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Cancer Treatment Decision Making in Aging Minorities

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2019

Abstract

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by

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MPH, University of Oklahoma, 1995

BBA, Langston University, 1990

Dissertation Submitted in Partial Fulfillment

Of the Requirements for the Degree of

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Abstract

Cancer incidence is high for aging minority and underserved populations, yet research is limited about patient-provider communications with aging racial and ethnic minority populations. Achieving high-quality cancer care is crucial to reducing health disparities for this population. However, potential shortages in professional health personnel, the cost to treat cancer, a strained health care system, and large aging populations contribute to the problem. The purpose of this qualitative study was to understand the personal experiences of aging minorities during cancer treatment decision making when communicating with their cancer care providers. Purposive sampling methods used to recruit 10 minority women and men born between 1946 and 1964 who had experienced communicating with providers and making cancer treatment decisions. In-depth semi-structured interviews and thematic analysis of qualitative data was conducted. Important findings were barriers related to miscommunication with providers, the need for more time with the cancer doctor, and mistrust of the medical profession. Participants perceived poor interpersonal communication with providers as causing a lack of understanding regarding their cancer treatment options, which affected their decision making regarding their treatment. Barriers to communication included long wait times at public or teaching health care systems for follow up cancer care services. The findings of this study could be useful to assist health care providers in improving communication with their cancer patients, reducing cancer health disparities, and increasing the quality of cancer care for this population.

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Dedication

I dedicate this study to cancer survivors in my family and those whose lives prematurely taken from this devastating disease.

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Chapter 1: Introduction to the Study

Introduction

Treatment decision-making with cancer is critical to successful care, mainly through effective patient-provider communications where information that is provided to the patient’s satisfaction. It is essential that providers communicate information about the patients’ specific cancer diagnosis, expected outlook, options available to treat the disease, and potential side effects, in order to succeed in providing quality care (Sheppard, Adams, Lamdan, & Taylor, 2010). In the study I used a qualitative approach to investigate phenomena related to patient-provider communication with aging Baby Boomer minorities and investigated how communication influences clinical decision-making.

Public health practitioners and policymakers are important in promoting healthy aging (Centers for Disease Control and Prevention [CDC], 2013). Cancer is a public health matter (CDC, 2013); public health can meet the developing needs of an aging society (Holtzman & Anderson, 2012). The incidence of cancer projected to increase among racial and ethnic minorities in the coming years (Edwards et al., 2014; Rahib et al., 2014). Moreover, by 2030, one in every five Americans—about 72 million people—will be over the age of 65. Statistics indicate the cumulative projected incidence of cancer will escalate by 45%, from 1.6 million to 2.3 million (Smith, Smith, Hurria, Hortobagyl, & Buckholz, 2009). The site-specific cancers that primarily affect older adults and minorities in 2030 will be breast, colorectal, lung, and prostate. Estimating projections for incidence and mortality cancer rates can change due to prevention, advances in treatment and changing demographics (Smith et al., 2009). Cancer rates for many sites are also expected to rise among minorities and older adults by 2030 (Tables 1 and 2), from 21% to 28% (Smith et al., 2009; Figure 1).

Table 1

Projected Cancer Patients by Age and Sex from 2010 Through 2030

Cancer Site and Year	All		Age 65+		Women		Men	
	No.	%	No.	%	No.	%	No.	%
All								
2010	1,599,000	—	967,000	—	761,000	—	838,000	—
2020	1,957,000	22	1,302,000	35	900,000	18	1,057,000	26
2030	2,318,000	45	1,618,000	67	1,049,000	38	1,269,000	51

Table 2

Projected Cancer Patients by Racial Ethnicity from 2010 Through 2030

Cancer Site and Year	White		Black		Asian and Pacific Islander		American Indian and Alaska Native		Multiracial		Hispanic	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
All												
2010	1,268,000	—	165,000	—	41,000	—	6,000	—	12,000	—	107,000	—
2020	1,480,000	17	217,000	31	64,000	58	8,000	39	18,000	45	171,000	59
2030	1,658,000	31	272,000	64	94,000	132	10,000	76	24,000	101	260,000	142

Source: Smith, Smith, Hurria, Hortobagyl, & Buckholz, 2009

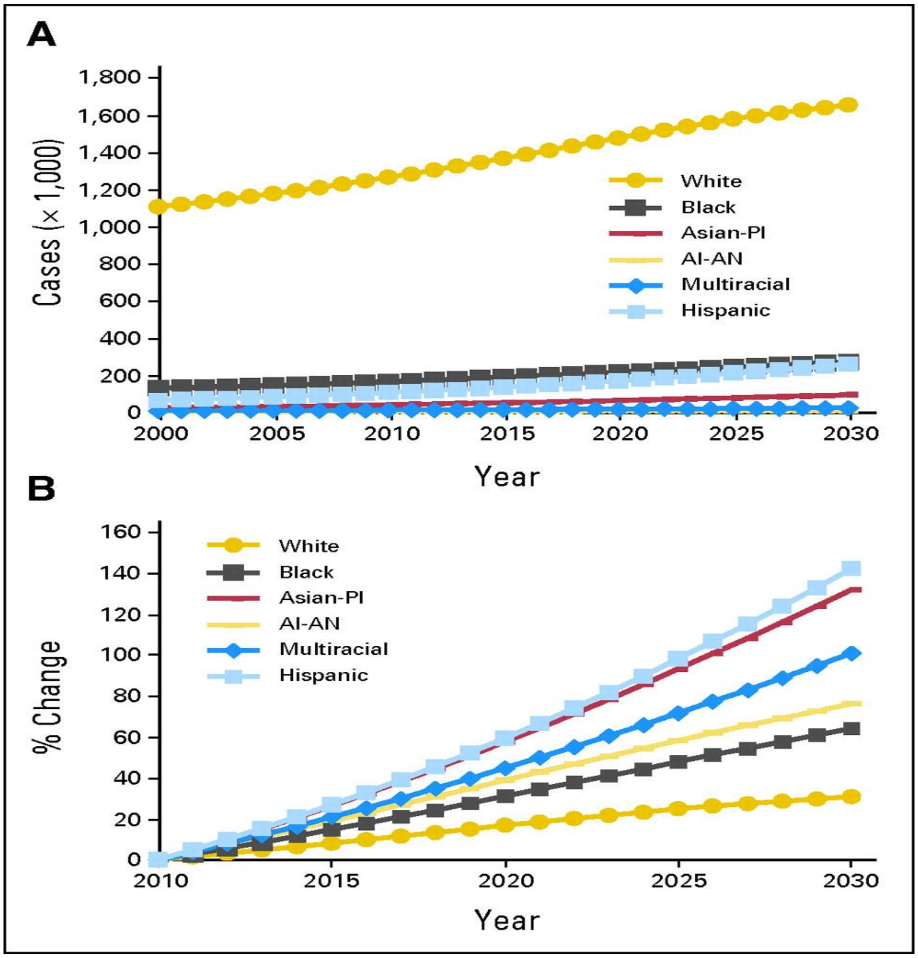

Figure 1. Cancer projections by race and origin in the United States by 2030.

Despite the continued growth of aging populations in the United States, research shows limited information exploring aging minorities involved in their own cancer care (Sysmonds, Lord, Mitchell, & Raghaven, 2012). Improving quality outcomes could influence cancer health disparities as this racially and ethnically diverse population ages (Nathan, Marshall, Cooper, & Huang, 2016). The incidence of cancer for older minorities presents multiple challenges. For example, cancer and treatments can be affected by age, race or ethnicity, genetic and biological influences, and physician and patient discussions.

Barriers to cancer treatment in older minorities include poverty, access to transportation, illiteracy, mental health, disabilities, cultural influences, access to quality cancer care, and poor language communications (U.S. Health and Human Services, Office of Disease Prevention and Health Promotion, 2014).

This qualitative phenomenological research directly observed cancer treatment decision-making experiences among minorities born between 1946 and 1964—post World War II individuals. Quality cancer treatment includes patients and families educating themselves about treatment decisions and selecting effective treatment options that could reduce the growth of cancer while maintaining the quality of life during the cancer treatment process (American Cancer Society [ACS], 2016; Institute of Medicine [IOM], 2013). Additionally, a disproportionate number of African American, Asian, Hispanic or Latino, and American Indian/Alaska Native persons are likely to suffer a greater disease burden. Understanding patient-provider communication, a review of the role and impact of culture and socioeconomic status on cancer health disparities is significant.

Background of the Study Problem

Cancer is a leading cause of death of all ethnicities among both men and women (CDC, 2015). Screening can prevent many types of cancer including breast, colon, cervix, lung, or prostate and early detection may mean less intrusive treatment and better patient outcomes. Individuals who smoke, have poor diets, engage in limited physical activity, have a family history of the disease, and are exposed to certain environmental risk factors are at high risk for cancer (ACS, 2015). Cancer statistics show that over 1.6

million individuals were projected to be diagnosed with cancer in 2017 (ACS, 2016), and the incidence of cancer was highest for the aged, minorities, and underserved populations (CDC, 2011; O'Keefe, Meltzer, & Bethea, 2015). ACS data for 2016 found that 595,690 people died from cancer that year (ACS, 2016). Approximately 86% of individuals over 50 years old are at risk for cancer (ACS, 2016).

The first wave of Baby Boomer Americans turned 65 in 2011, and 10,000 Americans celebrate their 65th birthdays each day (Pew Research Center, 2010). Consequently, cancer cases anticipate growing among this specific population of older Americans (White et al., 2014; ACS, 2016). The last wave of the Baby Boomer population (those born in the 1960s) will be 65 in the year 2029. This increase in the aging population in the United States will have wide impact on public health, social services, and healthcare. It will be important to promote healthy aging (CDC, 2013).

Addressing cancer health disparities among aging minorities is critical to the health objectives for the United States through the *Healthy People 2020* program (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2014). Overarching goals of *Healthy People 2020* are to achieve high quality health care, eliminate health disparities, and advance the health of all groups in the United States (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2014). Efforts to reduce cancer health disparities require effective patient-provider communication strategies (Smedley, Stith, & Nelson, 2003). However, ineffective patient-provider communication strategies for cancer treatment for minority and underserved populations may result in negative cancer care treatment and outcomes (Sheppard et al., 2011). Several benefits of effective patient-provider communications strategies for cancer treatment are provision of information to help patient decision-making with cancer care and good communication to strengthen patients' social support networks, reduce anxiety, deliver high-quality cancer care, and improve quality of life (Mead et al., 2013; Wilkins et al., 2012). Numerous studies confirm the importance of effective patient-provider communications for initial cancer treatments, which result in improved survival outcomes (Epstein & Street, 2007; Palmer et al., 2014).

Although morbidity and mortality of cancer have decreased and technological advances in cancer treatment have increased, minority populations experience lower cancer survival outcomes (IOM, 2013; Zonderman, Ejiogu, Norbeck, & Evans, 2013). Medically underserved racial and ethnic groups often present with a greater cancer burden, resulting in late stage diagnosis and poor survival outcomes, as compared to Whites (Byrd et al., 2011; Thompson et al., 2013). Moreover, medical providers who may be limited in their efforts to communicate to aging ethnic minorities (Schwartz, Lowe, & Sinclair) compound poor cancer outcomes. These populations are often low socioeconomic status, un- or underinsured, with limited health care access and underrepresentation in clinical trials, all of which create delays in receipt of cancer treatments in minority populations (IOM, 2013). Aging African American, Asian, Hispanic or Latino, and American Indian/Alaska Native populations disproportionately suffer a greater cancer burden (National Cancer Institute [NCI], 2015). According to the U.S. Census, between 2016 and 2030, White (not Hispanic) population age 65 and over is expected to increase by 39% compared to 89% for older racial and ethnic minority populations (U.S. Census Bureau, 2017).

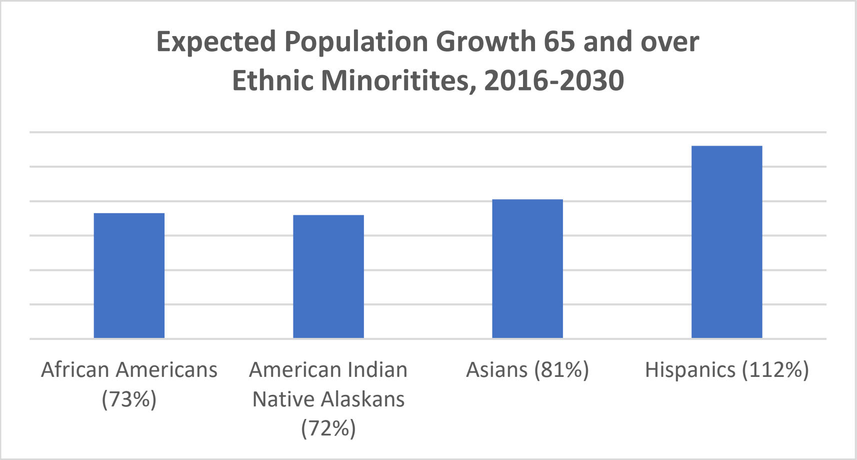

Figure 2. Expected population growth 65 and over, ethnic minorities, and 2016-2030. Source: U.S. Census Bureau. (2017). Population Division, Annual Estimates of the Resident Population by Sex, Age, Race, and Hispanic Origin for the United States and States: April 1, 2010 to July 1, 2016.

Problem Statement

There is limited research concerning the impact of patient-provider communications and cancer treatment decision-making options among aging racial-ethnic minorities who may have multiple communications challenges. Provider understanding of diverse cultural norms along with low health literacy of patients may affect access to cancer care (Epstien & Street, 2007; Sheppard et al., 2010). Cancer treatment options include surgery, radiation therapy, chemotherapy, hormone therapy, and immune therapy, all of which depend upon the type and size of cancer and whether cancer has spread to other parts in the body (ACS, 2015; NCI, 2015). From diagnosis to the sophisticated treatment options available, several things influence cancer treatment. First is the financial burden many families experience. Another is patients’ limited experience with healthcare systems, and a third is understanding cancer care and treatment information in decision-making. Furthermore, structural barriers that include inadequate health insurance, the complexity of the health care system, the treatment facility operating hours, wait times to receive treatment, and access to transportation (ACS, 2016) impact cancer treatment. Patient-provider communication also affects specific cancer treatment delivery (ACS, 2016). Lastly, the clinician can also contribute to poor patient-provider communication and poor prognosis due to lack of training and insensitivity to patients’ cultural backgrounds and the psychosocial, sexual, and emotional issues experienced by cancer patients (Epstein and Street, 2007).

