregoing medical care could have a devastating impact on screening and treatment for late effects and can reduce quality of life.

Foregoing medical care among adult CCS has not been examined by race/ethnicity or stratified by health insurance. To this end, the current study used survey data collected in the St. Jude Lifetime Cohort Study (SJLIFE) to examine differences in foregoing medical care due to cost by racial/ethnic group as well as health insurance type. Given that foregoing medical care maybe

influenced by various predisposing, enabling, and need factors, the analysis used a stratification by health insurance type and race/ethnicity groups with adjustments for demographic and socioeconomic factors, childhood cancer treatment, and perceived health status. Ultimately, this investigation aims to quantify the extent of racial/ethnic disparity in healthcare access and utilization in the high-risk vulnerable population of adult CCS.

Methods

Study Population and Data Collection

To assess foregoing medical care among adult CCS, this study employed cross-sectional data collected by surveys administered in SJLIFE. SJLIFE is a retrospective cohort study with prospective clinical follow-up established to investigate the late effects of childhood cancer and its treatment in all 5-year survivors who were treated for childhood cancer at the St Jude Children's Research Hospital (SJCRH). The SJLIFE health surveys assess health outcomes and status including health service utilization, perceived health status, current and past health problems, as well as social and demographic factors included insurance access, insurance type, income, and financial hardship. SJLIFE participants have a campus visit and complete surveys every two years. The data used in the current study included survivors who are US citizens and were 18+ years old at the time of survey completion (Figure 2). Citizenship was identified by survey response to a question on insurance assess which included a response for those who were not US citizens. The study data was collected between July 1, 2015 to June 30, 2017, and for multiple St. Jude visits within the same two years periods, the most recent survey data for those survivors was used within that period. The SJCRH's Institutional Review Board approved the study protocol and written informed consent was obtained from all SJLIFE participants.

Conceptual Framework

Figure 3 displays the conceptual framework we developed for assessing forgone medical care in adult CCS in SJLIFE, utilizing the Andersen Healthcare Utilization Model [48-50]. The Andersen model has been broadly used to describe a wide range of healthcare utilization as it identifies factors that can facilitate or impede use of health services based on three types of factors: predisposing; enabling; and need [48-50]. Predisposing factors such as age and gender affect individuals' natural tendency to use or forgo medical care. Enabling factors include resources that enable an individuals' utilization such as insurance coverage and socioeconomic status (income & education). Need factors relates to the individuals' actual need for healthcare services use such as perceived health status [48-50]. Using this framework, the study examined racial/ethnic disparities in foregoing medical care among adult CCS as well as disparities in foregoing medical care by insurance status.

Variables

The following variables used in the study were selected based on a priori knowledge: age, gender, cancer diagnosis, treatment modalities, and perceived health status. The exposures of interest in the study was Race/ethnicity. Insurance types was investigated as a potential effect modifier, and both income and education were assessed as potential confounders. Within the context of the Andersen model, age, gender, cancer diagnosis, and treatment modalities served as predisposing factors. Income and education served as enabling factors, and perceived health status served as need factors.

Forgone care. The outcome of interest was Forgone medical care. Forgone medical care was defined by participants' responses to the following survey question: "In the last two years, was there a time that you needed to see a doctor or go to the hospital but did not go due to finances?" This question contained two binary response categories (yes and no).

Insurance Status. Insurance status was determined based on responses to questions about whether participants currently had health insurance coverage and, if so, what type of coverage that they have. Insurance type was then classified into three groups: participants with no insurance were classified as having "none"; insurance provided through participant's employment, parent or spouse, or self-purchased were classified as "private"; and insurance provided by through Medicaid, military, or public assistance program were classified as "public".

Race/ethnicity and other demographic variables. All demographic variables were obtained from SJLIFE survey data. Race/ethnicity was defined based on the participants' responses and survivors were classified as "NH White", "NH Black", or "Hispanic": survivors of other or multiple race/ethnicity groups were excluded from this analysis. Age and gender were also self-identified. Income information was obtained from the participants' survey responses and categorized into seven groups (Don't Know, Less than $19,999, $20,000-$39,999, $40,000-$59,999, $60,000-$79,999, $80,000-$99,999, and over $100,000). Similarly, education level was obtained from survey responses and categorized into eight groups (No High School Diploma, High School Diploma, Some College, Training after high school, College graduate, Post-graduate level, Unknown, and Other).

Other variables. Perceived health status was defined based on the self-reported and categorized into three groups: *excellent*/*very good, good*, or *fair/poor*. Treatment era was obtained from medical records and categorized into four groups (< 1970, 1970 -1979, 1980-1989, 1990 +). Childhood cancer diagnosis was obtained from medical records and categorized into the following: Acute lymphoblastic leukemia, Acute myeloid leukemia, Central nervous system (CNS), Chronic myeloid leukemia, Ewing sarcoma family of tumor, Germ cell tumor, Hodgkin lymphoma, Nasopharyngeal carcinoma, Neuroblastoma, Non-Hodgkin lymphoma, Osteosarcoma, Rhabdomyosarcoma, Soft tissue sarcoma, and Wilms tumor.

Statistical Analysis

The analysis was cross sectional. Three race/ethnic groups of childhood cancer survivors were characterized and compared with respect to age, gender, cancer diagnosis, treatment era, clinical variables, and perceived health status using chi-square tests [Table 1]. Insurance type was stratified across the three race/ethnic groups. To examine the association between foregoing medical care and race/ethnicity with specific insurance types, a multivariable logistic regression model was constructed to estimate the odds ratios (ORs) and their 95% CIs associated with foregoing medical care and race/ethnicity stratified by insurance type. Purposeful selection was utilized to determine the variables that would remain in the model. A stratified variable of both race/ethnicity and insurance type were created to assess possible interaction. The model estimated the association between foregoing medical care in the last two years with the combination of race/ethnicity and insurance status, adjusting for age, gender, cancer diagnosis, treatment era, treatment modalities, clinical variables, and perceived health status. To adjust for socioeconomic status (SES), income and education were added to the model individually. An a priori decision

was made to keep all confounders in the model following interaction examination. Statistically significant differences in analyses were determined by p-value of less than 0.05. All statistical analyses were performed using SAS 9.4, and all statistical tests were two-sided.

Results

Study Sample Characteristics

There were 3,235 survivors identified as eligible with complete data (after 697 were removed due to missing study variables and 40 survivors who identified as biracial, other minorities, or did not respond were also removed.) with 2,717 (84.0%) who identified as NH White, 452 (14.0%) as NH Black, and 66 (2.0 %) as Hispanic. In terms of treatment era, proportionally more HIS survivors were treated in more recent era than NH White or NH Black survivors (table 1). Consequently, proportionally more HIS survivors were in the 20–29 years age group than NH White or NH Black survivors, while NH white and NH Black survivors were more proportionally in the 30–39 years and 40+ years age groups than HIS survivors.

Proportionally more NH Blacks reported "Fair/ Poor" health compared to the other racial/ethnic groups (Table 1). Conversely, more HIS survivors reported having "Excellent/ Very Good" health status compared to NH Whites survivors, while more NH Whites survivors reported having "Good" health status. (Table 1). Approximately half (54.8%) of survivors had an education level of some college or below, 40.1% reported a household income below $40,000 and 16.0% reported $80,000 or above. Proportionally more NH White survivors had college level or higher education compare to NH Black survivors or HIS survivors. In terms of annual household income, proportionally more NH Whites survivors reported higher income and having private insurance coverage compared to NH Black survivors or HIS survivors.

Results without adjusting for income and education

Results (Figure 4, table 2) showed that, after adjusting for age, gender, cancer diagnosis, treatment era, treatment modalities, and perceived health status, compared to the odds of forgoing medical care in the last two years in NH Whites with private health insurance, NH Whites with no insurance had a 4.63 (95% CI 3.59 – 5.98) times the odds, NH Whites with public insurance had 0.88 (95% CI 0.68 – 1.16) times the odds, NH Blacks with private insurance had 2.02 (95% CI 1.21 – 3.13) times the odds, NH Blacks with no insurance had 8.93 (95% CI 5.69 – 14.01) times the odds, NH Blacks with public insurance had 1.07 (95% CI 0.69 – 1.64) times the odds, HIS with private insurance had 0.28 (95% CI 0.06 – 1.24) times the odds, HIS with public insurance had 0.84 (95% CI 0.26 – 2.68) times the odds, and HIS with no insurance had 0.98 (95% CI 0.18 – 5.50) times the odds. The small HIS sample size contributed to the wide 95% CIs and estimated ORs are not precise.