According to the IOM (2013), quality cancer care happens when patients and families are the center of information exchange so they can make informed cancer treatment decisions. Effective patient-centered communications in cancer include open communications between cancer patients and the clinical team using evidence-based research to: (a) inform everyone about treatment options, (b) share decision making to influence patient outcomes, and (c) more fully involve patients with their care (Gagliardi et al., 2014; IOM, 2013; Epstein & Street, 2007). Shared control versus a physician control partnership is interrelated to the cancer patient’s level of education, ethnicity, gender, and participation in the cancer encounter (U.S. Department of Health and Human Services, National Institutes of Health [NIH], 2015]). Poor healthcare literacy in older adults impact a cancer patient’s ability to communicate with physicians or clinical staff about chronic diseases (IOM, 2011). Inadequate healthcare literacy can also lead to high mortality due to poor health status (CDC, 2016).

The incidence of cancer is highest for aging minority and underserved populations (CDC, 2013). Racial and ethnic minority patients have multiple barriers to cancer treatment including access to care, culture, language, and low health literacy understanding about cancer diagnosis (Ko, Zuniga, Peacher, Palomino, & Watson, 2016). Some studies suggest that culture, issues of trust, poor healthcare literacy, or limited understanding of cancer prevention and control information may affect communication inequities (Palmer et al., 2014).

Studies have documented recommendations to improve cancer communications for racial and ethnic minorities require practitioners to be culturally competent and effectively deliver information for decision-making about cancer treatment (Surbon 2010; Moore & Spiegel, 2004). Several studies show persistent challenges and disparities in clinical and patient communication and decision-making for cancer treatment among ethnic minority groups (Ko, et al., 2016; Palmer et al., 2014). In a systematic review of medical communications with racial-ethnic minorities, Ko et al. (2016) identified gaps in the effectiveness of clinician-patient communication among racial ethnicities. Other studies showed that physicians provided more limited health information to ethnic minority patients than to non-Hispanic White patients (U.S. Agency for Healthcare Research and Quality [AHRQ], 2015). In similar study, researchers examined racial and ethnic disparities in patient-provider communication and follow-up cancer care among older cancer survivors. Researchers concluded that Asians survivors perceived the worst follow-up cancer care with providers on quality care ratings as compared to Whites (Palmer et al., 2014). In this research study, I explored an important gap in understanding what patient-provider communication characteristics influence health outcomes of cancer patients, particularly how they affect cancer treatment decision-making for aging racial and ethnic minorities. Understanding the impact of these influences on cancer is critical to providing high quality cancer care for racial ethnic populations and reducing health disparities (NCI, 2017; CDC, 2013).

Purpose of the Study

The purpose of the study was to understand the personal decision-making experiences of aging minorities during cancer treatment when communicating with their cancer care providers. While there are studies that examine the cancer treatment experiences of non-Hispanic White men and women, there is limited understanding of the experiences of Baby Boomer minorities undergoing cancer treatment and care. This study focused on cancer treatment decision-making and patient-provider communication from the perspectives of minorities born between 1946 and 1964. This population often has less access to quality cancer care and may have fewer options to participate in cancer care decision-making (ACS, 2014). Information that does not effectively address the needs of Baby Boomer minority patients is a major concern in cancer treatment for this population. Understanding how this population perceives their own cancer diagnosis and treatment options is critical in reducing mortality and increasing cancer survival rates.

Research Questions

The research questions guided the in-depth interviews, which was the primary collection tool to identify cancer treatment decision-making processes based on patient-provider communication of African American, Asian, Hispanic or Latino, and American Indian/Alaska Native patients. The following research questions informed the study:

> Research Question 1: Do inadequate time allowed for medical decision-making and lack of active listening and empathy by care providers prove to be barriers to patient-provider communication for Baby Boomer minorities?
>
> Research Question 2: What are facilitators for post-cancer treatment (e.g., access to quality care and supportive networks) that improve quality of life of Baby Boomer minority cancer survivors? What are the barriers to improved quality of life?

Understanding the differences between barriers and facilitators in cancer treatment decision-making and the types of treatments received by Baby Boomer minorities could help identify appropriate interventions for improving patient-provider cancer communication and reduce cancer disparities among aging minorities.

Conceptual Framework

The conceptual framework for this research was the social-ecological model (SEM). Public health officials for interventions at various levels to influence specific cancer care behaviors have used the SEM. The SEM was created by Bronfenbrenner (1979) and expanded by McLeroy, Bilbeau, Steckler, and Glanz (1988) to further the understanding of relationships between individual- and population-based determinants of behavioral health from an ecological perspective (Moore, Buchanan, Fairley, & Smith, 2015). The SEM framework identifies factors that influence behavior at multiple levels of an intervention designed to implement or encourage change at individual, interpersonal, organizational, community, and policy levels (McLeroy et al., 1988). Thus, the SEM framework's multiple levels of influence used to improve health systems for cancer patients and reduce health disparities of minority aging populations through public health policies and programs (Moore et al., 2015). For example, activities at the community level of the SEM can facilitate comprehensive cancer control coalitions implement activities to support cancer survivorship among aging minorities have access to quality cancer care.

Nature of the Study

This was a qualitative research study. A phenomenological study was the most appropriate methodology to examine the beliefs and influences that guide aging minorities' experiences with cancer treatment decision-making and communicating with their providers. Phenomenological studies focus on lived experiences or events in people's lives that can better understand their perspectives and how they see their world (Husserl, 1970). Timely and accurate communication better informs decision-making critical to helping cancer patients navigate the myriad challenges present in a healthcare system in order to receive effective cancer treatment. The aim of this study was to outline improvements in patient-provider communication and provide insights into health care system changes that could improve cancer treatment outcomes. For this study, 10 men and women participant who are cancer survivors currently undergoing cancer treatment and were asked about their cancer treatment experiences. The data collection method was semi-structured interviews and observation of the participants to understand cultural nuances. In this research, I sought to determine effective interventions designed to eliminate or reduce cancer health disparities for aging minorities and to increase their quality of care for improved health outcomes.

Definitions of Terms

I used the following terms in developing an understanding of cancer treatment decision-making among minorities born between 1946 and 1964:

Cancer: A group of abnormal cells that divide into multiple cells and can invade healthy tissues (CDC, 2016).

Cancer staging: The extent of the cancer, such as the size of a tumor and if the tumor has metastasized in the body (NCI, 2015).

Cancer survivor: A person diagnosed with cancer and still living with the disease (CDC, 2016).

Cancer treatment: Treatment for cancer patients. Cancer treatment plans include surgery, radiation therapy, and chemotherapy (CDC, 2016).

Decision-making or shared decision-making: Collaborative activities that encourage health care professionals and patients to make medical decisions together as an approach to improving the provider-patient communication process (NCI, 2015).

Health equity: The social and medical determinants of access to health care for individuals to attain positive health outcomes (Braveman et al., 2011; U.S. Health and Human Services, Office of Disease Prevention and Health Promotion, 2014).

Health disparities or inequalities: are adverse differences in health status among populations; unfair healthcare (justice) systematically linked among socially disadvantaged populations with poor health (Braveman et al., 2011; NCI, 2015; U.S. Health and Human Services, Office of Disease Prevention and Health Promotion, 2014).

Patient-centered care: A type of care that promotes effective communication between patients and their families and clinicians and health systems, to engage patients as active participants in their care to improve health care outcomes and increase patient satisfaction. (Epstein and Street, 2012).

Patient-provider communication: Effective interpersonal communication between patients and health care providers to improve health outcomes and adherence to treatment recommendations (Epstein and Street, 2007; Sheldon, Haoung, Berry, 2011).

Quality of life: A person's overall sense of well-being and ability to complete a variety of activities following cancer treatment (NIH, 2016).

Social determinants of health: A complex web of the physical environment, health services, and societal factors that shape the conditions in which individuals live that promote health and avoid health inequalities (U.S. Health and Human Services, Office of Disease Prevention and Health Promotion, 2014; Stewart & Wild, 2016).

Assumptions

The assumptions of this study were that participants' goals were quality, healthy cancer treatment outcomes as long-term cancer survivors. I explained the questions to the participants to help ensure accurate data collection, and the participants conveyed their experiences of cancer treatment decision-making by responding appropriately to the questionnaire. I also assumed the participants had a previous cancer screening or waited until late stage after receiving a diagnosis of cancer. I assumed the participants' interacted with their cancer providers' communication style.

Scope and Delimitations

This study examined themes of experiences by Baby Boomer minorities and their perceptions of cancer care treatment for older adults. These themes included shared decision-making, communication with and trust of the cancer care provider, and the level of satisfaction with cancer treatment. I did not observe interaction with clinicians but discussed with participants' their previous cancer treatment decision-making experiences. Aging is a risk factor for cancer, and this study focused on midlife minority men and women between 54 to 72 years old. The participants of this study have had limited access to cancer care were low SES aging minorities. The results of the study may not be generalizable to a larger population.

Limitations to the Study

This qualitative study was limited to a small sample size of Baby Boomer minorities living in Atlanta, Georgia. The study was limited to patients living with any form of cancer. Either persons living with cancer or those diagnosed with cancer at some point throughout their lifetimes. A potential bias was limited to the selection of participants who are only a sample of the population they represent. The results from this small sample size may not be generalizable. Measures were taken to ensure the accuracy and confidentially of participant data in the analysis.

Significance of the Study

This study, conducted with aging Baby Boomer minorities from Atlanta, Georgia, contributes to the body of knowledge regarding patient-provider communication experiences and the subsequent influences of those communications on cancer treatment decision-making. The findings might prompt additional research to discover effective interventions to improve patient-provider communication and eliminate cancer health disparities for the targeted population. The implications of this knowledge are that it could have the potential to promote a positive social change through cancer care providers who assist aging minority cancer survivors to have a better quality of life while receiving cancer treatment. The cancer study can potentially replicate to other public health interventions to increase population-based cancer screening and control efforts.

Implications for Social Change

There are several implications for positive social change resulting from this research. Among them are informing public health organizations about cancer health disparities among aging racial and ethnic groups in the United States. While cancer mortality rates have decreased in general population studies, cancer incidence remains high among certain racial and ethnic minorities (Halpern, 2015; National Cancer Institute [NCI, 2015]; Ramirez, 2013). Positive social change implications of this study may be improvements in access to cancer treatment and better patient-provider communication; another may be to provide insights into health systems changes needed to improve cancer outcomes and reduce health disparities for racial and ethnic minorities. A final social change implication could be to advance the quality of life among aging minority individuals by improving the experiences of cancer survivors through public health programs and policies.

Summary

In conclusion, despite access to cancer screening and technological advances in cancer care and treatment, more progress is necessary to reduce new cancer cases and increase quality cancer care for aging racial and ethnic minorities. In this phenomenological study, I sought to identify patient experiences and the provider behavioral influences that affect patient-provider communication and contribute to cancer health disparities among Baby Boomer minorities. The study was an examination of this population's beliefs, perceptions, and experiences when discussing provider communications about cancer diagnosis and treatment.

In Chapter 2, I address relevant literature on cancer treatment decision-making that supports the need for the study. In Chapter 3 expanded, I address the methodology used for data collection and answer research questions. Chapter 4, presents research findings from the in-depth interviews of study participants, and in Chapter 5, I interpret the results and make recommendations for the research needs of the population under study.

Chapter 2: Literature Review

Introduction

In this study, I examined the relationship between patient-provider communications among minority Baby Boomer individuals' cancer treatment decision-making. A substantial number of studies identify the importance of patient and provider interactions for positive clinical outcomes; however, much of the current literature relates only to health disparities. The review for this study was limited to literature on aging and cancer health disparities faced by underserved aging minority populations regarding cancer treatment and patient outcomes.

Literature searches identified related qualitative studies on cancer epidemiology, health disparities and health equity, differences in cancer incidence among Baby Boomer minorities, and patient-provider communication about cancer treatment in aging minority populations. My research inquiries sought peer-review literature, public health reviews, and books. The databases searched included MEDLINE and Psych Info. Keywords and phrases used for the search were *cancer health disparities, inequalities, racism*, *gender, race, ethnicity*, *underserved, patient satisfaction, patient-provider communication, patient navigation, race concordance,* and *aging minorities.* The articles selected for this review explored topics on cancer health disparities and research on aging minority populations. I analyzed the studies published between 2007 and 2017 in this review using a literature matrix to examine the research questions, methodologies, and research designs, samples, analyses, and recommendations for future cancer studies.

Conceptual Framework

There have been few studies specifically on aging racial and ethnic minorities and their cancer care decision making. The SEM was the framework used to guide this study; it helped me explain the interrelationship between aging minorities and cancer providers and to articulate the importance of effective communication with multiple levels of influences on cancer prevention and control.

The SEM primarily focuses on the individual and population levels that determine health behavior at intrapersonal, interpersonal, organizational, community, and public policy levels (Moore et al., 2015; Fielding, Teutsch, & Breslow, 2010; McLeroy et al., 1988). These levels of the SEM describing health behavior are all interdependent (McLeroy et al., 1988):

- The intrapersonal level or individual behavior refers to knowledge, attitudes, personal and demographic characteristics that influence health behavior (McLeroy et al., 1988).
- The interpersonal level is social support systems of family, friends, co-workers, and others persons that can influence health behavior (McLeroy et al., 1988).
- The organizational level refers to institutions in organizational settings such as a school or workplace that plays a significant role in health behavior (McLeroy et al., 1988).

- The community level speaks to relationships among groups, institutions, organizational structures, and neighborhoods that impact access to care and influence health behavior (McLeroy et al., 1988).
- The policy level concerns public policies from local, state, national governmental agencies that affect health behavior (McLeroy et al., 1988).

In an earlier study, Earp, Altpeter, Mayne, Viadro, and O’Malley (1995) designed an intervention to direct minority, rural women 50 years and older to mammography screening in a five-county region of North Carolina. The researchers used various theoretical constructs of the social ecological model; PRECEDE model for health promotion, the Health Belief Model and the Stages of Change model for behavior change to increase breast cancer screening in older minority women. The social change implication was to reduce cancer mortality among racial ethnic populations. Studies have suggested that low-income African American are more likely to die of breast cancer as compared to White women (Hall & Johnson-Turbes, 2015).

McNeill et al. (2009) developed an intervention based on the social ecological framework that examined health behavior through a randomized controlled trial to increase colorectal cancer screening among low-income racial and ethnic minority adults over 50 years of age in public housing units. The researchers examined social support and social networks in public housing residents and trained peer health advisors to increased rates for colorectal cancer screening among residents. The study examined 12 housing sites to determine if residents received a recommendation for colorectal cancer screening, health insurance status, and other health related outcomes.

The public health action model for cancer survivorship developed by Moore et al. (2015) was an integrated model of the SEM. This framework was significant in addressing the public health needs of cancer survivors through the National Action Plan for Cancer Survivorship (Moore et al., 2015). This integrated SEM model includes a collaboration of intrapersonal and interpersonal networks, community and organizational groups, and policies (Moore et al., 2015; Figure 3).

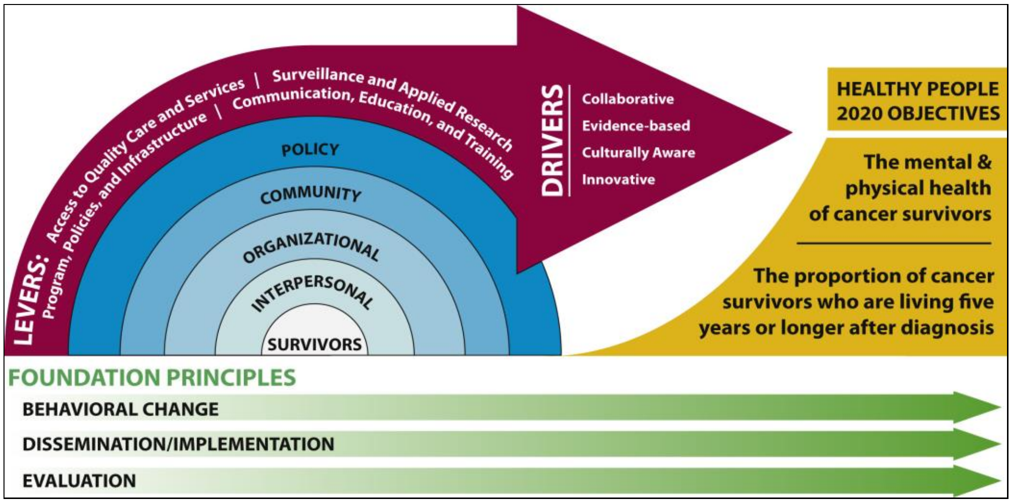

Figure 3. Diagram of SEM an integrated framework. Source: Adopted from Moore et al., 2015

Health Disparities and Health Equity

Health disparities defined by multiple entities and often used in the literature to describe inequality in utilization of health care services. An IOM (2013) report describes health disparities as "differences in access to available health care" (p. 29). In 2000, Congress passed Public Law 106-525 known as the Minority Health and Health Disparities Research and Education Act of 2000 (NCI, 2016). The law authorized the

NCI to establish the National Institute for Minority Health and Health Disparities to improve health lives of minorities (NCI, 2016). The NCI defines health disparities as follows: "A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population" (Minority Health and Health Disparities Research and Education Act of 2000, p. 2498).

Several factors determine health disparities (CDC, 2013). One is socioeconomic status, which influences a person's position in society. Socioeconomic status may be determined by income, educational attainment, occupation, health care access, and financial wealth (Saydah, Impertore, & Beckles, 2013; CDC, 2013). According to CDC's *Health Disparities and Inequalities Report*, researchers concluded that higher education and incomes contribute to better access to health care (CDC, 2013). The same report found that having only a high school diploma along with living in poverty negatively affects health outcomes. The CDC report described disparities with multiple diseases, risk factors, environmental assessments, social determinants, and access to health care (CDC, 2013). Barriers to cancer treatment and accessing health care services are critical for underserved and geographically confined ethnic minority populations (NCI, 2015). Other factors that complicate poor cancer outcomes include higher levels of environmental carcinogens, risk factors such as cigarette smoking and poor diet, and lack of health education about health risks (CDC, 2013, IOM, 2013, NCI, 2015). Studies show that some people with low socioeconomic status are at a higher risk of disease due to environmental exposures (CDC, 2013, O'Keefe et al., 2015). Individuals of low socioeconomic status also have limited access to nutritious foods that may lower cancer risk (O'Keefe et al., 2015).

In addition to socioeconomic status, other social determinants cause health disparities. These include where a person is born and raised, where they work, and their age; also, the delivery of health care (CDC, 2013). According to the World Health Organization (Stewart & Wild, 2016), "the social determinants of health are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries" (p. 6). Additional social determinants of health include race and ethnicity, sex, sexual orientation, age, and disability (CDC, 2014). Data from CDC's *Reaching Ethnic Approaches to Community Health* obtained from surveillance of several U.S. communities showed racial and ethnic communities have a high burden of disease and limited access to health care services in comparison among the majority populations in the same area (CDC, 2014).

Disparities of Cancer Incidence in Baby Boomers Minorities

Many governmental and non-governmental agencies track cancer incidence of all populations and minority populations. Data from the ACS estimate that around 1,685,210 new reports of cancer diagnosis projected in 2016 and 1,630 people will die each day from cancer in 2016 (ACS, 2016). The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) project new cases reported as 448.7 per 100,000 individuals annually (NCI, 2016). Mortality data show 168.5 per 100,000 individuals annually was based age-adjusted 2009-2013 cases and fatalities (NCI, 2015). In 2013, an estimated 14,140,254 people living with cancer in the United States among all cancer

(NCI, 2015) one out of every 25 Americans is a cancer survivor (ACS, 2014). The potential for cancer increases with advancing age (CDC, 2013); with 86 percent of cancers diagnosed are those individuals over 50 years old in the United States (ACS, 2016).

Although there continues to show notable gains overall health of Americans (*Healthy People* 2020), disparities in the morbidity and mortality specifically among African Americans, Hispanics, Native Americans, Alaska Natives, and Asian Pacific Islanders remains a serious health threat (CDC, 2015). The NCI defines cancer health disparities as “adverse differences in cancer incidence, prevalence, and mortality” (NCI, 2015). Disparities also exist due to geography or region of the country. The elderly, disabled people, and uninsured populations in the study population often reside in rural places where shortages of medically qualified personnel. In addition, seniors in these rural areas—who live below the poverty line, must often travel long distances to seek medical care (CDC, 2015).

There is also a continuing increase of minority populations with cancer in the United States (NCI, 2015). Data from the Administration on Aging (AoA) indicate aging adults of color have expanded an additional 3.2 million between 2003 to 9.5 million in 2013 (AoA, 2013). The older population estimated growth is around 21.1 million in 2030 (AoA, 2013). The aging white population is forecasted a 50 percent increase from 2013 to 2030 for those individuals over 65 in comparison to 123 percent for aging adults of color (AoA, 2014). The changing demographics of racial and ethnic minorities aging statistics are the results of the aging Baby Boomers cohort.

The Baby Boomers Cohort

According to U.S census data, the Baby Boomers cohort (U.S. Census Bureau, 2014) has drastically altered populations. Therefore, it is important to understanding this group and it will shape the demographic composition of the United in the future. This birth cohort is responsible for the significant rise in birth rates between 1946 and 1964 (U.S. Census, 2014). This generation has influenced many sectors such housing, recreation, business, healthcare, education, and government as they move into retirement and old age (AoA, 2013). The first year the Baby Boomers generations turned 65 was in 2011. By 2029, this generation will make up over 20 percent among the U.S. population (AoA, 2013; U.S. Census, 2014). Within this cohort is more racially and ethnically diverse and is expected to grow into a majority population by 2043 (AoA, 2013; U.S. Census, 2014).

Race and Ethnic Composition of Baby Boomers Minorities

The composition of minorities represents a range of races and ethnicities where 21.2 percent of those age 65 and over: 8.6 percent were African-Americans; 3.9 percent were Asian or Pacific Islander; 0.5 percent were Native American;; 0.1 percent were Native Hawaiian/Pacific Islander, and Hispanic represented 7.5 percent of the older population AoA, 2013; U.S. Census, 2014).

Racial and ethnic minority populations have increased from 6.3 million in 2003 (17.5 percent of the older adult population) to 9.5 million in 2013 (21.2 percent of older adult populations according to data from the Administration of Aging (AoA, 2013).

Population projections statistics show increase of 21.1 million racial and ethnic minorities in 2030 (28.5 percent of older adults) (AoA, 2013; U.S. Census, 2014).

Demographic Changes for Cancer

Disparities in cancer treatment and outcomes have become an increasing health challenge among ethnic minorities. The reasons for health disparities are complex, but demographic changes account for much of them. Many barriers to quality care include jobs, housing, level of education, and racial discrimination accounts for health disparities.

Economic Burden of Cancer among Minorities Born between 1946 and 1964

The aging of America indicates more individuals can receive a diagnosis of cancer. The increase in the overall population of aging minorities is likely to affect the burden of cancer care, especially since research shows specific minorities have higher prevalence cancers and lower survival rates than whites (ACS, 2015). The cost to treatment cancer in the United States is massive, and cost continue to increase due to individuals living longer as cancer survivors (Yabroff, Lund, Kepka, & Mariotto, 2011). Factors contribute to the cost of cancer and make the disease a burden include health care expenditures, productivity losses due to prolonged treatments, and out of pocket cost for cancer patients and their families. According to the Congressional Budget Office (GBO), national health care expenditures make up 18 percent of the Gross Domestic Product (GDP), but projected estimates will rise to 25 percent of GDP by 2037 (GBO, 2012). Moreover, direct medical costs associated with the burden of cancer include hospitalizations, surgeries, physician visits, radiation therapy, chemotherapy, or immunotherapies that measure by insurance payments or patient out-of-pocket cost (Yabroff et al., 2011).

Cancer costs vary according to the phase and type of cancer diagnosed. In 2010, the net monthly cost for senior women with breast cancer was $1923 and $5,740 for lung cancer (Yabroff et al., 2011). The total cost of cancer in 2010 estimated around $124.5 billion dollars. For example, higher cost is associated to treat female breast cancer at $16.5 billion, colorectal cancer at $14.1 billion, and prostate cancer at $11.9 billion (Yabroff et al., 2011). Future estimated cancer cost projected to reach $157.8 billion by 2020 (Yabroff et al., 2011). However, estimates from the AHRQ estimate the direct cost to treatment of cancer in the United States (total of all health care expenditures) in 2013 were $74.8 billion (AHRQ, 2014; NCI, 2015). Cost, as a barrier that generally prevents many from receiving access to quality cancer care, is also a barrier to Baby Boomers aging minorities receiving optimal healthcare. Finally, targeted therapies for new cancer treatments and technological advances in genetic mutations for improving treatment responses for specific diseases are expensive and increase the cost of cancer care (AHRQ, 2014). Health disparities in cancer affect specific racial and ethnic minorities (CDC, 2016; U.S. Office of Minority Health [OMH], 2015). Here are some examples:

All cancers with lower life expectancy likely affect African Americans for men and women of any race or ethnicity group as compared to whites (NCI, 2015; OMH, 2015). African American women are 40% have a greater risk of death from breast cancer; whereas many African American men do not survive past 5-years from lung, colon, and prostate cancers for example (NCI, 2015; OMH, 2015).

American Indian/Alaska Native populations have lowest rates of cancer as compared to whites. American Indian/Alaska Native men and women have high incidence of liver, gastrointestinal, and renal diseases and greater risk of death from these diseases (NCI, 2015; OMH, 2015).

Asian Americans have lower incidence of cancer rates than the non-Hispanic white populations. Asian/Pacific Islander men and women have a higher mortality rate of stomach cancer (NCI, 2015; OMH, 2015).

Native Hawaiians/Pacific Islanders have a high probability for receiving a diagnosis for cancer. American Samoan women have a high mortality of cervical cancer. American Samoan and Native Hawaiian men also have high rates of cancer (NCI, 2015; OMH 2015). Native Hawaiian men are highly likely to die from any form of cancer (OMH, 2015). In the U.S., territories of Guam and Micronesia populations have incidence of liver cancer, versus the majority population (NCI, 2015; OMH, 2015).

Hispanic American men and women have lower cancer rates than the non-Hispanic white population. For Hispanic men, the rate of prostate cancer is low. Hispanic women have lower incidence rates of breast cancer, but higher mortality of cervical cancer (OMH, 2015).

Public Health Efforts to Win the War on Cancer

Numerous studies have been published that document efforts by the United States to win the “war on cancer.” The United States President (NCI, 2016) announced a “War on Cancer” in 1971. Later that year, Congress amended the Public Health Service Act and passed the National Cancer Act of 1971 (P.L. 92–218); that later authorized National

Cancer Institute (NCI) to strengthen the scope of funding for cancer treatment research (NCI, 2016; Frieden et al., 2008). However, funding for this massive initiative was limited to cancer prevention research.

Secondary prevention efforts to reduce cancer mortality and help to achieve winnable battle against cancer through successful through screening and early detection initiatives. Several of these initiatives address breast and cervical cancer. Breast cancer leads as a cause of death for many women of all ethnicities (CDC, 2014c). Annually, many women are determined to have breast and cancer cancers and die from these diseases (CDC, 2014c). Screening mammograms and Pap test helps to find female cancers ahead of time when these diseases are most treatable to decrease mortality for these two cancers (CDC, 2014c).

Other legislation enacted to aid to lower cases of cancer in the United States. In 1990, Congress passed the Breast Cancer Mortality Prevention Act of 1990 (CDC, 2016b). The law authorized the Centers for Disease Control and Prevention (CDC) to create the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) (CDC, 2016b). The CDC provides dollars to the 50 United States, the District of Columbia, five U.S. territories, and 11 American Indian/Alaska Native tribes or tribal organizations (CDC, 2016b). The NBCCEDP provides women with access to cancer screening and diagnostic services to ages 50-64 who are also low income and under-insured or uninsured (CDC, 2016). NBCCEDP data shows from 1991 to 2015 that more than 4.9 million women were served, providing over 12 million breast and cervical cancer screenings, and diagnosed more than 71,000 breast cancers, 3845 invasive cervical cancers, and 175,688 premalignant cervical lesions, of which 40 percent were high-grade (CDC, 2016).

Another public health effort aimed at winning the war on cancer focused on colorectal cancer. CDC’s Colorectal Cancer Control Program (CRCCP) provides funding to states and tribal organizations to screen men and women for colorectal cancer (CRC) through education and policy and systems change (CDC, 2013). CRC affects men and women. CRC is number two in causes of death in the United States (CDC, 2014). According to the U.S. Preventive Services Task Force (2016), a CRC recommended screening test could save lives through a high-sensitivity fecal occult blood test, sigmoidoscopy, and colonoscopy. These tests can locate cancer early before it moves to higher level of progression and treat the disease quicker.

Cancer Treatment Disparities among Baby Boomer Minorities

Addressing the challenges of aging minority populations to promote cancer treatment is critical for the future of cancer services (AHRQ, 2015). Some of the challenges in general are a shortage of oncology personnel, the soaring cost to treat cancer, and the changing demographics due to the number of aging Baby Boomer minorities diagnosed with cancer. Another challenge is delivering accessible affordable cancer care to aging minorities; assist them with shared treatment making decisions with their cancer care providers. According to Smith et al. (2009) argued that the number of cancer deaths would grow unless efforts to improve cancer treatment for underserved older adults and racial ethnic minorities.