Results after adjusting for income and education

The odds ratios were generally attenuated by the addition of income and education to the model above across race and ethnicity groups and insurance types (Figures 5-6, Tables 3-4). Results showed that, after adjusting for age, gender, cancer diagnosis, treatment era, treatment modalities, perceived health status, income, and education, compared to NH Whites with private health insurance, NH Whites with no insurance had a 3.20 (95% CI 2.44 – 4.21) times the odds, NH Whites with private insurance. NH Blacks with private insurance had 1.63 (95% CI 1.12 – 2.36) times the odds, NH Blacks with no insurance had 5.64 (95% CI 3.52 – 9.02) times the odds, and NH Blacks with public insurance had 1.07 (95% CI 0.69 – 1.64) times the odds. HIS with private insurance had 0.66 (95% CI 0.42 - 1.04) times the odds when compared to NH whites with

private insurance. HIS with public insurance had 0.26 (95% CI 0.06 – 1.14) times the odds, HIS with public insurance had 0.66 (95% CI 0.12 – 3.62) times the odds, and HIS with no insurance had 0.65 (95% CI 0.20 – 2.14) times the odds. However, the small HIS sample size contributed to the wide 95% CIs and estimated ORs are not precise. Overall, these results showed that the enabling factors of health insurance, income and education contributed significantly to adult CCS's decision to forgo medical care after adjusting predisposing or need factors in Andersen Healthcare Utilization Model.

Discussion

The purpose of this study was to assess the racial/ethnic disparity in foregoing medical care in the last two years among adult survivors of childhood cancer in the SJLIFE cohort. The current study is the first study to report racial and ethnic differences in the foregoing medical care by insurance type among adult CCS. We found an association between foregoing medical care and insurance types among NH Blacks, even after adjusting for age, gender, cancer diagnosis, treatment modalities, and treatment era. Within the context of Andersen Healthcare Utilization Model, the results suggest that the predisposing (age & gender) and need factors (health status) alone were not enough to explain foregoing care among SJLIFE CCS and that enabling factors (insurance type) and race/ethnicity were crucial. Specifically, insurance type had a striking association with foregoing care; those with no insurance were much more likely to forgo medical care than those with insurance (public or private) among both NH Whites and NH Blacks; and those with public insurance had no difference in foregoing care across all three race/ethnicity groups, and furthermore their rate of foregoing care was the same (or little lower) in comparison with NH Whites with private insurance. Overall, the model results provided a summary of characteristics associated with foregoing medical care among CCS by identifying predisposing, enabling and need factors.

The results showed that having health insurance was an important factor in a participant's decision to forego medical care among NH Whites and NH Blacks. NH Blacks with private insurance were, however, two times more likely to forego medical care compared to NH Whites with private insurance. This suggest that there may be differences in the private insurance coverage, which still makes access to care unaffordable. In a 2019 publication, Zheng et al. showed a relationship between foregoing medical care for financial reasons and high-deductible health

insurance in cancer survivors [46]. Their study found that survivors who had high-deductible health insurance plans were more likely to forego medical care for financial reasons compared to survivors who had low-deductible health insurance plans. These findings suggest that the type of private insurance coverage may be acting as a barrier to access to care among privately insured cancer survivors [46].

Within the current study, insurance type was one of the most important factors that determined a participant's decision to forego medical care. The results support the hypothesis that insurance is a strong predictor of foregoing medical care. Additionally, insurance coverage could be the result of job status, competing needs, and other barriers, all prevented participants from having access to health insurance. In fact, studies have shown that Blacks and Hispanics are less likely to have private insurance and more likely to receive Medicaid or to have Medicare as their only insurance and are more likely to lack continuity in health care use [46].

The findings that NH Blacks were two times more likely to forgo medical care than NH Whites under private insurance are consistent with previous studies in both the general population [13, 16-18,26-28] and adult-cancer survivors with minorities being more likely to delay or forgo medical care [22, 28-30]. Several studies found that racial or ethnic minority survivors of adult cancers who reported financial hardship were significantly more likely to delay medical care compared to their NH White counterpart [14-15, 20-23].

There was no significant difference in foregoing medical care due to cost between HIS and NH Whites with private insurance. This result is interesting considering that previous studies have reported that, in the general population, HIS face barriers to access to healthcare resulting from lower follow up care, underutilization, and being more likely to delay or forgo medical [67,69]. These results are also consistent with the findings the AHRQ reports [54- 55]. These results could

be due to specific areas of the United States where the SLIFE HIS survivors live and access care. For example, HIS survivors living in Medicaid expanded states such as California may have easier ability to access care, regardless of cost, due to the states' better healthcare systems and infrastructure. Studies from Sanchez et al. in 2015 and Sommers et al. in 2015 have found that HIS reported having better health status and access to care since ACA was enacted [66-67]. In addition, studies have shown that Mexican Americans living in majority Mexican American neighborhoods may have greater levels of social support and social cohesion, and better access to resources compared to Mexican Americans living in neighborhoods where they are the minority [77]. Finally, the results could be due to bias as the Hispanics in the cohort having access to care in foreign countries such as Mexico [74-76, 78-79]. Given that, the largest population of HIS live in the US states that border Mexico, a country with universal health insurance, it is possible that Mexican American survivors may seek care in Mexico [Figure 7, 87]. Overall, the results observed between forgoing medical care and all insurance types among Hispanics compared to NW Whites with private insurance warrants further investigation.

Importantly, there were no statistical difference in foregoing medical care across the race/ethnicity groups among those with public insurance and their odds ratio of foregoing care in comparison to NH Whites with private insurance was close to, and lower than, 1.0, suggesting that public insurance not only eliminate the racial/ethnicity-related disparity in foregoing care among childhood cancer survivors, but also equalizes those who do not have private insurance with those who do. A study showed that NH Black adult-cancer survivors with health insurance are twice as likely to go without medical care services as NH White counterpart due to significant out-of-pocket expenses [22]. Our results found that SES factors (income and education) did attenuate the disparity for NH Blacks relative to NH Whites. Income and education are examples of social

determinants of health that may be related to foregoing medical care as minorities within the US tend to fare worse in terms of job status, health literacy, and poverty rates [22,56-57,60-61]: adjusting for these explained partly the apparent disparities we observed. Recent studies have also shown that social contextual factors such as minority discrimination, perceived racism, and healthcare related stigmas play a role in foregoing medical care services [82- 85]. The fact that income and education adjustment did not explain the apparent disparities completely indicates that more social factors that could influence foregoing medical care differentially across race/ethnic groups must be considered [55,57,61,85].

This research has several limitations. First, the data were collected from a single institution and may not be generalizable to all long-term CCS. Second, the OR estimates are not precise for the HIS survivors due to their small size in the SJLIFE cohort. In addition, the SJLIFE cohort did have slight differences earlier in terms of gender, cancer diagnosis, SES factors, and other variables [89-91]: two studies that assessed the limitations of the cohort found the differences were not substantial [90-91]. As the sample in this study was selected from all eligible in the cohort, selection bias due to participant selection procedures is less likely. Finally, the data used are cross-sectional and thus unable to determine causal relationship between some of the study variables and foregoing medical care.

This investigation evaluated foregoing medical care with SJLIFE adults CCS who perceived a need for healthcare but did not seek it; however, it did not consider those not perceiving the need for healthcare. Therefore, the odds of foregoing medical care may have been underestimated to some extent. However, survivors are clinically assessed at SJLIFE visits comprehensively: thus, the need for medical care is well established and survivors are informed of their care need at the SJLIFE visits. Another potential limitation is that we were unable to

distinguish types of private and public insurance because the survey did not include details of the insurance. Future studies would benefit from incorporating multiple-item measures to better account for these limitations.

Given the impact of public insurance seen in this study, future studies examining the influence of the Affordable Care Act (ACA) would be of interest. If the national policies were effective as it was enacted to make affordable health insurance available to more people and lower the costs of health care [40, 60], childhood cancer survivors should enjoy the impact of ACA in the access to care and also in health outcomes. The status of states that have or have not expanded Medicaid is shown in Table 2. Future studies could also look at the role that contextual factors play into the relationship between race/ethnicity of adult CCS and foregoing medical care as the current study focused mostly on individual factors. Several studies have shown that contextual factors such as geography (living in a rural area versus urban area), state inequality level (Gini coefficient), and the availability of health services in the survivors' neighborhood may influence foregoing medical care [79-85]. These factors could affect foregoing medical care because survivors in the SJLIFE cohort may experience racial discrimination or live in areas designated as Health Professional Shortage Areas (HPSAs), Medically Underserved Areas (MUAs), or Medically Underserved Populations (MUPs) by the US Department of Health and Human Services Health Resources and Services Administration [87-88]. HPSA designation indicates a shortage of primary medical care, dental or mental health providers in an urban or rural area, population groups, or medical or other public facilities. MUAs have a shortage of primary care health services for residents within a geographic area where residents have a shortage of personal health services. MUPs are specific sub-groups of people living in a defined geographic area with a shortage of primary care health services who often face economic, cultural or linguistic barriers to health care

[87-88]. By focusing on these factors that potentially affect access to care, research on foregoing care can facilitate more organized and effective medical practices that improve care and establish meaningfully improved access to care interventions that promote improved health outcomes.

In summary, race/ethnicity and insurance status were associated with whether a childhood cancer survivor utilized or had to forego medical care due to finance despite the need. Ensuring access to health services is particularly important for adult CCS in order to address their medical needs. Given the medical needs of this growing clinical population, identifying and understanding how factors such as race/ethnicity and insurance impact access to care and eventually health outcomes are critical for both medical professionals and policy makers. Policy makers must create more policies that ensure access to health care and insurance for vulnerable populations such as CCS. In addition, health providers must utilize these findings to identify and help CCS who face financial barriers in accessing care.

Overall, this study has one major implication for policy makers in terms of improving access to Medicaid for all states. This study's findings highlight the need for policy that ensures access to and use of health care services through free/low-cost public health insurance coverage for adult CCS. The Affordable Care Act has increased access to health care and provisions to make the cost of health care more affordable in the overall population [30,40,61,67-68]. These findings show the need to remove insurance as a reason for forgoing medical care among adult CCS and the power of public insurance that would ensure necessary primary care visits and eliminate delay in obtaining medical care.

Table 1. Demographic characteristics of white and minority participants.

SJLIFE Population (n = 3275)	NH White (n = 2717)	NH Blacks (n =452)	Hispanic (n =66)	P-Value
Gender (%)				0.10
Male	1436 (52.9%)	215 (47.6 %)	29 (43.9%)	
Female	1281 (47.1%)	237 (52.4 %)	37 (56.1%)	
Age group (%)				<0.001
≤20 years	82 (3.0%)	19 (4.20%)	4 (6.1%)	
20–29 years	870 (32.0%)	192 (42.5%)	40 (60.6%)	
30–39 years	985 (36.3%)	148 (32.8%)	17 (25.8%)	
40–49 years	600 (22.1%)	69 (15.3%)	4 (6.1%)	
50+ years	180 (6.6%)	24 (5.3%)	1 (1.5%)	
Treatment Era (%)				<0.001
< 1970	91 (3.4%)	13 (2.9%)	0 (0.0%)	
1970 -1979	450 (16.6%)	47 (10.4%)	1 (1.5%)	
1980 -1989	875 (32.2%)	133 (29.4%)	10 (15.2%)	
1990 +	1301 (47.9%)	259 (57.3%)	55 (83.3%)	
Diagnosis (%)				<0.001
Acute lymphoblastic leukemia	866 (31.9%)	80 (17.7%)	27 (40.9%)	
Acute myeloid leukemia	88 (3.2%)	19 (4.2%)	9 (13.6%)	
Central nervous system (CNS)	331 (12.2%)	53 (11.7%)	6 (9.1%)	
Chronic myeloid leukemia	19 (0.7%)	2 (0.4%)	3 (4.6%)	
Ewing sarcoma family of tumor	77 (2.8%)	2 (0.4%)	2 (3.0%)	
Germ cell tumor	60 (2.2%)	29 (6.4%)	1 (1.5%)	
Hodgkin lymphoma	332 (12.2%)	54 (12%)	4 (6.1%)	
Nasopharyngeal carcinoma	6 (0.2%)	14 (3.1%)	1 (1.5%)	
Neuroblastoma	121 (4.5%)	17 (3.8%)	3 (4.6%)	
Non-Hodgkin lymphoma	214 (7.9%)	25 (5.5%)	4 (6.1%)	
Osteosarcoma	95 (3.5%)	27 (6%)	4 (6.1%)	
Rhabdomyosarcoma	94 (3.5%)	24 (5.3%)	1 (1.5%)	
Soft tissue sarcoma	74 (2.7%)	23 (5.1%)	1 (1.5%)	
Wilms tumor	159 (5.6%)	43 (9.5%)	1 (1.5%)	
Treatment Exposure (%)				0.013
Radiation	1536 (56.5%)	228 (50.4%)	28 (42.4%)	
Perceived Health Status (%)				0.004
Excellent/Very good	1129 (41.6%)	166 (36.7%)	38 (57.4%)	
Good	991 (36.5%)	157 (34.7%)	16 (24.2%)	
Fair/Poor	597 (22.0%)	129 (28.5%)	12 (18.2%)	
Insurance status (%)				<0.001
Uninsured	412 (15.2%)	119 (26.3%)	20 (30.3%)	
Private Insurance	1720 (63.3%)	185 (40.9%)	34 (51.5%)	
Public Insurance	522 (19.2%)	141 (31.2%)	9 (13.6%)	
Annual Income in USD (%)				<0.001
Don't Know	308 (11.3%)	77 (17.0%)	20 (30.3%)	

Less than $19,999	388 (14.3%)	136 (30.1%)	10 (15.2%)	
$20,000-$39,999	492 (18.1%)	110 (24.3%)	12 (18.2%)	
$40,000-$59,999	443(16.3%)	51 (11.3%)	12 (18.2%)	
$60,000-$79,999	363 (13.4%)	30 (6.6%)	5 (7.6%)	
$80,000-$99,999	248 (9.1%)	26 (5.8%)	3 (4.6%)	
Over $100,000	475 (17.5%)	22 (4.9%)	4 (6.1%)	
Education (%)				<0.001
No High School Diploma	215 (7.9%)	48 (10.6%)	8 (9.1%)	
High School Diploma	461 (17.0%)	84 (18.6%)	15 (22.7%)	
Some College	680 (25.0%)	133 (29.4%)	14 (21.2%)	
Training after high school	124 (4.6%)	24 (5.3%)	1 (1.5%)	
College graduate	737 (27.1%)	83 (18.4%)	13 (19.7%)	
Post-graduate level	320 (11.8%)	33 (19.7%)	13 (19.7%)	
Unknown	144 (5.3%)	35 (7.7%)	3 (4.6%)	
Other	83 (3.1%)	17 (3.8%)	3 (4.6%)	
Outcome Variable (%)				
Forgone medical care: No (%)	2042 (75.2%)	272 (60.2%)	56 (84.8%)	<0.001
Forgone medical care: Yes (%)	675 (24.8%)	180 (39.8%)	10 (15.2%)	

Table 2: Adjusted odds ratio of foregone care by race and NH White Private Insurance

Race and insurance type	Odds Ratio (OR)	95% CI	P-value
Within Non-Hispanic White			
Public Insurance vs. NH White Private Insurance	0.88	0.68 – 1.16	p=0.367
No Insurance vs. NH White Private Insurance	4.63	3.59 – 5.98	p<0.001
Non-Hispanic Black vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	2.02	1.40 – 2.90	p<0.001
Public Insurance vs. NH White Private Insurance	1.07	0.69 – 1.64	p=0.779
No Insurance vs. NH White Private Insurance	8.93	5.69 – 14.01	p<0.001
Hispanic vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	0.28	0.06 – 1.24	p=0.094
Public Insurance vs. NH White Private Insurance	0.98	0.18 – 5.50	p=0.985
No Insurance vs. NH White Private Insurance	0.84	0.26 – 2.68	p=0.762

*Adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, and perceived health status.

Table 3: Adjusted odds ratio of foregone care by race and NH White Private Insurance

Race and insurance type	Odds Ratio (OR)	95% CI	P-value
Within Non-Hispanic White			
Public Insurance vs. NH White Private Insurance	0.62	0.46 – 0.83	p=0.001
No Insurance vs. NH White Private Insurance	3.33	2.55 – 4.36	p<.0001
Non-Hispanic Black vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	1.67	1.16 – 2.42	p=0.006
Public Insurance vs. NH White Private Insurance	0.68	0.43 – 1.06	p=0.091
No Insurance vs. NH White Private Insurance	5.74	3.59 – 9.16	p<.0001
Hispanic vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	0.25	0.06 – 1.09	p=0.064
Public Insurance vs. NH White Private Insurance	0.66	0.12 – 3.55	p=0.623
No Insurance vs. NH White Private Insurance	0.68	0.21 – 2.18	p=0.512

* Adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, income, and perceived health status

Table 4: Adjusted odds ratio of foregone care by race and NH White Private Insurance

Race and insurance type	Odds Ratio (OR)	95% CI	P-value
Within Non-Hispanic White			
Public Insurance vs. NH White Private Insurance	0.59	0.44 – 0.80	p<.0001
No Insurance vs. NH White Private Insurance	3.20	2.44 – 4.21	p<.0001
Non-Hispanic Black vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	1.63	1.12 – 2.36	p=0.010
Public Insurance vs. NH White Private Insurance	0.66	0.42 – 1.04	p=0.073
No Insurance vs. NH White Private Insurance	5.64	3.52 – 9.02	p<.0001
Hispanic vs. Non-Hispanic White			
Private Insurance vs. NH White Private Insurance	0.26	0.06 – 1.14	p=0.074
Public Insurance vs. NH White Private Insurance	0.66	0.12 – 3.62	p=0.629
No Insurance vs. NH White Private Insurance	0.65	0.20 – 2.14	p=0.477

* Adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, income, education, and perceived health status