Historically, older adults and minorities have been under-represented in cancer clinical trials. Some barriers for clinical trials participation eligibility include comorbidities of the patient, transportation to the study site, other financial obstacles, the drug not paid by Medicare as an investigational treatment (Smith et al., 2009). Data from the U.S. Food and Drug Administration (FDA), there are biological differences and genetic variations in clinical trial participation (FDA, 2016). Some drugs can be more toxic in one ethnic group than they would be in another; contraindications to other drugs such as antidepressants and blood-pressure medications means they might be less effective in one group than in another. However, clinical trials are the only method to determine disparities in efficacy by racial and ethnic group (FDA 2016). Lack of minority participation in clinical trials may also be due to a lack of trust. The Tuskegee Syphilis Study conducted between 1932 and 1972 where the U.S. Public Health Service, is an example where scientists recruited poor black sharecroppers in Alabama to study syphilis (CDC, 2015). However, the investigators continued the study long after penicillin discovery to treat syphilis (CDC, 2015; FDA, 2016). As a result, safeguards for clinical trials participants among minorities and other population require institutional review boards of scientists, physicians, and lay individuals to ensure safety and effectiveness in drugs and protect rights of human subjects in research (FDA, 2016).

Patient-Provider Communication and Cancer Treatment

Efforts to eliminate cancer health disparities require effective patient-provider communication strategies (AHRQ, 2015). Information that does not effectively address the needs of Baby Boomers minority patients is a major concern in cancer treatment for this population. First, the healthcare professional workforce is under-represented among racial and ethnic minorities that increases access to care (OMH, 2011). Race-concordant relationships where health professionals treat patients different are often barriers to effective communication (Schoenthaler et al., 2012). Therefore, policy efforts to increase workforce diversity in clinical practice needs better patient-provider communication with aging minorities. The lack of effective patient-provider communication strategies for cancer treatment of minority and underserved populations may result in poor cancer care outcomes (Sheppard et al., 2010). One benefit of effective patient-provider communications in cancer treatment means patients make better informed decisions about their cancer care and treatment; another benefit of improved communication is social support networks are strengthened; anxiety is reduced, higher-quality cancer care is delivered, resulting in an improved quality of life (Mead et al. 2013).

Communication styles and the quality of care affect the health outcomes (Bylund, Peterson, & Cameron, 2012; Quillin et al., 2009). Few studies have focused specifically on minorities born between 1946 and 1964 on patient and provider communication influences the health outcomes of cancer survivors and their treatment decision making.

Patient-provider communication is a critical ingredient to the quality of life affecting health care quality before and after cancer treatment and increase cancer survivors in the United States (Epstein & Street, 2007). In earlier studies by Ong and colleagues, (1995) doctor-patient communication includes several components such as fostering a good interpersonal relationship, exchanging information to healing, and making treatment or medical decisions. Some researchers suggest understanding cancer information can increase cancer survivorship associated with cancer care (Arora, Reeve, Hays, Clauser, & Girvan, 2011; Song, et al., 2013).

Effective patient-provider communication happens when the patient assumes an active role in their cancer care. Hibbard and colleagues (2013) concluded that patients who are actively engaged in their care are confident in communicating with providers, making, and maintaining decisions that are important to their long-term cancer survival. Studies on long-term cancer survivors among racial ethnic populations reveal poor communication, and lower self-efficacy in making medical decisions, and more inferior quality of care on their follow-up patient cancer care as compared to whites Palmer et al. (2014). Researchers also suggest providers should periodically provide communication follow-up to encourage racial ethnic minority patients engaged about their cancer care (Palmer et al., 2014). Consequently, providers should increase their knowledge of cultural competence training for cancer care working with racial ethnic minorities (Palmer et al., 2014).

Arora’s (2003) findings on provider communication indicate individual behavior has a great impact on the patient’s health outcomes, as patients are already devastating of having received a diagnosis of cancer. However, studies on provider perceptions of patient-provider communication identify a breakdown in cancer care communication at multiple levels including patient, provider, and health system level and suggest integrating multi-level perspectives is essential to delivering patient-centered cancer care (Prouty et al., 2014). Reyna, Nelson, & Han (2015) discuss more evidence-based principals from several theoretical perspectives for interventions to support better decision making in cancer where the patient understands all the facets of the cancer experience.

Cancer Survivor Studies

In a study understanding the importance of quality follow-up cancer care, Arora et al. (2011) at the NCI developed the Assessment of Patients' Experience of Cancer Care (APECC) study, a population-based study of cancer survivors' experiences of receiving follow-up care. The primary goals of the APECC study were to develop and pilot test a survey instrument that would assess cancer survivors' perceptions quality of their cancer care. The study also identified socioeconomic, clinical, and patient-level factors to rate their quality of care, and evaluate the relationship between the survivors' assessment with the overall ratings (Arora et al., 2011). A pilot study to test the effectiveness of the APECC survey conducted by NCI researchers and in collaboration with the Northern California Cancer Registry, a partner of NCI's Surveillance, Epidemiology, and End Results (SEER) program. The study design included the recruitment of eligible cancer survivors diagnosed with leukemia, bladder, or colorectal cancer 2-5 years before enrolling in the APECC study, and be at least 20 years of age. Cancer survivors must have received follow-up care within the last 12 months, and respond to cancer survivors' experiences listed on the survey. A cross sectional mailed APECC survey and information letter describing the study sent to 1,572 were eligible cancer survivors to participate in the study, 774 or 49% responded or returned the questionnaire. The study sample consisted of 623 cancer patients, or 81% of respondents indicated they had received follow-up care in the last 12 months. Demographic data showed nearly 60% of participants had colorectal cancer; 14% had leukemia, and 28% had bladder cancer, all received cancer treatment in the past year; and 50% had multiple comorbidities (Arora, et al., 2011).

The APECC survey included 33 areas to assess survivors' perceptions of the quality of their follow-up care in the last 12 months. The results of researchers suggest that underserved populations may be at risk of experiencing poor outcomes, and a better continuity of care may lead to good patient experiences (Arora, et al., 2011). The researchers concluded that physician knowledge of cancer patients is a key quality indicator; improving patient-centered cancer care may improve patient’s experience through communication and better coordination of care (Arora, et al., 2011). A limitation of the study is not able to compare follow up care experiences some racial ethnic minorities’ subgroups due to low sample size.

In another study, Palmer et al. (2014) examined racial and ethnic disparities in patient-provider communication among cancer survivors using the survey data from the Follow-Up Care Use among Survivors (FOCUS) study, a population-based study of eligible cancer survivors conducted between March 2005 and 2006. The sample size of 1196 cancer survivors that were randomly selected from the Los Angeles and Northern California Surveillance SEER registries. The eligible cancer survivors diagnosed with colorectal, prostate, endometrial, or ovarian cancer, age 21 at diagnosis, males and females among non-Hispanic white, African America, Hispanic and Asian completed the survey on physician use for cancer related follow up care. The results indicate that African American, Asian and Hispanic survivors report poor patient-provider quality ratings and health outcomes as compared to Whites (Palmer et al., 2014). The researchers concluded that more research to address racial ethnic disparities in cancer survivors to improve patient experiences and quality of life outcomes (Palmer et al., 2014).

Patient-Centered Care

The IOM reported in their *Crossing the Quality Chasm* and recommended improvements in “health care delivery that should be patient-centered, meaning care should be responsive to individual patient preferences, needs, and perspectives and ensure that patient values guide clinical decisions” (IOM, 2001). The National Cancer Institute (NCI) created a conceptual framework for understanding patient-centered care for patient-provider cancer communication and developed an evidence-based monograph, *Patient Centered Care Communication in Cancer Care*, (Epstein and Street, 2007) working with multiple experts in oncology, primary care, and patient advocates (Arora, Street, Epstein, & Butow, 2009). The monograph describes the interaction of patients, families, clinicians, health care organizations understand cancer communication research for cancer treatment and shared decision-making (Epstein & Street, 2007; Figure 4).

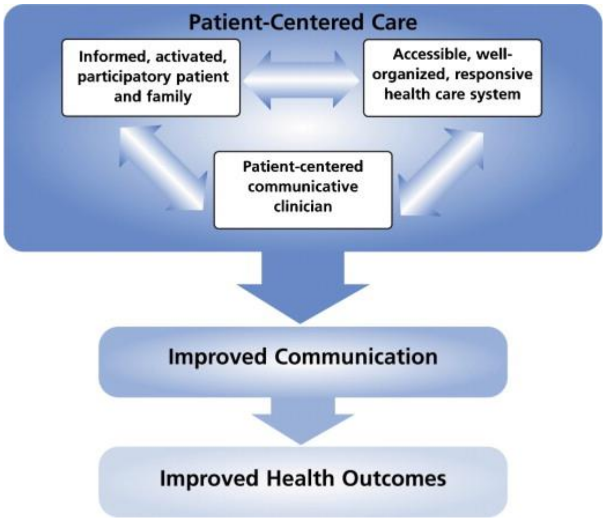

Figure 4. Model of patient-centered care. Source: Epstein, R.M., Street, And R.L. Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

Shared Decision Making

Shared decision-making is effective when patients know about cancer treatment options, risks, benefits, and their values and preferences considered into treatment decision-making (Katz, Belkora, & Elwyn, 2014). For many patients with cancer, discussions can be complicated about specific options for treatment and continuing cancer care. Several studies continue to plague disparities among certain racial groups on treatment choice and their attitudes in communication with providers regarding cancer treatment decision making (DeSantis and Naishadham, 2013; Haider, Scott, Rehman, et al., 2013). In many cases, minority patients experience less satisfaction of care including trusting the clinicians in communication about their cancer care (Thomas, Goff, Tsang, et al., 2013).

According to Luo, Spolverto, Johnston, Haider, and Pawlik (2015) shared decision-making studies account for several factors that determine cancer treatment choice for racial ethnic minorities including not treating the cancer or best supportive care, non-surgical treatments such as chemotherapy, radiation therapy, or surgery. Patient and provider communication is critical in what choice of therapy the patient chooses for minority patients. Differences in cancer treatment vary across different minority groups, and patient-physician communication, decisional control preferences, and cultural attitudes contribute to cancer options for minority patients (Luo et al., 2015). The researchers argue that while the physician is the initial person of information patients rely on, physicians may act poorly in providing accurate and timely information to minority patients making them limited informed about specific treatment options for their treatment satisfaction (Luo et al., 2015). The final cancer treatment decision lies with the patient and the family when they are engaged in their decision (Luo et al., 2015). The quality of patient-provider communication and decision-making can influenced by related to cultural attitudes. Culture barriers among certain minority cancer patients include fatalism, medical mistrust and lack of the health care providers and individuals who have suffered from medical discrimination (Yanez et al., 2012).

Mead et al (2013) conducted a systematic review of studies for shared decision-making and concluded that a shared decision approach to cancer care should extend beyond the general patient-provider to import key individuals and community members in the cancer treatment decision-making process. A conceptual model to access decision making for cancer treatment among racial ethnic populations was created to identify the multiple determinants of cancer treatment (Figure 5) that include levels of influence for the patient, family, community, and provider (Mead et al., 2013). Researchers argue that the SMD approach is not necessarily appropriate for every cancer patient (Mead et al., 2013). Addressing culture and personal preferences for treating cancer through effective patient center communication may improve adherence to treatment, may reduce the delays of cancer care for racial ethnic minorities (Mead, et al., 2013).

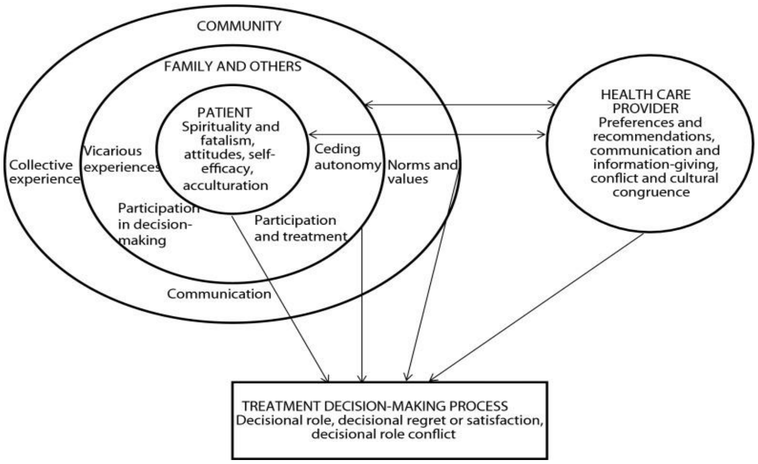

Figure 5. A conceptual model cancer treatment decision-making racial ethnic minority patients. Source: Adopted from Mead et al., 2013.

Cancer cases are expected to increase as the U.S. population ages and leads as a cause of death. As an example, for older women with breast cancer will affect many older women and increase among racial and ethnic minority women (CDC, 2014). Multiple health disparities exist for breast cancer treatment among older minority women; socioeconomic status, poor treatment decision-making outcomes, access to health services, family involvement, language barriers, and acculturation of immigrant populations (Luo et al., 2015). African American and Latina women receive poorer patient-physician communication and are less likely to receive aggressive breast cancer treatment like breast-conserving surgery, and radiation treatment as compared to whites (Yanez, Stanton, & Maly, 2012). Understanding more about cancer treatment decision making for aging minority populations can improve cancer disparities and health equity among vulnerable populations.

Summary

This chapter has presented the Baby Boomer population is living longer than any birth cohort in United States history, so it poses new challenges not seen in before modern healthcare. The health disparities in this cohort, born between 1946 and 1964 are well known. Moreover, the cancer rates expected to rise as this population ages and become more diverse. Having a good patient-provider communication system is essential to lowering cancer health disparities among the study population that makes decisions about cancer treatment. Cultural and ethnic factors, treatment delays due to in effective communication, workforce shortages, distrust of providers and healthcare system factors, the rising cost of cancer all contribute to cancer health disparities and quality cancer care for aging Baby Boomer minorities.

Chapter 3: Methodology

Introduction

The purpose of this study was to understand the personal experiences of aging minorities during cancer treatment decision making when communicating with their cancer care providers. The preceding section focused on the current literature related to Baby Boomer ethnic minorities' decision making for cancer care treatment. The age cohort for this study was individuals between 50 and 74 years of age. Cancer health disparities in this cohort include an awareness of patient-provider communication and the quality of cancer treatment decision-making this communication facilitates. In this chapter, I outline a phenomenological research paradigm for this study along with the specific aims of the study, the setting, and the sample used to examine the lived experiences of participants. Additionally, in this section I discuss the participant selection process (inclusion and exclusion criteria), the role of the primary investigator, measures taken to protect all study participants, and data collection and data analysis procedures.