Table 5. **Status of State Action on Medicaid Expansion as of December 2019**

Have Not Expanded Medicaid	Expanded Medicaid by January 2014	Expanded Medicaid After January 2014
Alabama	Arizona	Michigan
Florida	Arkansas	New Hampshire
Georgia	California	Pennsylvania
Idaho	Colorado	Indiana
Kansas	Connecticut	Alaska
Maine	Delaware	Montana
Mississippi	District of Columbia	Louisiana
Missouri	Hawaii	
Nebraska	Illinois	
North Carolina	Iowa	
Oklahoma	Kentucky	
South Carolina	Maine	
South Dakota	Maryland	
Tennessee	Massachusetts	
Texas	Nevada	
Utah	New Jersey	
Virginia	New Mexico	
Wisconsin	New York	
Wyoming	North Dakota	
	Ohio	
	Oregon	
	Rhode Island	
	Vermont	
	Washington	
	West Virginia	

Figure 2: Consort Flow of data extraction and cleaning
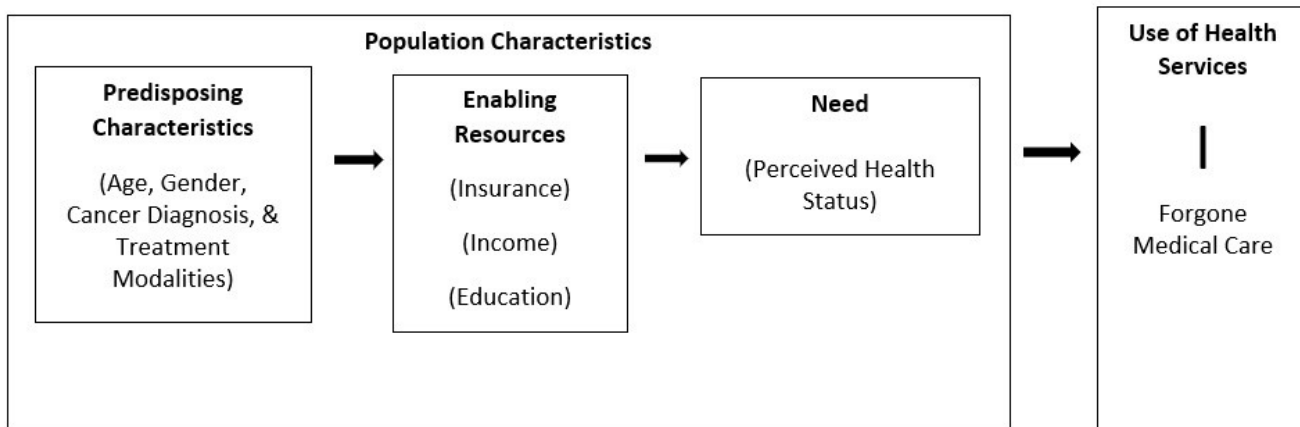
Figure 3: Conceptual Framework (Andersen Healthcare Utilization Model) Used in This Study for Investigating Framework for Foregoing Medical Care among Adult Survivors of Childhood Cancer.
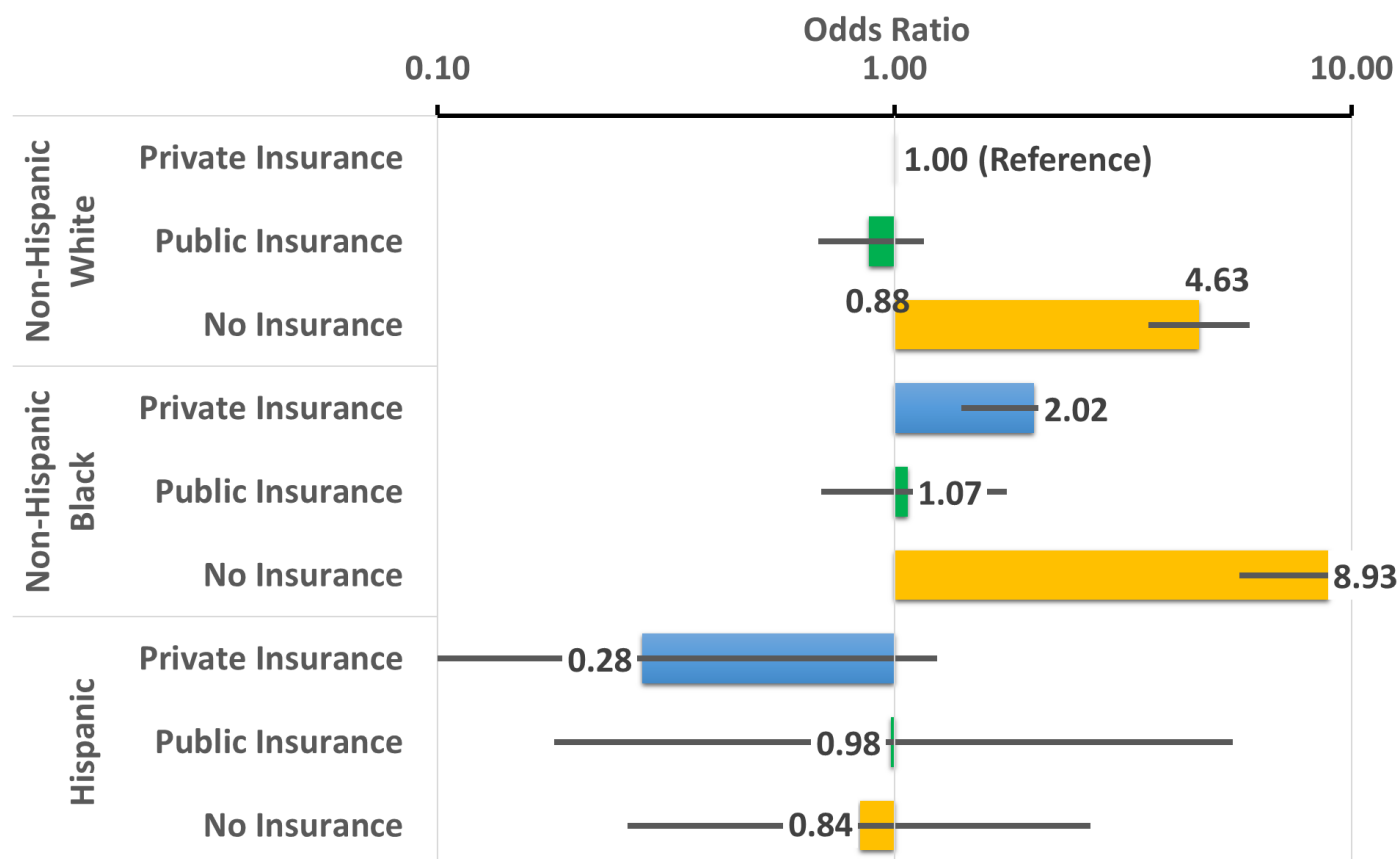
Figure 4: Odds ratio of forgone care by race and insurance type adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, and perceived health status.
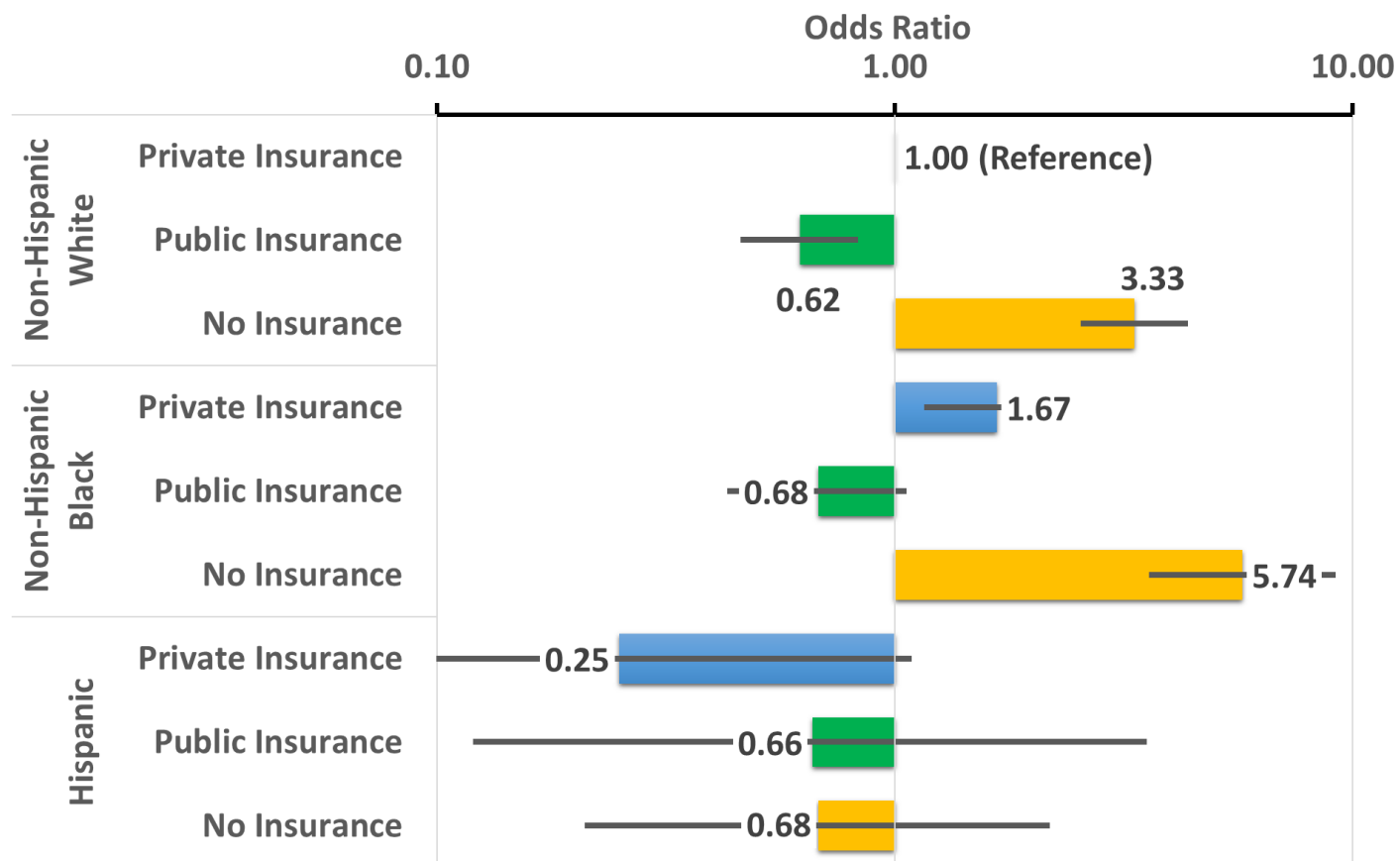
Figure 5: Odds ratio of forgone care by race and insurance type adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, income, and perceived health status.