Research Plan and Design

I selected a phenomenological research method. Phenomenology studies focus on lived experiences or events in people's lives and provides a framework for evaluating perception in a way that can further aid in understanding participants' perspectives. The core attributes of phenomenology make it a good choice for qualitative inquiry as it allows for insight into the possible influences of perceptions on behaviors and actions (Creswell, 2009). A phenomenological researcher is concerned describing a person's experiences about how they see the world (Giorgi, 2008; Speziale & Carpenter, 2007).

The interview was the data collection tool that I used to explore experiences of participants as a basis for this qualitative study. According to Giorgi (2008), questions for qualitative interviews should be broad and open-ended, allowing the participants opportunities to share their points of view. Active listening on the part of the researcher and probing for clarity are essential to getting participants to describe their experiences (Bevan, 2014).

The central phenomena studied were experiences of minorities born between 1946 and 1964 when making decisions concerning cancer treatment. I sought to understand the disparities in cancer diagnosis and treatment among this population group, especially as it related to the influence of patient-provider communication on treatment decisions for underserved racial and ethnic minorities diagnosed and treated for various types of cancers. Understanding specific healthcare-related factors in cancer treatment decisions may help determine interventions for the study population. The qualitative approach supported exploration and probing of study participant experiences, and the phenomenological research design resulted in obtaining good descriptive information (see Creswell, 2009).

Research Questions

The research questions guided the in-depth interviews, which were the primary collection tool to identify cancer treatment decision-making based on patient-provider communication. The specific inquiries for this qualitative research were:

Research Question 1: Do inadequate time allowed for medical decision-making and lack of active listening and empathy by care providers prove to be barriers to patient-provider communication for Baby Boomer minorities?

Research Question 2: What are facilitators for post-cancer treatment (e.g., access to quality care and supportive networks) that improve quality of life of Baby Boomer minority cancer survivors? What are the barriers to improved quality of life?

I used open-ended questions to gather data that provided insight about the experiences of the research subjects (see Penner & McClement, 2008; see Speziale & Carpenter, 2007). Campbell (2016) suggested that open-ended questions must have a raw theme to urge participants to describe how the phenomenon had influenced their lives and how the experiences uniquely affected them. In this study, in-depth interviews were the primary collection tool to answer the research questions.

Descriptive variables such as race and ethnicity, educational attainment, age, sex, marital status, and insurance coverage information collected to inform the study. I asked specific questions about participants' experience with cancer treatment decision making. For example, one question was, "I like to you to share your cancer treatment decision-making experiences in the past 2 years." (Arora, et al., 2011; see Palmer, 2014; see Sheppard, et al., 2010). These interview questions measured patient-provider communication and cancer treatment decision making from follow up care experiences as perceived by the study participants. I used probes to solicit more details or to clarify answers, and I categorized responses into themes in a matrix. I asked the following interview questions to uncover participant perceptions of cancer treatment decision making and provider communication:

1. Describe how you first learned about your cancer diagnosis.
2. Did your cancer doctor discuss treatment options you could understand for making decisions about your cancer treatment process? If so, what did the doctor discus?
3. How long after the cancer, diagnosis was your cancer treatment decision made.
4. Did your cancer doctor encouraged your involvement to ask important questions about your cancer treatment options? If so, how?
5. Did your doctor encourage you to voice your opinion (agree or disagree) about your cancer treatment or specific treatment recommendations?
6. Please describe how family members or significant individual(s) influenced your cancer treatment decision.
7. In what ways did family members or significant individual(s) communicate with your doctor about your cancer treatment options?
8. In what ways do you feel your age played a role in your cancer treatment decision making?
9. In what ways do you feel your financial resources played a role in your cancer treatment decision making?

10. Did your spiritual or religious beliefs influence your cancer treatment decisions? If so, please if it helped or hindered you dealing with this serious physical illness?
11. In looking back, what things do you think the medical care team could do to improve quality cancer care with patients?
12. Are there any additional comments you would like to provide about your cancer treatment decision experiences?

These interview questions modified using the APECC population-based survey developed by researchers at the NCI (2011). The APECC survey was designed to measure perceived quality of cancer care follow-up from the cancer survivors' experiences, assess the satisfaction of care within 12 months, and to understand cancer patients' participation in their decision making for cancer treatment and follow up cancer care (NCI, 2011). Researchers assessed key factors critical to patient-provider communication necessary to promote quality of care after treatment for cancer survivors (Arora et al., 2011; Palmer, 2014). For example, areas of follow-up care experiences assessed were: (a) access to care, (b) physicians' communication, (c) medical care team communication, (d) health promotion, and (e) coordination of care. Some questions used in the survey that informed physician communication ratings included: "In the past two years, how often did your cancer-related follow-up care physician(s):

(a) Listen carefully to you,

(b) Explain things in a way you could understand,

(c) Show respect for what you had to say,

(d) Encourage you to ask all the cancer-related questions you had, and

(h) Involve you in decisions about your medical care as much as possible.

This tool allowed me to gain a deeper and richer understanding of cancer survivors' experiences of this aging population-based study with members of racial and ethnicities minorities in order to understand the barriers and facilitators for increasing quality cancer care.

Role of the Researcher

My role in this study I gathered and analyzed the data from the participants by conducting personal interviews. I narrowed the research problem down to the gaps in the literature. As a public health professional, I understand the challenges of aging and the growing cancer concerns of Baby Boomers as they age. To mitigate potential researcher bias I was open to and flexible in meeting the needs of the participants. I did not encourage participants to share information they were not ready to share or make them discuss topics that were not relevant to the specific research.

Participant, Recruitment Strategy, Sample, Size

Understanding racial ethnic differences for cancer treatment and decision-making is imperative to reducing health disparities among aging minority patients. Qualitative methodology is well suited for a phenomenological study for which previous research is limited on the experiences of aging minority populations when discussing cancer treatment options with their physicians. Potential participants eligible for recruitment will be individuals between the ages of 54-72. Study participants are diagnosed with a cancer such as breast, cervical, colorectal, prostate or other diagnosed cancer within Stage I or higher, and are experiencing cancer treatment in the past 24 months from no surgery, chemotherapy, radiation therapy, or surgery. Study participants were English speaking and are mentally competent. Study participants can be male or female.

The study size population will be up to 15 individuals born between 1946 and 1964 who are cancer survivors and for purposes of this study are sufficient sample size to answer the research questions. In a similar study, Obikunle (2016) examined the personal experiences of 14 African American women, 40 years and older, perceived barriers to breast cancer screening. A sampling strategy, I selected for this qualitative study is random sampling technique that allows the researcher to use semi-structured interviews for the described research design. The specific criteria for the study that individuals are members of various ethnic and racial minority groups to facilitate the information necessary for response to the interview questions. This study, conducted in the metropolitan area of Atlanta, Georgia at a Community Health Center (CHC) that serves primarily low socioeconomic status cancer survivors. Previous studies show that underserved minority populations exhibit a higher disease burden as compared to whites; they often have late stage diagnosis and poor survival outcomes for cancer (Byrd et al., 2011; Thompson et al., 2013). Baby Boomer minorities also receive fewer cancer treatment services compared to whites (NCI, 2016). The first eligibility criterion to participate in the study is to be an individual who self-identifies as one of the following racial or ethnic backgrounds: African American, Asian, Hispanic or Latino, American Indian/Alaska Native. Participants must also self-identify as a cancer survivors. Additional criteria are to be between 54 and 72 years of age, speak English, and identify the CHC as their access to oncology care. Qualitative methodology is well suited for a phenomenological study for which previous research is limited on the experiences of aging minority populations when discussing cancer treatment option with their physicians.

As a sampling strategy, I selected for this qualitative study is semi-structured interviews for the described research design. The specific criteria for the study that individuals are members of various ethnic and racial groups to facilitate the information necessary for response to the research questions.

Study participants recruited from the follow up care conducted at a Federally Qualified Health Center (FQHC) or Community Health Center (CHC) that serves primarily low socioeconomic status minority populations in a metropolitan area of Atlanta, Georgia. Previous studies show that underserved minority populations many times exhibit a higher disease burden as compared to whites; they often have late stage diagnosis and poor survival outcomes for cancer (Byrd et al., 2011; Thompson et al., 2013). Baby Boomer minorities also receive fewer cancer treatment services compared to whites (NCI, 2016).

Participant selection was from a range of racial and ethnic aging minorities that consisted of African Americans, Hispanic or Latina, Asian/Pacific Islanders, American Indian/Alaska Native. All participants included, informed of the purpose of the study, their rights as participants, and that they understand the consent form included in the study.

A goal for the sample size was 15 participants for this study. After obtaining demographic data from the participants, semi-structured face-to-face interviews conducted at a CHC setting to allow participants to articulate their cancer treatment experience, decision making, and patient-provider communication. The participants had the opportunity to share additional information about their cancer care experiences and follow up from the researcher if necessary.

Data Collection

The study intended to analyze data regarding the phenomena, context, and themes through direct observation and interaction experienced by minorities born between 1946 and 1964 and their experience in receiving cancer care. After the Walden University's Institutional Review Board (IRB) approval, I collected data in Atlanta, Georgia. The IRB is a formal committee established for responsible, ethical review and oversight of studies according to the U.S. Department of Health and Human Services Office for Human Research Protection, Regulations 45 CFR Part 46 (2018).

Participants were asked open-ended questions to explore their experiences with patient-provider cancer treatment and care. All of the interviews were conducted in Atlanta, Georgia. The researcher worked closely with the CHC to identify eligible cancer participants to send an invitation letter describing the study. The researcher contacted study participants. Participants who agreed to the interview completed the informed consent for research. Interviews were recorded and transcribed into a Microsoft Word document and identify common themes for the research study. Names were not be assigned to the interview instrument, but participants were assigned a numeric code for identification of each study participant. The sample size was small, limited to 15 participants to maximize the saturation of data.

For confidentiality, interviews were face-to-face. The investigator probed participants’ cancer treatment experiences. Each interview lasted no more than 60 minutes. An interview instrument by the researcher ensured each participant answers all the same general questions to solicit their individual experiences about cancer treatment and communication with their provider. Interviews were in a comfortable environment conducive to capturing the essence of their experiences while maintaining accuracy, privacy, and confidentiality of the data. The participant had the opportunity to provide feedback to add to richness to the data collected.

Data Management and Analysis

The analysis of all patient data collected through audio-recorded interviews by the researcher, and transcribed into a Microsoft Word document. Once transcribed, the researcher read the interviews while also listening to the recordings. Then the paper copy of the research material documents kept in a secure storage file. All interviews verified for accuracy, patient responses were analyzed using NVivo software for qualitative study data analysis. Specific data themes analyzed to examine Baby Boomer minorities’ cancer treatment experiences.

Transcripts data analyzed from themes that pertained to Baby Boomers minorities’ cancer treatment experiences. The themes that emerge related to the barriers and facilitators of patient-provider communication, health system factors that influence cancer treatment decision making. A stratified analysis by racial ethnic differences of patient-provider communication perceptions and cancer treatment decisions conducted.

Reliability and Validity

Specific steps to ensure reliability and validity in this study in the study. Validity in this qualitative research study determined the trustworthiness of the instrument to design to gather the data collection from participants. The face-to-face interviews were at the Community Participants' conference room or study participant's home. The face-to-face interviews of participants' data recorded for accuracy from the research findings. The data transcribed for reliability, and the transcripts read while simultaneously listening to the audio-recorded interviews. A final copy of the transcript provided to the participants to identify their experiences relative to the study and share feedback, if necessary.

Summary

Information in this chapter includes the research design, and specific methodology of the study. The researcher presented a rationale for each section. Furthermore, data collection, management, and analysis techniques identified. The selection of the participants, where the interviews took place and shared experiences was determined. Finally, this chapter supports the choice to use a qualitative approach to gather information from the study population. Semi structured interviews guided this qualitative study to gather patient experiences of cancer treatment for this research. Chapter 4 the results from the analysis and implications of findings for public health for cancer and aging Baby Boomer minorities are highlighted.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to examine health disparities among aging minorities during cancer treatment about decision making when communicating with their cancer care providers. In this chapter I describe the interview instrument, community partners, study setting, recruitment of participants, and data collection technique and analysis. I conducted in-depth face-to-face interviews with 10 cancer survivors during the months of January and April 2018. Individuals born between 1946 and 1964 were eligible for the study. This chosen study cohort of interest was the aging Baby Boomer population who had experienced cancer. Participants must have been in cancer treatment for at least 2 years.

Research Tool

The data collection tool consisted of an interview guide (see Appendix B) I developed with twelve demographic questions and twelve open-ended questions for individuals who experienced any form of cancer. The first half of the interview guide consisted of basic demographic questions of age, education level, and type of cancer. The remaining section of the interview guide included interview questions that addressed two research questions:

> Research Question 1: Do inadequate time allowed for medical decision-making and lack of active listening and empathy by care providers prove to be barriers to patient-provider communication for minority Baby Boomers?

Research Question 2: What are facilitators for post cancer treatment (e.g., access to quality care and supportive networks) that improve quality of life of Baby Boomer minority cancer survivors? What are the barriers to improved quality of life?

Recruitment of Participants

I recruited two community partners in North Georgia to locate participants to interview for the cancer study. After the IRB application approval, I sent an introduction letter and letter of cooperation (see Appendix A) requesting participation in the study to seven county area multipurpose resource centers in neighborhoods that serve a diversity of aging ethnic minorities explaining the purpose of the study to directly observe cancer treatment decision-making experiences among minorities. I received two signed letters of cooperation from organizations willing to participate in the study. The community organizations that were unwilling to participate in the study declined to provide signed letters. Prior to the interviews at the community organization partners, I contacted the directors of the organizations to set up a time to place a copy of the recruitment flyer seeking eligible study participants willing to talk about cancer care experiences with their care provider.

Setting

This study conducted in two counties of the Atlanta, Georgia area with a diverse population that include older minorities. Cancer is the second leading cause of death in Georgia; 45,000 individuals diagnosed with cancer and 15,500 die annually from this disease according to the Georgia Cancer Data Report (McNamara, Bayakly, & Ward, 2016). Some cancer deaths in Georgia are preventable by detecting cancer early when treatment is most effective. Racial disparities in breast, cervical, prostate, colorectal, lung, and kidney cancers are apparent, with African American women and men in Georgia having higher age-adjusted incidence and mortality rates than Whites (McNamara et al., 2016).