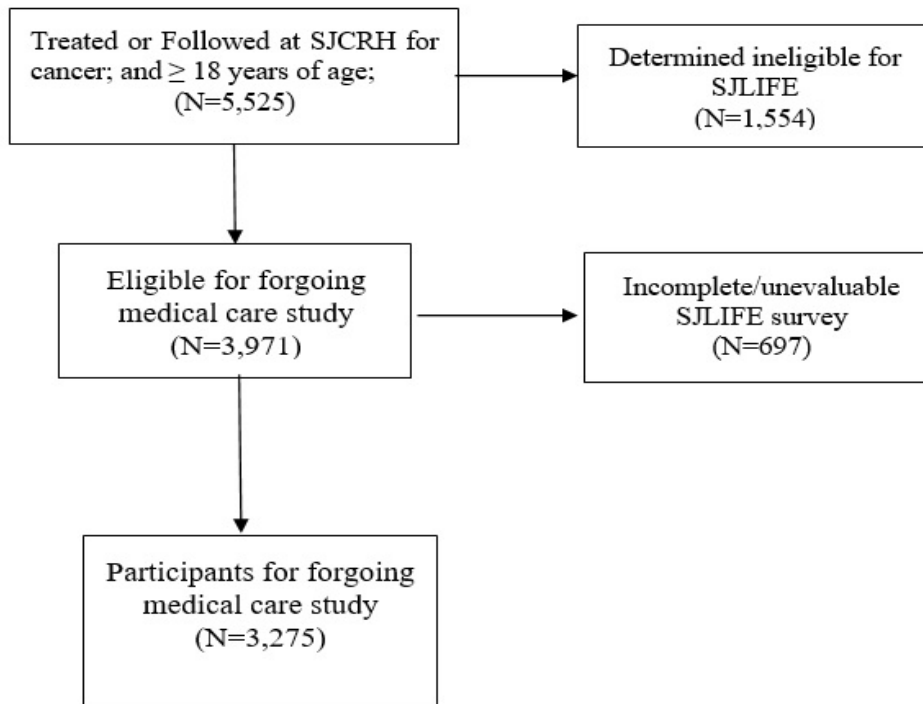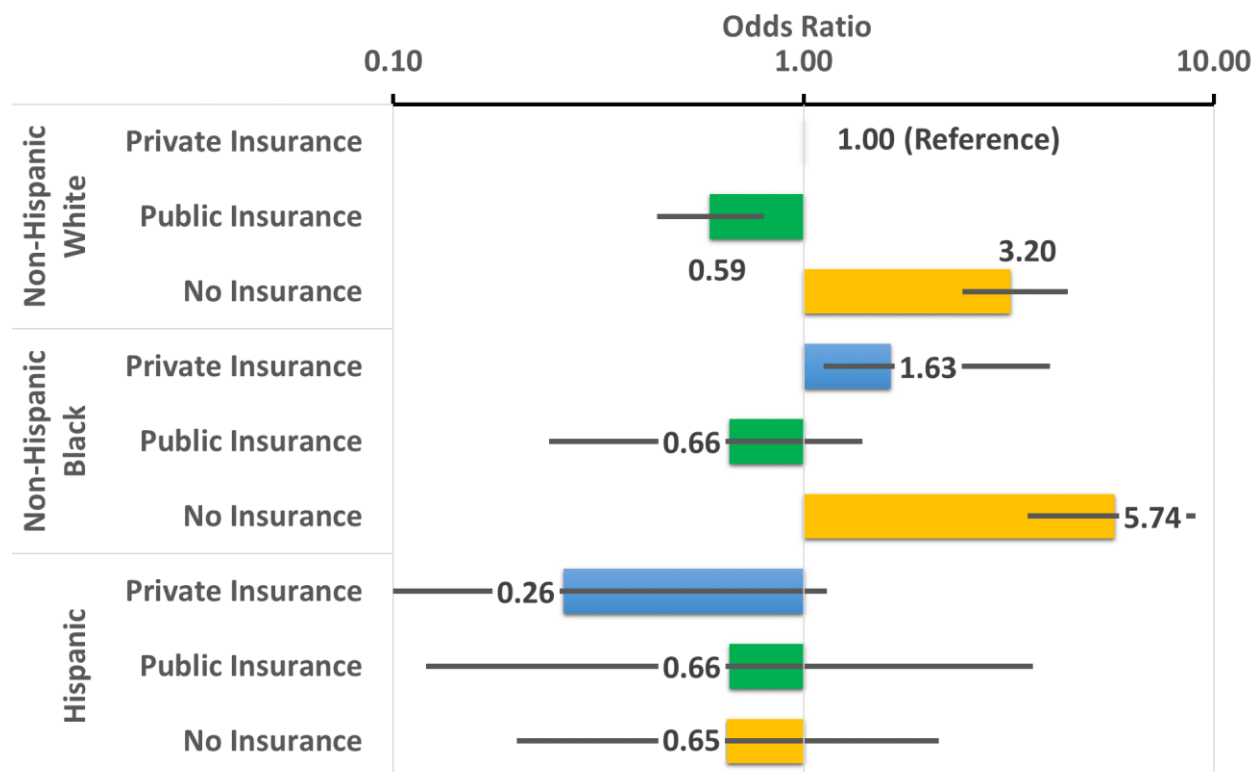**Figure 6: Odds ratio of forgone care by race and insurance type adjusted for age, gender, cancer diagnosis, treatment modalities, treatment era, income, education, and perceived health status.**
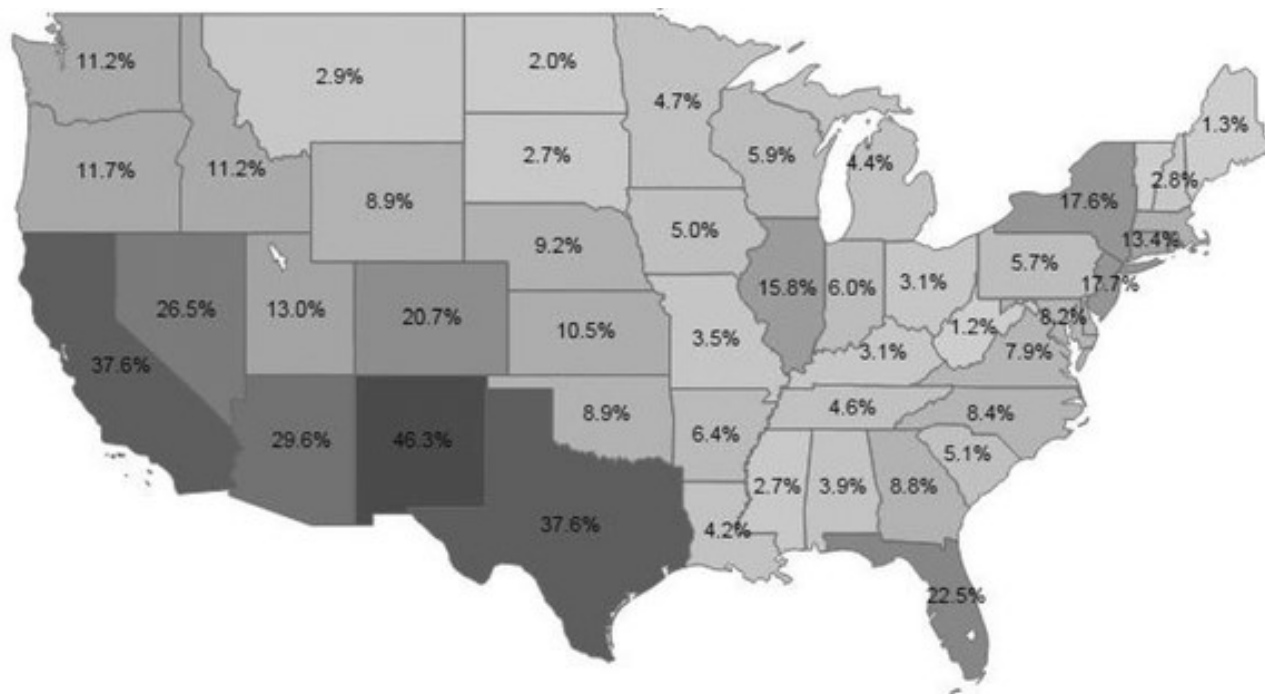
Figure 7: Percentage of Hispanic population in the US from the 2010 Census
 [Source: Redistricting data first look at local 2010 census results. US Census Bureau, 2010.
(Accessed 21 Oct 2019, 2019, at
https://www.census.gov/newsroom/releases/archives/2010_census/press-kits/redistricting.html)].