Community Partner Organizations

For this study, Community Partner Organization A and Community Partner Organization B both agreed to be included in the study. Both these organizations are multiple-purpose centers that offer services for communities, specifically seniors over 55 years of age. They also provide information, referrals, and professionals to facilitate better quality of life for senior citizens in these counties. Community Partner Organization A is a multi-purpose senior center that offers programs for active seniors that promote mental, physical, and emotional well-being. Community Partner Organization B is a multiple-service organization servicing community members with such services as family health education including offering a cancer support group. To be eligible for the cancer study, prospective participants needed to: (a) be male or female; (b) born between 1946 and 1964; (c) speak English and identify as Asian American, African American, Native American, or Hispanic/Latino; and (d) diagnosed with any form or stage of cancer and have made cancer treatment decisions within the last 2 years.

Data Collection

I received approval from Walden University IRB (approval number 10-11-17-0147607) prior to visiting the respective community partner organizations to collect data. I contacted the directors of the community partner organizations to schedule a time to visit to speak with them about my specific research agenda and address any questions or concerns they may have. Both Community Partner Organization A and B directors agreed the best time to visit and post recruitment flyers were during the busiest hours when many participants would gather for activities. I placed recruitment flyers where most prospective participants gathered with the goal of meeting those who met the criteria and where ready to participate.

To facilitate the recruitment of potential participants, an information-sharing seminar with other volunteer service organizations such as AARP (American Association of Retired People) and VISTA (Volunteers in Service to America) during lunch hour was a good opportunity to meet members of Community Partner Organization A and share information about the cancer study. I also spoke with the cancer support group of Community Partner Organization B to share information about the importance of cancer screening and that as a person ages they are most at risk for developing many types of cancers. I was able to schedule interviews with prospective study participants to set a time convenient for them for interviews. During the initial visit, I explained the purpose of the study with each participant, reviewed the informed consent document with them, and addressed any questions they had about their participation in the study.

Sample Selection of Participants

For this qualitative study, I used purposeful sampling techniques to identify the cancer study participants. The eligible participants included men and women from the Baby Boom cohort, defined as those individuals born between 1946 and 1964. After each interview, study participants were given a $25 gift card for their time and participation. Additionally, I advised participants that their names or other identifying information kept confidential. Participants understood that a pseudonym would identify their research participation in the study to maintain confidentiality. The participants who agreed to move further in the study process (*N* = 10) read, understood, and the signed consent forms. The study participants retained a copy of the consent form.

I conducted interviews during weekdays when participants visited Community Partner Organizations A and B. The interviews were face-to-face, in-depth, and open-ended. An interview guide provided the data for consistency among study participants (see Appendix B). The required sample size to understand the personal experiences of aging minorities regarding cancer treatment decision making when communicating with their care providers was 10 participants. All interviews were audio recorded with permission of the participant. The interviews lasted 45 minutes to 1 hour. During each interview, I would probe and asked additional questions to gather rich data from the participants while capturing the participants' reactions during the reflective writing.

Demographics

The interview guide included twelve demographic questions. The sample included a total of 10 men and women. The age range of participants was 55-72 years of age with a mean age of 64.3 years. There were seven females and three males. The participants were African Americans (*n* = 7), Hispanics (*n* = 2), and Asian (*n* = 1). Some of the study participants reported to be married (*n* = 4). Only three participants were still working full-time jobs and seven were retired. The level of education of the study participants ranged from high school graduates (*n* = 3) to graduate degrees (*n* = 4). The participants reported an annual income range of under $25,000 to over $100,000. The health insurance status of participants varied, with Tricare/VA (*n* = 1), Medicare (*n* = 4), Medicaid (n = 2), private employer insurance (*n* = 4) with one individual reporting having dual coverage. One individual also reported not having insurance during the interview after a lapse in Medicaid coverage. Table 3 highlights the demographic information collected during the in-depth interviews.

Data Analysis

For this study, I used the qualitative software NVivo 11 for Windows designed by QSR International. I reviewed all the transcriptions several times to identify common themes in relation to my two research questions. I used subcategories to describe the participants’ verbal responses to the cancer treatment experience. As proposed with the van Kaam method (Moustakas, 1994), I used the full descriptive analysis regarding the lived experiences to generate the main themes. The NVivo 11 for Windows software allows the researcher to code, sort, and analyze data summaries from each transcript. The NVivo software offers useful tools to prepare the analysis, work with the interviews, and find emerging themes for the study.

I saved the audio recordings and transcripts and uploaded them to NVivo 11 software for qualitative research to maintain data management and storage. According to Woods, Paulus, Atkins, & Macklin (2016), qualitative data analysis software such as NVivo is capable of allowing the researcher to synthesize multiple processes ensuring adequate data management and analysis techniques are in place to complete the research project. The NVivo software assisted in reducing manual processing time and allowed me and to center efforts at improving the quality of the study (see Welsh, 2002).

Table 3

Demographic Characteristics of Cancer Survivors

Participant Characteristics	Frequency
Age (Born 1946-1964)	
50-59	
60-69	2
70-72	4
	4
Gender	
Male	
Female	3
	7
Race	
African American	7
Hispanic	2
Asian	1
Family Income	
Below $25,000	3
$25,000-$35,000	1
$35,000-$50,000	3
$50,000-$75,000	1
Above $75,000	2
Marital Status	
Married	4
Divorced	2
Single	2
Widowed	2
Educational level	
Less than high school	
High school/GED	3
Some college	3
College graduate	4
Health Insurance Status	
Tricare/CHAMPVA	1*
Indian Health Service	
Medicare	4
Medicaid	2
Private / Employer	4
Self-Pay	
No Insurance	

*Dual health coverage

Participants reported seven different cancer types: breast cancer (*n* = 7), colorectal (*n* = 1), prostate (*n* = 1), lung (*n* = 1), and kidney (*n* = 2) cancer. Two participants reported a dual cancer diagnosis and shared a painful discussion about having concurrent cancer treatments. All 10 women and men reported less than 6 months to commence their cancer treatment decision. All participants received conventional cancer treatment including surgery, chemotherapy, and or radiation; only one participant received hormone therapy as an alternative treatment. The cancer characteristics of study participants are identified in Table 4.

Table 4

Cancer Participant Summary

Characteristics	Frequency
Cancer Type	
Breast	7
Prostate	1
Colon/rectal	1
Cervical/Ovarian	
Leukemia	
Lung	1
Kidney	2*
Time making Cancer Treatment Decision	
<6 months	10
>6 months	
Cancer Treatment Decisions	
Conventional Treatment	10
Surgery	
Chemotherapy	
Radiation	
Adjuvant/Alternative Treatment	1
Hormone therapy	
Immune therapy	
Targeted therapy	

* Two study participants had dual cancers

Table 5 provides a summary of cancer characteristics for each participant. The participant's names were changed to protect their confidentiality. The table describes their cancer type, stage of cancer at diagnosis, specific cancer treatment, and length of time with the cancer provider.

Table 5

Cancer Participant Summary

Participant*	Cancer Type	Stage of Cancer At Diagnosis	Cancer Treatment	Time with Cancer Provider
1 Helen	Breast	Stage II	Surgery, Chemotherapy, Radiation	3-4 years
2 Amy	Breast	Stage III	Surgery	5 years
3 Kim	Breast	Stage IV	Surgery, Chemotherapy	2 years
4 Beverly**	Breast/Kidney	Stage III	Surgery; Mastectomy, Chemotherapy	5 years
5 Jawanda	Breast	Stage III	Surgery, Chemotherapy	3 years
6 John**	Prostate/Kidney	Stage IV	Surgery, Radiation, Hormone	5 years
7 Mateo	Lung	Stage I	Surgery	2 years
8 Sofia	Breast	Stage III	Surgery, Radiation	2 years
9 Faye	Breast	Stage IV	Surgery, Radiation	2 years
10 Cho	Colorectal	Stage IV	Surgery, Radiation	3 years

*Actual names changed to protect participant confidentiality.
**Dual cancers

Themes

The data analysis from the in-depth interviews revealed nine major themes that emerged: (a) Cancer diagnosis, (b) Understanding and response, (c) Provider information giving, (d) Engaged patients, (e) Influence of social networks, (f) Cancer knowledge, (g) Financial burden, (h) Spirituality, and (i) Quality of cancer care. These themes highlighted the complex nature of patient-provider communication when discussing treatment decision making for older minority Baby Boomers.

Research Questions

The two research questions answered by the data collected from interviews and listed in this section. All participants were asked thinking back when they were diagnosed with cancer and communication they received from the doctor regarding cancer treatment decision making.

Research Question 1

To identify what participants perceived as cancer treatment decision making, the first research question asked if inadequate time allowed for medical decision-making and lack of active listening and empathy by care providers proved to be barriers to patient-provider communication for minority Baby Boomers. From the first research question, four themes emerged.

Theme 1

Cancer diagnosis. This theme highlighted the importance of participants are being screened for cancer during a routine or annual examination is significant to detect the disease in early stages. Study participants shared how they first learned of their cancer diagnosis:

> *Helen*: I went for my annual mammogram check-up. I have had annual mammograms for the past 30 years. I was called back for another test because there was a spot on the breast x-ray. A biopsy was done and confirmed I had the breast cancer. I was so shocked!
>
> *Amy:* I had a routine mammogram. The doctor took tissue from breast, did the biopsy, and said it was malignant breast cancer. I was scared and shocked I would get the cancer. That was my third time having mammograms since my late forties.
>
> *Kim:* My husband felt the lump under my breast. It was painful. I was also in an auto accident and the ER doctors saw the spot in my chest area. Further testing from the mammogram, MRI, ultrasound, a biopsy, a PET scan, confirmed breast cancer.
>
> *Beverly:* I did a breast self-examination and felt a large lump in my left breast. The doctors say it was breast cancer Stage III. I had one breast removed with the chemotherapy. A year later, found out I had the cancer in my kidney.
>
> *Jawanda:* I felt a lump in my breast self-exam and then I went to the doctor. I got the mammogram. I had a lump in both breast. One side was much larger than the other was. It was surgery on one breast.
>
> *John:* I actually had cancer three times. The first was kidney cancer disease. I had prostate cancer twice. I first found out about the cancer when I went to the doctor for stomach problems. My doctor noticed the treatment was not going very well

> from the diarrhea. So, doctor checked for MRI, found spot in one of the kidneys. Dr. said, it was kidney cancer and treated 3-5 years. The cancer came back and I went in for treatment for the prostate. The third time or this most recent cancer was the follow up the prostate exam where the PSA check had extremely elevated.
>
> *Sofia:* I moved from another country a couple years ago. After my husband got insurance I went to the doctor because my nipple was turning pinkish. Doctor did the mammogram, a biopsy, MRI and confirmed me positive for the breast cancer.
>
> *Faye:* I found out during my annual mammogram. I had large breast with cystic fibrosis. All testing confirmed breast cancer Stage IV.

Theme 2

Understanding and response. In this theme, **s**tudy participants revealed their perception of comfort level in understanding the provider communication and making decisions about cancer treatment:

> *Helen:* I did not understand at first. The doctor said I have Stage II breast cancer. The primary doctor gave me a list of cancer doctors to choose. I researched and found a particular female doctor where she explained to me the mastectomy vs the lumpectomy procedures. I felt comfortable with her and chose to have the lumpectomy procedure. The doctor did not rush me into making the decision.
>
> *Amy:* To me the cancer surgery doctor did not discuss very much. I did not understand everything in a way that made sense to me. He said we could do a

lumpectomy with chemo and radiation and remove my left breast. Later, I chose to have the breast completely removed.

Kim: The cancer doctor did not discuss much and did not give me many options other than surgery with aggressive chemotherapy. I was somewhat able to understand and feel comfortable with the cancer treatment decision.

Sofia: The doctor did not discuss. In addition, I did not know what to ask the cancer doctor. I just trusted everything the doctor said. He was Hispanic and spoke Spanish like me. It was easy for me to communicate with him easy to trust and to communicate. He never told me we have this option or that. I told him to do what we need.

John: After three cancers, I learned after each cancer – doctor say I have cancer. Then what is the best treatment option? I will locate the best doctors. The doctors were competent.

Mateo: No. Well, the doctor just explained I need surgery in a hurry.

Jawanda: No. The doctor communicate he was 99/100% sure that everything is ok. I did not feel comfortable.

Faye: A biopsy confirmed the diagnosis to determine the cancer. As a nurse, I understood procedures. However, after discussion, the doctor gave me an option of lumpectomy vs. mastectomy. I chose to undergo the lumpectomy.

Participants responded to a follow-up questions regarding how long they waited before making the cancer treatment decision. Participants verbalized their specific values and time preferences to moved forward with the cancer treatment recommendation after communicating with the doctor after the cancer diagnosis:

> *Helen:* I waited to after my two-week vacation and returned for breast cancer surgery. The doctor encouraged me not to put off longer having the procedure. I was ready to move on have it done.
>
> *Beverly:* Immediately.
>
> *John:* The decision was quick without hesitation.
>
> Amy: I waited a couple weeks and decided to have the breast removed. I wanted the cancer out of my body.
>
> *Sofia:* When doctor decided surgery and treatment I need, it was a month later before I decided. I told doctor I just wanted to have Thanksgiving with my family. The doctor described removing left my breast.
>
> *Faye:* It was an immediate decision at the time of notification of diagnosis and procedures.
>
> *Kim:* After the cancer doctor recommendation after the diagnosis, I waited a couple of weeks before deciding to have the surgery and aggressive chemotherapy. I had the chemotherapy, then surgery. However, the doctor found more cancer.

Theme 3

Provider information giving. This theme includes perceptions of participants made to whether the doctor encouraged them to get involved by asking any questions about their cancer treatment option. Each participant expressed his or her perception of the cancer doctor:

> *Amy:* The doctor was not very encouraging to me. He told me we could do lumpectomy or mastectomy, A or B – that is it! The treatment decision based on the information given to me at the time.
>
> *John:* All doctors encouraged my participation. I was confident with the surgical doctor for the entire procedure.
>
> *Jawanda:* Yeah! All doctors on my cancer care team communicated with me individually and discussed everything and I had many questions to ask them.
>
> *Kim:* Not really. This doctor gave me some websites and other organizations to look on the computer about cancer, what I should expect. I was told; learn about it on my own time. He referred a monthly breast cancer support group. I did not participate.
>
> *Sofia:* Doctor no talk too much to ask me questions. It was so overwhelming. I did not know what to ask. He just say if I remove the breast and have the reconstruction. So another breast cancer survivor say no to breast reconstruction. I wanted to save my nipple. Doctor let me take control. I did not get another second opinion.
>
> *Faye:* Yes. The doctor was very good, said bring someone with me, and write down all my questions before coming to next visit. As a nurse, I did not always do that, but glad the female doctor was very knowledgeable. I had the best

> information about breast cancer. In addition, the woman at the American Cancer Society provide me some useful information.

Theme 4

Engaged patients. This theme relates to if the doctor encouraged aging minority Baby Boomers to voice their opinion (agreed or disagreed) with the cancer decision test or specific treatment recommendation(s). Participants expressed their experiences during the shared decision-making process:

> *Faye:* After speaking with doctor, the decision was simple. She explained to me the difference between the lumpectomy and mastectomy. She said we'd take the lump out or take the breast off. I said I did not see a need to remove my breast. I saw picture of cancer and bottom line the choice was mine. The doctor did not persuade me.
>
> *Sofia:* No. I did not question doctor recommendation.
>
> *Amy:* No. I thought having the cancer mean I was going to die. The doctor say no previous history in my family of breast cancer.
>
> *Beverly:* No.
>
> *Kim:* No. This doctor did not explain much. I was alone. He was not a good doctor and I could not understand him much from his accent. He said I should read website information.
>
> *Jawanda:* Nope the doctor did not encourage me to speak, but something did not feel right in my spirit that the mammogram was good. I got a second opinion. Then a second doctor confirmed through biopsy that I have breast cancer.

Research Question 2

Research question two explored facilitators for post cancer treatment, such as access to achieving quality cancer care and supportive networks that improve quality of life for Baby Boomer minority cancer survivors as well as barriers to such quality of life. Five themes emerged from in-depth interviews from the second research question.

Theme 5

Influence of Social Networks. This theme includes influence of family or significant persons on their cancer treatment decision. Study participants voiced the significance of having strong support systems:

> *Helen:* Strong support from sisters and children shared in the treatment decision and the surgery. It was important to deal with it and move on with or without family involvement. There was no need to put the surgery off any longer.
>
> *Jawanda:* My siblings and children were a strong support system.
>
> John: My beautiful wife was on significant in treating all my cancers. A good of friends and colleagues as well.
>
> *Sofia:* Yes. Although husband not very talkative. Family member encourage me to make my own decision. They did not try to talk me out of doing the breast reconstruction.
>
> *Amy:* No one encouraged me. I pretty much kept it quite to myself. I did share the breast cancer with my children.

> *Faye:* No other family members or friends influenced my decision of breast surgery or cancer treatment decision. I think family members should be supportive of the cancer treatment decision.

Participants also responded to a follow up question if a family member or significant person communicate with their doctor about their cancer treatment option:

> *Helen:* Daughter was there every step of the way, communicated with doctor, and shared information about my treatment to other family members. My daughter was there to ask questions and make notes for other family members.
>
> *Kim:* My husband was supportive and spoke with doctor in a way he could understand. My mother also spoke with doctors and they were supportive.
>
> *Amy:* My daughter spoke to doctor on my behalf and getting as much information to explain to me. It helped me understand the procedures of making the cancer decision.
>
> *Sofia:* My daughter talk to cancer doctor but she was in another state. The doctor was very quiet. Sometimes, I wish I asked more things. I just did not know what to expect. Someone gave book to read about breast cancer but I was afraid to read about the breast cancer. It is like, you want to know, but then you do not want to know.
>
> *Faye:* I was alone in the decision-making process. No children or other family members.

Theme 6

Cancer knowledge. This theme highlighted the participants' perception of the incidence of cancer and risk factors for aging.

> *Kim:* No. I was shocked and felt I was much too young to have cancer. I know that I should receive cancer treatment or I die. I went with the doctors' recommendation.
>
> *Mateo:* No. I was 65 when the cancer came.
>
> *Amy:* No. I was over 50 years old with a teenage son. I want live as long as I could. I never thought I would get cancer - maybe something else!
>
> *Beverly:* Nope. I had an emergency the cancer came so late.
>
> *Helen:* No. I did not think I would get the cancer at this age. However, the doctor said older women do better with chemo treatments than the younger women do. I have been relatively healthy and amazed I lived this long without having any type of surgery.
>
> *John:* Not really. My first type cancer I was 51 and with cancer again I am 62.
>
> *Sofia:* No. I did not think that at my 68 age I wanted to go through the breast cancer. If I were younger, I would not do it. It was too painful! It was hard. The women in the cancer support group had the breast reconstruction. Some were happy, but I learned every woman is different.
>
> *Faye:* No. I was 62 at the time of the breast surgery.

Theme 7

Financial burden. This theme included the study participants financial resources affected their cancer treatment decision making such as their health insurance status, incurred any out of pocket costs as a barrier to pay for their cancer treatment and follow up care. Participants echoed concerns over cancer cost:

> *Amy:* I had health insurance, but it was not enough. It was not a good plan. I had a health savings. I had to pay for my mammogram from the health savings. The other x-rays were included in balance on hospital and doctor bill and making payment arrangements or $3000.00 or more for the out of pocket costs. I paid co-pays for the follow up treatment visits.
>
> *Beverly:* I had little insurance and I was eligible for Medicaid treatment that covered the surgery so had $0 to pay out of pocket.
>
> *Helen:* I had Medicare and a Medicare Supplement insurance plan with high deductible option. My only payment has been for prescription drug co-pays. I did look at the bills for the procedures and saw the statements were over $5,000 per visit. It is expensive! I have had no other co-pays on x-rays, or chemo-treatment. I am blessed!
>
> *John:* I pay for two insurances Medicare and Tri-Care. It easy to pay for two insurance than have out of pocket treatment cost. Medicare is the primary insurance and Tricare is secondary. I was in an HMO with the first cancer. I had to choose the available doctors within the HMO pool so I could get the greatest and latest treatment. The first cancer I was thousands of dollars in debt in cost

sharing. The second cancer with Tri-care only with my total out of pocket was about $500. The third cancer and treatment, Medicare and Tri-Care both paid for the radiation treatment. Between these I am current out of pocket cost is $15 per treatment co-pay and transportation to the treatment center.

Kim: My financial situation was important. I had no insurance. I received a positive diagnosis with breast cancer at health clinic that does free mammograms for women from the state. Medicaid funds paid for my breast cancer treatment. I paid no other out of pocket cost.

Sofia: My husband had health insurance at the time of surgery, but we pay a lot out of pocket. In the beginning, there were so many tests for me. It was very expensive. Each time I visit the doctor, I would have to pay $250-300 dollars to prepay – cash or charge! I had lot of bills after the surgery, almost $2000 my husband put on the credit card and we tried to pay off the hospital as quick as possible.

Faye: I had the insurance plan. I paid the 20% co-pay of the charges they sent me bills and I paid them. Later on, I had forgotten I had purchased a cancer supplement policy and it that paid me directly. I still have the cancer supplement plan just in case of a recurring cancer.

Theme 8

Spirituality. This theme included faith, beliefs in a higher power. Participants expressed their beliefs to ease hem through the cancer treatment process:

Amy: I prayed about the cancer. Through prayer and meditation.

Kim: Yes. I am a woman of God. I prayed for healing and asked why this happened to me. It is not cancer that kills; its treatment procedures that reduce the risk of dying.

Helen: Through my strong faith, I have not suffered, amazing treatment process, and great doctors. I have faith in God and a good attitude helps! I had no reason to be sad about the cancer. God takes care of me.

Jawanda: Yes, just simple prayer.

John: Having faith, a strong supportive family. If you do not have a strong support group its difficult with not one or three cancers. Co-workers put me on a prayer list that went around the world. The prostate survivors group and great doctors.

Sofia: Prayer was the only thing that kept me strong. I used to cry a lot. I no cry much now. I keep talking about it. It gets better after two years. The radiation make me so tired. The people at senior connections and Latin community support group were great. I do things now that bring me peace.

Faye: I just prayed for healing through the entire procedure.

Cho: I give thanks to Allah.

Theme 9

Quality of cancer care.

This theme reflects on what the medical or cancer team and to improve quality of cancer. Participants identified their perception of quality of care in communication with providers and follow-up cancer care treatment:

Amy: I think my quality of cancer treatment was poor. I was supposed to have a person from American Cancer Society to visit for support group and counseling but they never followed up with me about where to get the prosthesis bra.

John: My cancer care team was great supportive group. I felt the cancer team on the last two cancers were competent. I am better informed about cancer.

Helen: My quality of cancer care was excellent. The cancer surgical staff and radiation clinic was on point. They told me to call any time.

Kim: The cancer doctor was bad. I have had good doctors and bad doctors. The most important thing communication is good to discuss with a patient face to face and not give them a website you do not understand. I wish I had spoken with another cancer doctor to understand the process better. I did not have enough insurance in the beginning.

Mateo: Excellent care team communicate all phases to understand.

Sofia: I think I had great cancer care from the doctors and oncologist, and cancer team. It was good having the doctor speak Spanish and from my same country to make the journey easy for me.

Faye: I think I got the best cancer treatment. It was good to have the primary care and oncologist doctors who really cared for me personally. Working as a nurse, I knew which doctors and hospital were the best to choose from around here.

As a follow up question, study participants shared additional information regarding their cancer care treatment experiences:

John: Wish I knew more about the insurance process in the beginning.

Cho: I never got the cancer screening years ago and now it is seem too late for me.

Helen: My experience with diagnosis to the chemo treatments was good. I was on a new cancer treatment but my body rejected the initial treatment. I reduce the stress and worry. I am going on year 3 surviving the cancer.

Jawanda: Some people do not like to talk about their cancer, but they should stay active if they can.

Kim: The doctor gave me information to make the treatment decision. It was all up to me. I am thankful to have endured this process. I am feeling better and increasing my weight and my hair growing back. Looking at minorities for cancer is important.

Sofia: I feel fortunate that the doctors found the cancer early enough when I came from my country time enough for cancer diagnosis to treat me. I was crying to doctors and they say not to cry because I am still alive. I am much better and happy now. It is a new day for me.

Faye: I thought my cancer experience was a spiritual journey despite the chemo and radiation. It just made me a better person to help someone else on the journey.

Mateo: Nothing else to say.

Quality of Study

In an effort for this study to be credible in areas of cancer health disparities among aging minorities is dependent upon quality of data and research findings. The goal of this phenomenological study focuses on lived experiences of cancer patients through a myriad challenges present in a healthcare system is critical to understanding timely and accurate communications to have better inform decision making for effective cancer treatment. To ensure the study meets the essential criteria of trustworthiness in this qualitative research study was credible, confirmable, and dependable to gather the data collection from participants (Guba and Lincoln, 2007).

1. Credibility – confidence in truth of findings using data triangulation using multiple data sources to increase and understanding of the study. The study participants were recruited from more than one community partner to share their various perspectives.
2. Confirmability – ensure the transcripts from participants were verbatim of each respective interview. In addition, notes were taken during the interview process to gather richness of data collection.
3. Dependability – this process was done while simultaneously listening to the audio-recorded interviews provided by the participants to identify their experiences relative to the study for feedback to review.

Summary

The purpose of the study was to understand the personal experiences of aging minorities during cancer treatment decision making when communicating with their cancer care providers in an urban area of North Georgia. Chapter 4 describes processes of collecting and analyzing data from the minority cancer survivors regarding their perceptions of patient and provider communication during the cancer treatment decision making. Purposeful sampling was done to study this phenomenon. Participant responses from in-depth interviews ask specific questions from the interview guide.

The first research question explored the participants' experience with cancer treatment decision making and patient-provider communication. The majority of the participants seemed satisfied with the patient-provider communication and access to cancer care treatment they received. However, a couple of participants felt provider communication was inadequate about their cancer treatment. The second research question looked at the importance of spiritual and social networks and barriers to access to quality cancer care. Many participants felt they received good quality of cancer care. Family, friends, and faith was significant to the participants. Chapter 5 will further address the interpretation of the cancer study findings, limitations of the study, and conclusions, social change implications, and researcher's recommendations to increase quality cancer care for surviving aging minority populations.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to examine the personal experiences of aging minorities during cancer treatment decision making when communicating with their cancer care providers. Multiple studies identified the significance of quality patient and provider communication between older individuals with cancer and their care provider. The literature is limited on studies that focus on specific experiences with cancer decision making and communication with providers for this population.

I conducted a phenomenological research approach with in-depth face-to-face interviews among 10 individuals about their cancer experiences when communicating with their cancer care providers. Phenomenological research focuses on the participants' worldview of experiences to understand a phenomenon under investigation (Creswell, 1994). The investigator relies on the richness of descriptive in-depth interviews to understand their experiences, and then analyzes the data to generate common themes from the phenomenon.

I identified the cancer treatment decision-making experiences of 10 individuals born between 1945 and 1964. In this chapter, I discuss an interpretation of the findings based on the research questions and themes related to cancer treatment decision-making as identified from participant data. I also provide the conceptual framework, limitations of the study, recommendations for future research, social change implications, and summary.

Interpretation of the Findings

Study participants shared brief personal demographic information including age, gender, race, income; marital status, educational level, and health insurance status (see Table 3 in Chapter 4). Participants included a total of 10 women and men who were at least 2 years post diagnosis. The majority of the participants were retired. The average participant was 64.3 years of age. The number of cancer survivors age 65 and older is projected to rise in part due to aging population trends, changing demographics, and improvements in cancer care (Bluethmann, Mariotto, & Rowland, 2016; White, Hayes, & Richardson, 2015).

Most participants reported having surgery and chemotherapy as primary treatments for their specific cancer type (see Table 6, Chapter 4). Many participants reported late stage of their cancers at diagnosis. Although this study did access late stage cancers, the current research indicates some late stages of cancer are highly associated with an increased risk of cancer death (Richardson, Tai, Rim, Joseph, Plescia, 2011; Henley et al., 2010). In addition, late stage cancers may be associated with fear, distress, and limited understanding of cancer treatment options (Schubart, Farnan, & Kass (2015). Screening cancer among specific demographic groups warrants early diagnosis of cancers (Wu, et al., 2015). Mobley and Kuo (2017) found that race or ethnicity for breast and colorectal cancer among African Americans, Hispanics, and Asians are more likely to receive late stage at diagnosis than Whites in most states are.

Cancer survivors comprise multiple racial ethnic backgrounds with various cancer types and other comorbidities (Bluethmann et al., 2016). In the United States, breast cancer is the most common cancer in women and CRC is the most common cancer in men (ACS, 2015, 2016). Despite progress in cancer care, disadvantaged populations are impacted by cancer health disparities, particularly racial and ethnic minorities, and the poor are disproportionately burdened by cancer (Smith & Hall, 2015; Zonderman et al., 2014). Multiple studies indicate African Americans have the highest incidence of and death rates from cancer compared to other racial and ethnic minorities (NCI, 2018; ACS, 2014; Maly, Umezawa, Ratliff, & Leak, 2011). According to Hummer & Gutin (2018), understanding the context of racial and ethnic health disparities, institutional and individual racism, lack of access to health care, and poor access to quality education and employment is necessary to interpret prevalence and mortality of all cancers among racial and ethnic minorities.