Chapter 4: Summary

This study examined foregoing medical care by race/ethnicity and insurance status among SJLIFE using a multivariable logistic regression. The results found a positive association between foregoing medical care and insurance types specifically private and no insurance among NH Blacks even after adjusting for age, gender, cancer diagnosis, treatment modalities, and treatment era. After including income and education in the model, CCS with no insurance were, on average, two times more likely to forgo medical care due to cost compared to CCS with private insurance. Our findings also showed that NHB survivors were more likely to forgo medical care compared to NHWs. These results support our hypothesis that there is a relationship between race/ethnicity, insurance status, and access to healthcare. Indeed, the large effect size in the model without the socioeconomic factors suggested that race/ethnicity did play a large role in foregoing medical care particularly for NHBs participants.

Interestingly, HISs shows less forgone care (without reaching statistical significance), which may suggest that they may have means to access care regardless of their insurance status. Moreover, there were no differences among survivors with no public insurance across all models. The findings of this study highlight the importance of expanding public insurance in improving access to care for survivors without creating or exacerbating racial/ethnic disparities. This study also suggests several areas for future research. It would be beneficial to assess the effects of the Affordable Care Act (ACA) policy on foregoing medical care for CCS particularly differences between Medicaid Expansion states and No Expansion states. Future studies should examine factors that were not included in the study such as clinical assessed chronic health conditions, number of local provider availability, neighborhood socioeconomic status, employment, and differences between urban and rural forgone medical care.

Finally, a follow-up qualitative study would helpful for understanding the different barriers that CCS face and why they decide to forgo medical care despite their need. For example, a qualitative case study approach is commonly used to investigate phenomenon within its real-life context using multiple forms of data collection and analysis to triangulate evidence, strengthening the conclusions, and answering explanatory how and why questions [92]. Using this approach, a study focused primarily on the experience and perceptions within an adult CCS's world would provide insight into what influences a survivor's ability to access health care evolving from their lived experiences. Furthermore, this study could incorporate the current analysis thus offering a rich source which would allow researchers to identify new or unexpected themes about foregoing medical care issues and conceptualize a more profound understanding of it from the adult CCS participants experience within their real-life context. Thus, the information obtained from this type of study would provide invaluable tool for addressing access health care issues among the SJLIFE cohort.

Though this study has its limitations including the HIS sample size, its lack of generalizability, and cross-sectional design, this study is the first to examine the effects of race/ethnicity and insurance on access to foregoing medical care among CCS. Despite the study's limitations, we did find statistically significant differences in the effects of expansion by race/ethnicity and insurance. These findings are valuable especially given the policy changes to ACA which has reduced Medicaid spending and insurance coverage to over 8 million Americans [30,38-41,61,67-68]. In fact, the uninsured rate of Americans has annually increased for the first time since ACA was passed under the current president [41]. The findings in the study show the importance of expanding public insurance to improve access to care for adult childhood cancer survivors in the US to reduce foregoing medical care.

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Appendix - Supplementary Methods

Table A1: Univariate Analysis of SJLIFE population by Race and Ethnicity

raceandethnic	Frequency	Cumulative Frequency
Black NH	452	452
Hispanic	66	518
Other	40	558
White NH	2717	3275

Chi-Square Test for Equal Proportions

Chi-Square	5998.0980
DF	3
Pr > ChiSq	<.0001

Sample Size = 3275

Deviations of raceandethnic
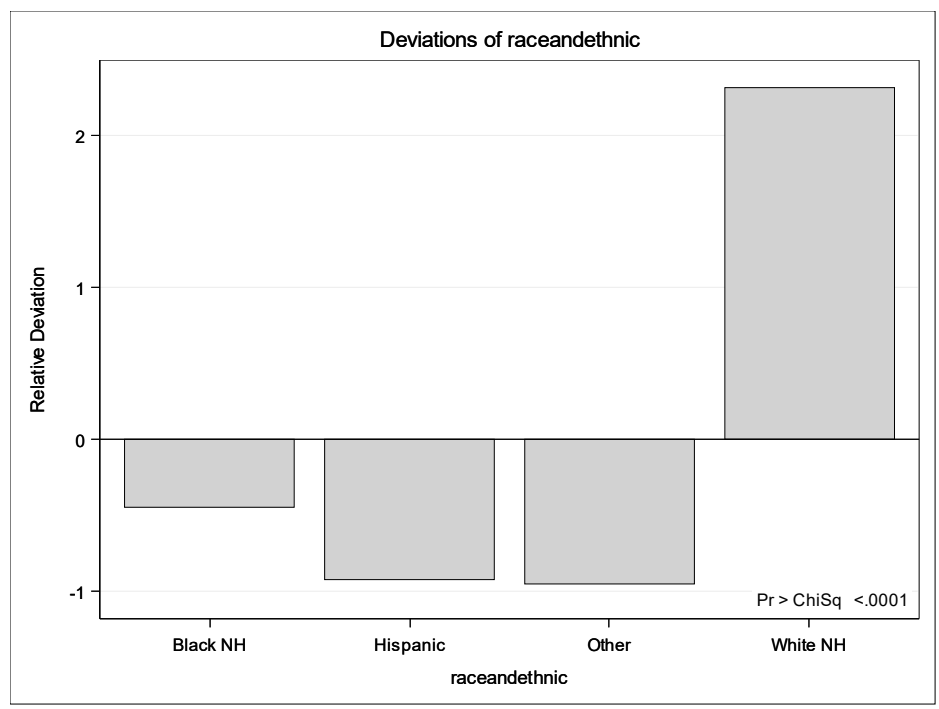
Table A2: Univariate Analysis of SJLIFE population by Insurance type

Insurancetype	Frequency	Cumulative Frequency
Missing	5	5
None	555	560
Othe	70	630
Priv	1965	2595
Publ	680	3275

Chi-Square Test for Equal Proportions	
Chi-Square	3803.7405
DF	4
Pr > ChiSq	<.0001

Sample Size = 3275

Deviations of Insurancetype

Pr > ChiSq <.0001
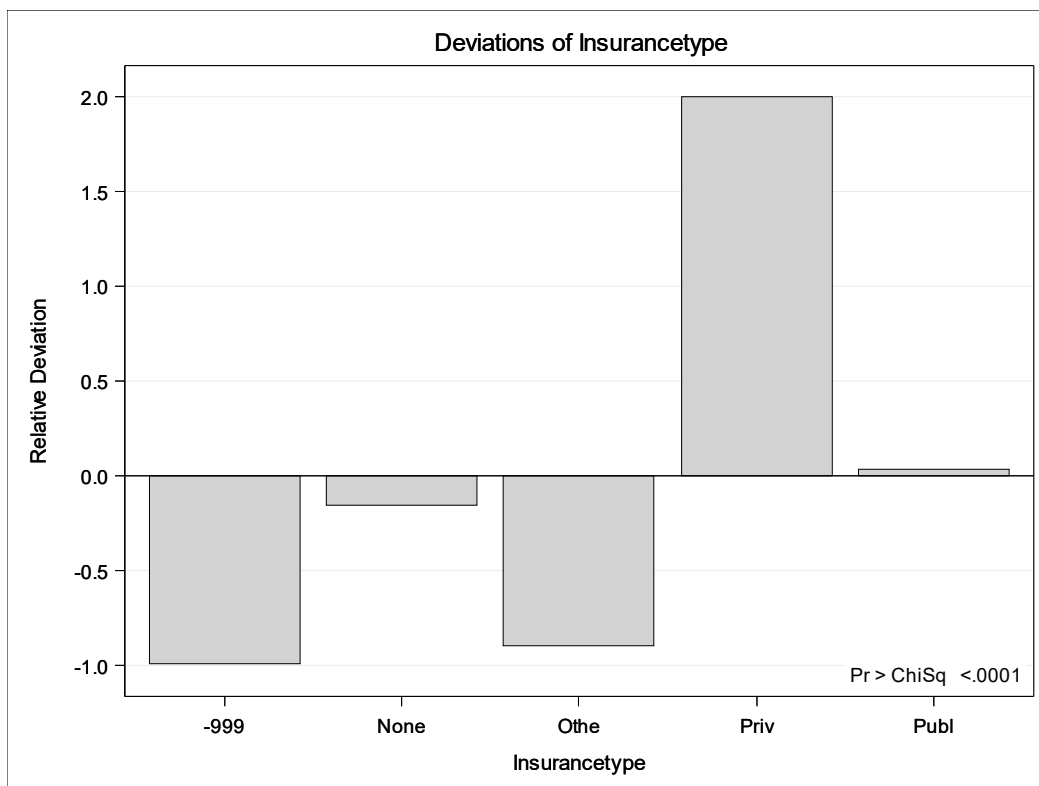
Table A3: Bivariate Analysis of SJLIFE population by Gender and Race/Ethnicity

Gender(gender)	raceandethnic				
Frequency **Col Pct**	**Black NH**	**Hispanic**	**Other**	**White NH**	**Total**
Femal	237 52.43	37 56.06	18 45.00	1281 47.15	1573
Male	215 47.57	29 43.94	22 55.00	1436 52.85	1702
Total	452	66	40	2717	3275

Statistics for Table of Gender by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	3	6.2114	0.1018
Likelihood Ratio Chi-Square	3	6.2087	0.1019
Mantel-Haenszel Chi-Square	1	5.2252	0.0223
Phi Coefficient		0.0436	
Contingency Coefficient		0.0435	
Cramer's V		0.0436	

Sample Size = 3275

Table A4: Bivariate Analysis of SJLIFE population by Age and Race/Ethnicity

Table of Age by raceandethnic

Age		raceandethnic			
Frequency Col Pct	**Black NH**	**Hispanic**	**Other**	**White NH**	**Total**
≤20 years	19 4.20	4 6.06	0 0.00	82 3.02	105
20–29 years	192 42.48	40 60.61	22 55.00	870 32.02	1124
30–39 years	148 32.74	17 25.76	14 35.00	985 36.25	1164
40–49 years	69 15.27	4 6.06	4 10.00	600 22.08	677
50+ years	24 5.31	1 1.52	0 0.00	180 6.62	205
Total	452	66	40	2717	3275

Statistics for Table of Age by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	12	63.1851	<.0001
Likelihood Ratio Chi-Square	12	67.7624	<.0001
Mantel-Haenszel Chi-Square	1	31.4159	<.0001
Phi Coefficient		0.1389	
Contingency Coefficient		0.1376	
Cramer's V		0.0802	

Sample Size = 3275

Table A3: Bivariate Analysis of SJLIFE population by Treatment Era and Race/Ethnicity

Treatment Era	raceandethnic				
Frequency Col Pct	**Black NH**	**Hispanic**	**Other**	**White NH**	**Total**
< 1970	13	0	0	91	104
	2.88	0.00	0.00	3.35	
1970 -1979	47	1	0	450	498
	10.40	1.52	0.00	16.56	
1980 -1989	133	10	10	875	1028
	29.42	15.15	25.00	32.20	
1990 +	259	55	30	1301	1645
	57.30	83.33	75.00	47.88	
Total	452	66	40	2717	3275

Statistics for Table of Treatment Era by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	9	62.0853	<.0001
Likelihood Ratio Chi-Square	9	75.7903	<.0001
Mantel-Haenszel Chi-Square	1	25.9897	<.0001
Phi Coefficient		0.1377	
Contingency Coefficient		0.1364	
Cramer's V		0.0795	

Sample Size = 3275

Table A4: Bivariate Analysis of SJLIFE population by Cancer diagnosis and Race/Ethnicity

Cancer diagnosis Frequency Col Pct	raceandethnic				
	Black NH	Hispanic	Other	White NH	Total
Acute lymphoblastic leukemia	80	27	11	866	984
	17.70	40.91	27.50	31.87	
Acute myeloid leukemia	19	9	2	88	118
	4.20	13.64	5.00	3.24	
Central nervous system (CNS)	53	6	7	331	397
	11.73	9.09	17.50	12.18	
Chronic myeloid leukemia	2	3	4	19	28
	0.44	4.55	10.00	0.70	
Colon carcinoma	0	0	0	6	6
	0.00	0.00	0.00	0.22	
Ewing sarcoma family of tumo	2	2	2	77	83
	0.44	3.03	5.00	2.83	
Germ cell tumor	29	0	0	60	89
	6.42	0.00	0.00	2.21	
Histiocytosis	3	0	0	18	21
	0.66	0.00	0.00	0.66	
Hodgkin lymphoma	54	4	2	332	392
	11.95	6.06	5.00	12.22	
Liver malignancies	3	0	0	21	24
	0.66	0.00	0.00	0.77	
MDS/Acute myeloid leukemia	0	0	0	2	2
	0.00	0.00	0.00	0.07	
Melanoma	2	0	0	19	21
	0.44	0.00	0.00	0.70	
Myelodysplastic syndrome	0	0	0	11	11
	0.00	0.00	0.00	0.40	
Nasopharyngeal carcinoma	14	1	1	6	22
	3.10	1.52	2.50	0.22	
Neuroblastoma	17	3	1	121	142
	3.76	4.55	2.50	4.45	
Non-Hodgkin lymphoma	25	4	4	214	247
	5.53	6.06	10.00	7.88	
Non-malignancy	2	0	0	2	4
	0.44	0.00	0.00	0.07	
Osteosarcoma	27	4	3	95	129
	5.97	6.06	7.50	3.50	
Other carcinoma	5	0	0	16	21
	1.11	0.00	0.00	0.59	
Other leukemia	0	0	0	3	3
	0.00	0.00	0.00	0.11	

Cancer diagnosis Frequency Col Pct	raceandethnic				
	Black NH	Hispanic	Other	White NH	Total
Other malignancy	0	0	0	18	18
	0.00	0.00	0.00	0.66	
Retinoblastoma	25	0	0	65	90
	5.53	0.00	0.00	2.39	
Rhabdomyosarcoma	24	1	0	94	119
	5.31	1.52	0.00	3.46	
Soft tissue sarcoma	23	1	2	74	100
	5.09	1.52	5.00	2.72	
Wilms tumor	43	1	1	159	204
	9.51	1.52	2.50	5.85	
Total	452	66	40	2717	3275

Statistics for Table of Cancer diagnosis by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	72	266.3559	<.0001
Likelihood Ratio Chi-Square	72	222.8623	<.0001
Mantel-Haenszel Chi-Square	1	33.0248	<.0001
Phi Coefficient		0.2852	
Contingency Coefficient		0.2742	
Cramer's V		0.1647	

Sample Size = 3275

Table A5: Bivariate Analysis of SJLIFE population by Treatment Exposure and Race/Ethnicity

Treatment Exposure Frequency Col Pct	raceandethnic				
	Black NH	**Hispanic**	**Other**	**White NH**	**Total**
No	224	38	20	1181	1463
	49.56	57.58	50.00	43.47	
Yes	228	28	20	1536	1812
	50.44	42.42	50.00	56.53	
Total	452	66	40	2717	3275

Statistics for Table of Treatment Exposure by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	3	10.8667	0.0125
Likelihood Ratio Chi-Square	3	10.8113	0.0128
Mantel-Haenszel Chi-Square	1	8.0647	0.0045
Phi Coefficient		0.0576	
Contingency Coefficient		0.0575	
Cramer's V		0.0576	

Sample Size = 3275

Table A6: Bivariate Analysis of SJLIFE population by Perceived Health Status and Race/Ethnicity

Perceived Health Status Frequency Col Pct	raceandethnic				
	Black NH	Hispanic	Other	White NH	Total
Excellent/ Very good	166	38	24	1129	1357
	36.73	57.58	60.00	41.55	
Good	157	16	11	991	1175
	34.73	24.24	27.50	36.47	
Fair/ Poor	129	12	5	597	743
	28.54	18.18	12.50	21.97	
Total	452	66	40	2717	3275

Statistics for Table of Perceived Health Status by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	12	28.9885	0.0040
Likelihood Ratio Chi-Square	12	29.1791	0.0037
Mantel-Haenszel Chi-Square	1	2.4564	0.1170
Phi Coefficient		0.0941	
Contingency Coefficient		0.0937	
Cramer's V		0.0543	

Sample Size = 3275

Table A7: Bivariate Analysis of SJLIFE population by Insurance type and Race/Ethnicity

Insurancetype Frequency Col Pct	raceandethnic Black NH	Hispanic	Other	White NH	Total
Missing	3 0.66	0 0.00	0 0.00	2 0.07	5
None	119 26.33	20 30.30	4 10.00	412 15.16	555
Othe	4 0.88	3 4.55	2 5.00	61 2.25	70
Priv	185 40.93	34 51.52	26 65.00	1720 63.31	1965
Publ	141 31.19	9 13.64	8 20.00	522 19.21	680
Total	452	66	40	2717	3275

Statistics for Table of Insurancetype by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	12	114.2140	<.0001
Likelihood Ratio Chi-Square	12	107.3543	<.0001
Mantel-Haenszel Chi-Square	1	7.7796	0.0053
Phi Coefficient		0.1867	
Contingency Coefficient		0.1836	
Cramer's V		0.1078	

Sample Size = 3275

Table A8: Bivariate Analysis of SJLIFE population by Income and Race/Ethnicity

income	raceandethnic				
Frequency Col Pct	**Black NH**	**Hispanic**	**Other**	**White NH**	**Total**
$20,000-	110 24.34	12 18.18	5 12.50	492 18.11	619
$40,000-	51 11.28	12 18.18	4 10.00	443 16.30	510
$60,000-	30 6.64	5 7.58	7 17.50	363 13.36	405
$80,000-	26 5.75	3 4.55	2 5.00	248 9.13	279
<$19,000	136 30.09	10 15.15	3 7.50	388 14.28	537
>$100,00	22 4.87	4 6.06	8 20.00	475 17.48	509
Don'tkno	77 17.04	20 30.30	11 27.50	308 11.34	416
Total	452	66	40	2717	3275

Statistics for Table of income by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	18	178.3169	<.0001
Likelihood Ratio Chi-Square	18	178.7262	<.0001
Mantel-Haenszel Chi-Square	1	0.8807	0.3480
Phi Coefficient		0.2333	
Contingency Coefficient		0.2272	
Cramer's V		0.1347	

Sample Size = 3275

Table A9: Bivariate Analysis of SJLIFE population by Education and Race/Ethnicity

Education Frequency Col Pct	raceandethnic				
	Black NH	**Hispanic**	**Other**	**White NH**	**Total**
Collegegrad	83 18.36	13 19.70	15 37.50	737 27.13	848
Gradeschool	5 1.11	2 3.03	0 0.00	47 1.73	54
HSdipolma/G	84 18.58	15 22.73	3 7.50	461 16.97	563
Other	17 3.76	3 4.55	0 0.00	83 3.05	103
Postgrad	28 6.19	11 16.67	8 20.00	273 10.05	320
Somecollege	133 29.42	14 21.21	9 22.50	680 25.03	836
Somehighsch	43 9.51	4 6.06	3 7.50	168 6.18	218
Trainingnot	24 5.31	1 1.52	1 2.50	124 4.56	150
Unknown	35 7.74	3 4.55	1 2.50	144 5.30	183
Total	452	66	40	2717	3275

Statistics for Table of Education by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	24	54.0975	0.0004
Likelihood Ratio Chi-Square	24	56.2021	0.0002
Mantel-Haenszel Chi-Square	1	17.2127	<.0001
Phi Coefficient		0.1285	
Contingency Coefficient		0.1275	
Cramer's V		0.0742	

Sample Size = 3275

Table A10: Bivariate Analysis of SJLIFE population by Foregone medical care and Race/Ethnicity

Foregonemedicalcare Frequency Col Pct	raceandethnic				
	Black NH	**Hispanic**	**Other**	**White NH**	**Total**
No	272 60.18	56 84.85	34 85.00	2042 75.16	2404
yes	180 39.82	10 15.15	6 15.00	675 24.84	871
Total	452	66	40	2717	3275

Statistics for Table of foregonemedicalcare by raceandethnic

Statistic	DF	Value	Prob
Chi-Square	3	51.9643	<.0001
Likelihood Ratio Chi-Square	3	49.6516	<.0001
Mantel-Haenszel Chi-Square	1	35.6574	<.0001
Phi Coefficient		0.1260	
Contingency Coefficient		0.1250	
Cramer's V		0.1260	

Sample Size = 3275

Table A11: Multivariable model fit statistics for Table 2 and figure 4

Model Fit Statistics		
Criterion	Intercept Only	Intercept and Covariates
AIC	3795.715	3190.922
SC	3801.809	3513.908
-2 Log L	3793.715	3084.922

R-Square	0.1946	Max-rescaled R-Square	0.2837

Testing Global Null Hypothesis: BETA=0			
Test	Chi-Square	DF	Pr > ChiSq
Likelihood Ratio	708.7926	52	<.0001
Score	694.7482	52	<.0001
Wald	523.3432	52	<.0001

Association of Predicted Probabilities and Observed Responses			
Percent Concordant	78.1	Somers' D	0.565
Percent Discordant	21.6	Gamma	0.566
Percent Tied	0.3	Tau-a	0.221
Pairs	2093884	c	0.782

Partition for the Hosmer and Lemeshow Test					
		foregonemedicalcare = yes		foregonemedicalcare = No	
Group	Total	Observed	Expected	Observed	Expected
1	329	17	14.23	312	314.77
2	320	32	27.15	288	292.85
3	325	34	37.05	291	287.95
4	330	41	46.64	289	283.36
5	337	57	59.31	280	277.69
6	329	66	70.59	263	258.41
7	328	98	92.09	230	235.91
8	328	119	122.43	209	205.57
9	328	179	166.75	149	161.25
10	321	228	234.77	93	86.23

Hosmer and Lemeshow Goodness-of-Fit Test		
Chi-Square	DF	Pr > ChiSq
6.3107	8	0.6125

Table A12: Multivariable model fit statistics for Table 3 and figure 5

Model Fit Statistics		
Criterion	Intercept Only	Intercept and Covariates
AIC	3795.715	3128.629
SC	3801.809	3488.179
-2 Log L	3793.715	3010.629

R-Square	0.2127	Max-rescaled R-Square 0.3100

Testing Global Null Hypothesis: BETA=0			
Test	Chi-Square	DF	Pr > ChiSq
Likelihood Ratio	783.0859	58	<.0001
Score	748.2734	58	<.0001
Wald	554.6457	58	<.0001

Association of Predicted Probabilities and Observed Responses			
Percent Concordant	79.7	Somers' D	0.597
Percent Discordant	20.1	Gamma	0.598
Percent Tied	0.2	Tau-a	0.233
Pairs	2093884	c	0.798

Partition for the Hosmer and Lemeshow Test

		foregonemedicalcare = yes		foregonemedicalcare = No	
Group	Total	Observed	Expected	Observed	Expected
1	328	13	11.35	315	316.65
2	328	22	21.79	306	306.21
3	328	27	31.79	301	296.21
4	328	44	43.98	284	284.02
5	328	58	57.40	270	270.60
6	328	76	73.04	252	254.96
7	328	95	94.96	233	233.04
8	328	125	125.74	203	202.26
9	328	173	172.33	155	155.67
10	323	238	238.62	85	84.38

Hosmer and Lemeshow Goodness-of-Fit Test		
Chi-Square	DF	Pr > ChiSq
1.2321	8	0.9963

Table A13: Multivariable model fit statistics for Table 5 and figure 6

	Model Fit Statistics	
Criterion	Intercept Only	Intercept and Covariates
AIC	3795.715	3133.532
SC	3801.809	3541.835
-2 Log L	3793.715	2999.532

R-Square	0.2153	Max-rescaled R-Square	0.3139

Testing Global Null Hypothesis: BETA=0			
Test	Chi-Square	DF	Pr > ChiSq
Likelihood Ratio	794.1832	66	<.0001
Score	758.0145	66	<.0001
Wald	560.1137	66	<.0001

Association of Predicted Probabilities and Observed Responses			
Percent Concordant	79.9	Somers' D	0.600
Percent Discordant	19.9	Gamma	0.602
Percent Tied	0.2	Tau-a	0.234
Pairs	2093884	c	0.800

Partition for the Hosmer and Lemeshow Test					
		foregonemedicalcare = yes		foregonemedicalcare = No	
Group	Total	Observed	Expected	Observed	Expected
1	328	11	11.14	317	316.86
2	328	23	21.33	305	306.67
3	328	25	31.39	303	296.61
4	328	47	43.49	281	284.51
5	328	57	56.77	271	271.23
6	328	76	73.16	252	254.84
7	328	94	94.94	234	233.06
8	328	122	126.18	206	201.82
9	328	176	173.25	152	154.75
10	323	240	239.36	83	83.64

Hosmer and Lemeshow Goodness-of-Fit Test		
Chi-Square	DF	Pr > ChiSq
2.3852	8	0.9669