Research Question 1

> RQ1: Do inadequate time allowed for medical decision-making and lack of active listening and empathy by care providers prove to be barriers to patient-provider communication for minority Baby Boomers?

The interview questions revealed that interpersonal relationships could affect the outcome of quality of patient provider communication and influence cancer treatment decision making among Baby Boomers. Having good social support structures with a family member or friend as a facilitator is valuable for good cancer treatment decision making. The barriers to good decision-making identified in this current study were patient-provider miscommunication, needing more time with the doctor, and mistrust of the medical profession. This finding is consistent with Mead et al (2013) that patients want more communication that is informative to guide their decisions for cancer treatment after the cancer diagnosis.

Theme 1: Cancer diagnosis. The study participants conveyed being overwhelmed with receiving the cancer diagnosis news after communicating with their providers during a follow up visit. The need for education of cancer prevention is critical for the older minority populations. All participants found out they were diagnosed with cancer during a follow-up examination the doctors' recommendation of other diagnostic testing to confirm the cancer diagnosis. One participant reported been diagnosed for cancer three times. Although this study does not assess screening adherence, this is a critical finding that is consistent with the current literature that having a medical provider's recommendation is a strong indicator of patients completing and getting screened for cancer for breast, cervical, prostate, and colorectal to find cancers early when they may be treatable or curable (CDC, 2018).

Theme 2: Understanding and response. This theme identified barriers to empathy, time listening, understanding, and response of participants when facing a complex decision. The study participants (*n= 7*) perceived poor interpersonal communication as a lack of understanding cancer treatment decision making when discussing cancer treatment options with their providers, along with other unmet information needs. Communication of empathy, caring, respect, and imparting sensitivity to the patient's health literacy is important for patients' ability to understand health information for adequate treatment decision making for cancer (CDC, 2016). Good cancer communication helps patients understand to the best of their ability (Ko et al., 2016; Manfredi, Kaiser, Matthes, & Johnson; 2010). For example, participants did not understand chemotherapy versus radiation therapy or other effective treatment options for their type of cancer. This finding is consistent with the finding that shared communication, patient-centered care, and patient-provider communication is essential for all individuals with cancer and helps patients to receive bad news, deal with the emotional impact of cancer, understand complex information, and handle dealing with multiple health professionals (CDC, 2016; Song, Hamilton., & Moore, 2012; Epstein & Street, 2011). Limited health literacy contributes to health disparities and is a critical barrier to quality cancer communication and completion of doctors' recommendations for routine screenings and treatment (NCI, 2018).

Theme 3: Provider information giving. In the current study, three out 10 participants indicated the providers did not encourage them to ask important questions about their treatment options. One participant, a nurse, was satisfied with her doctor's suggestion to write down all her questions about the breast cancer surgery before the next appointment. According to Song et al. (2012), patients not knowing specific questions to ask the provider are limited in cancer treatment discussions, which translates into lack of communication. Sofia said,

> The doctor did not discuss much. In addition, I did not know what to ask the cancer doctor. I just trusted everything the doctor said. He was Hispanic and speaks Spanish like me. It was easy for me to communicate with him, easy to trust and to communicate. He never told me we have this option or that. I told him to do what needed to be done."

This finding is consistent with research by Heiney, Messias, Felder, Phelps, & Quinn (2017) that concluded women trusted their providers' recommendation "just do it" and noted that trust may enhance adherence to breast cancer treatment. In contrast, findings from Ching-Li, Matthews, Dossaji, & Fullam (2017) examined patient-provider communication variables and concluded the majority of participants reported satisfaction with provider communication, were comfortable asking questions about their cancer diagnosis and treatment and with physicians discussing cancer diagnosis and treatment options with them.

Theme 4: Engaged patients. All study participants were unaware they had a voice in deciding their cancer care. The majority of the participants (*n* = 9) did not seek another surgical opinion to validate the initial recommendation but followed the doctors' recommendations. For example, one participant, stated, "The doctor communicate he was 99/100% sure that everything is ok with me. I didn't feel comfortable about the mammogram being good so I got a second opinion." The second doctor confirmed through biopsy that cancer was present. This finding is consistent with patients talking openly regarding their concerns and fears with cancer treatment options (Epstein & Street, 2011). The lack of communication leads to medical mistrust in the health institutions, dishonesty about the diagnosis and treatment recommendation, and discrimination, which results in underutilization of health services (Song et al., 2012; LaVeist & Williams, 2009).

Research Question 2

What are facilitators for post-cancer treatment (e.g., access to quality care and supportive networks) that improve quality of life of Baby Boomer minority cancer survivors? What are the barriers to improved quality of life?

Theme 5: Influence of social networks. All study participants indicated the strongest influence on their treatment decisions and follow up care was the loving support of family, friends, and higher power other than themselves. Family, friends, and or spiritual networks are essential for helping patients cope with cancer and promote healing during cancer treatment. This is consistent with findings from several studies that found social networks are effective to meet needs associated with improved survival of cancer (Yoo et al., 2010; Goodwin, 2007; Kroenke et al., 2006). Yoo et al. (2010) examined 47 older African American, Asian, Caucasian, and Latino women from various ethnically diverse populations and concluded women with strong informal support from family and friends are more likely to have higher quality interactions with medical professionals. Supportive networks also include collaboration of community partnerships to address cancer disparities among racial ethnic minorities to increase health outcomes (Molina, McKell, & Mendoza, 2016; Ramandhan et al., 2012).

Theme 6: Cancer knowledge. Participant perception was limited about cancer knowledge, risk factors, and increases of cancer, as a person gets older. This finding highlights the need for communicating cancer prevention, screening, detection, and treatment information critical for aging and racial ethnicities. In the United States, about

350,000 individuals diagnosed with breast, cervical, or colorectal cancer, and nearly 100,000 die yearly from these diseases (CDC, 2012).

Theme 7: Financial burden. Accessing high quality cancer care depends on ensuring aging minority Baby Boomers receive timely access to cancer treatment. The study identified barriers such as health care systems factors, transportation, provider communication, cultural, or out-of-pocket cost may impacts access to cancer care. Participants (n=2) reported a health systems barriers with long wait-times at public or teaching health systems for follow up cancer care. All participants reported having health insurance coverage to access their cancer care treatment. The health insurance status reported by participants varied, with Tricare/Veterans Administration (n=1), Medicare (n=4), Medicaid (n=2), private employer insurance (n=4). Two participants had medical insurance but reported being under-insured for cancer treatment. These participants were still able to receive cancer treatment services through other public or community services with no out of pocket cost. Another participant had dual insurance coverage. Multiple studies indicate that having access to health insurance is the most important indicator in determining receipt of timely access to cancer treatment (Walker et al., 2014; Halpern, 2008).

For the current study, out of pocket, participants when facing cost of treatment for co-insurance, high deductibles and premiums, and medication incurred cost. This is consistent with the current study on two insured participants several months paying for out of pocket cost to cover coinsurance, deductibles, and prescription drugs. Amy describes her out pocket experience: “I had to make payment arrangements or $3000.00

or more for the out of pocket costs. I paid co-pays for the follow up treatment visits." Three participants in the current study, over aged 65 insured under Medicare, indicated additional supplement plan coverage to helped pay for Medicare deductibles and coinsurance amounts reported substantially less out of pocket cost for cancer treatment. For example, Helen said, "I had Medicare and a Medicare Supplement insurance plan with the high deductible option. My only out-of-pocket payment has been prescription drug co-pays. I have not had other co-pays on x-rays, or chemo-treatment. I'm blessed!"

The impact of financial difficulties on patients with cancer are becoming well recognized with financial distress can associated with physical, social, and emotional functioning reported (Delgado-Guay et al., 2015). Findings from a research study on the impact of health care costs on well-being and treatment among cancer patients, suggest that insured patients undergoing cancer treatment experience substantial financial burden, and that having health insurance coverage does not eliminate financial distress experienced by many cancer patients (Zafar et al., 2013).

Income inequality and unemployment include disparities in access to health care and usually also associated with disproportionately lower cancer survival rates among many aging minorities (Abdelsattar et al., 2016). The Patient Protection and Affordable Care Act (ACA) extends Medicaid coverage to many cancer survivors who were unable to purchase affordable health insurance coverage in the individual Health Insurance Exchange Marketplace (ACA, 2010). The ACA expands access to care, largely through the Medicaid expansion, to individuals with 138% of those incomes near the national poverty levels (Nikpay et al., 2018; Rudowitz, 2014).

The Federal Government supports free or low cost breast and cervical cancer screening services across the United States to women who cannot afford cancer-screening services. This was important for helping Kim access cancer treatment care: “I had no insurance and was diagnosed with breast cancer at health clinic that does free mammograms for women from the state. Medicaid funds paid for my breast cancer treatment. I paid no other out-of-pocket cost.” Women diagnosed with cancer after receipt of breast or cervical cancer services through the National Breast Cervical Cancer Early Detection Program (NBCCEDP*)* are eligible for Medicaid coverage gain access to timely cancer treatment through the Breast and Cervical Cancer Prevention and Treatment Act of 2000, Public Law 106-354 (CDC, 2018). The law also extends coverage to American Indians and Alaska Natives who are eligible for health services provided by the Indian Health Service or by a tribal organization under the passage of the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001 (CDC, 2018).

Cancer costs are enormous. Estimates of the direct medical costs (total of all health care costs) for cancer in the United States in 2015 were $80.2 billion; with 52% for outpatient and physician office visits and 38% for inpatient hospital visits (ACS, 2018). In 2018, about 609,640 Americans expected to die of cancer (ACS, 2016). These deaths include uninsured and ethnic minority groups diagnosed with cancer at a later stage, when treatment is more extensive, costlier, and less successful (ACS, 2018). The implementation of the Affordable Care Act (ACA) helps to alleviate some of the burden of cancer for patients and families. For example, the ACA prevents health insurers from excluding coverage based on preexisting conditions, including cancer (ACA, 2010). Financial problems caused by cancer impact on quality of life (Fenn et al., 2014). It is important to provide people with information on cancer to understand their health coverage, seek financial assistance programs.

Theme 8: Spirituality. For study participants, the relationship between family members, friends have a strong influence on cancer treatment decision making. All participants discussed prayer, faith, family, and giving all blessings to God for bringing them through the cancer experience. This finding is consistent with Sterba, Burris, Heiney, et al. (2014) on religiousness and spirituality are essential to survivorship, and care giving following primary cancer treatment and racial and ethnic minorities more likely to rely on religious and spiritual faith to cope with emotional support.

Theme 9: Quality of Cancer Care. The majority of the study participants reported receiving good access and quality care in communication with provider about cancer treatment decision making. The participants verbalized that the importance of good interpersonal communication with provider as opposed a website or information pamphlet to learn about their cancer. Other participant factors include not knowing more about the insurance process, and getting a cancer screening years earlier when the cancer is detected and most treatable. These findings highlight the need for interventions aimed at insuring that patients and families are educated and empowered during the cancer care continuum. When patients are less empowered, during and after the cancer, treatment process can lead to poor health outcomes and reduce the quality of cancer care, and increase survival rates. (Cancer Support Community, 2016). Despite advances in technology, underserved populations suffer from disparities in cancer treatment outcomes for rural populations, and the elderly. Patient decision making may be influenced by attitudes and beliefs about specific treatments, life circumstances and competing demands, health literacy, and perceptions about the health care system (Frey et al., 2016). When patients are less empowered, during and after the cancer treatment process can lead to poor health outcomes, reduce the quality of cancer care, and increased survival rates. These findings suggest that engaged patients is a central goal for individuals living with cancer during the shared decision-making process.

Conceptual Framework

The SEM was the framework to develop my research agenda, data analysis and summary. The findings from this study focused on timely access to cancer treatment services influenced by the intrapersonal, interpersonal, community, organizational, and public policy.

The organizational level of SEM has a strong influence on patient-provider communication, cultural competency, and health literacy for cancer prevention for racial and ethnic minorities. For example, the organizational level of SEM is where individuals or patients have access to providers for cancer services. First, having a medical home for patients so that providers can communicate a recommendation or reminder for screening, and follow-up for patients’ access to cancer care. Stigma or fear of having received a diagnosis for cancer, financial burden, and or transportation to the treatment facility are access barriers. The organizational level of SEM also influences effective interventions to address cancer health disparities through collaborative approaches for cancer to engage patients, individual providers and health systems, academia, faith based organizations, media, and state health departments at work to reduce burden of cancer and improve the quality of life for cancer survivors. The policy level also addresses improvements in the overall health of cancer survivors *Healthy People 2020* and the Affordable Care Act (ACA) expands insurance reforms and improve access to cancer care with specific measures to eliminate barriers to reduce cancer health disparities among aging minorities.

Limitations of the Study

This study had some important limitations including the small sample size, geographic location, and potential for bias. The study was limited to a sample of 10 participants. The limited sample size may not accurately represent the perception of patient-provider communication among aging minority patients when discussing cancer treatment. The study was limited to an urban area of North Georgia; therefore, the study findings may not reflect the experiences of racial and ethnic minority Baby Boomers outside the study area. Additionally, the study did not account for cancer treatment side effects, biology of cancer, palliative or hospice care communications or other chronic conditions that advance cancer. The study did not collect data from health care providers who are critical to achieving effective communication for aging minorities. The data was reported by study participants, therefore, there is a potential for recall bias. Another limitation is that only two community organization partners agreed to participate in the study that limited the ability to recruit a diverse sample of racial and ethnic minorities. The majority of the study participants were African American, an ethnic group that is often under-represented in clinical studies. Despite these limitations, these participants have conveyed a unique perception of their cancer treatment decision-making experiences. This study may affect future outcomes research needs for aging racial and ethnic minorities.

Recommendations

This study looked at patient-provider communication to reduce cancer among aging racial and ethnic minority populations at high risk for cancer in the United States. The findings of this study contribute to the existing literature of minority Baby Boomers perception of patient and provider communication when making cancer treatment decisions. To reach this aging minority population health care providers should strengthen shared communication and decision-making strategies to improve quality and reduce cancer health disparities.

Another recommendation is increase education among the growing aging populations about access barriers to health insurance to increase their understanding of cancer care and patient cost of cancer treatments. Engaging patients with cancer and their families with communities strengthens support networks and increases the quality of life for cancer survivors. The literature is scant on patient perception of cancer among aging minority populations in community settings. A specific recommendation is for the inclusion of older racial ethnic populations in research interventions to better understand and respond to the needs of this population when communicating with providers about cancer treatment decision-making. For example, some older cancer patients may distrust the healthcare system, or providers who deliver inadequate or inequitable communication during the decision-making process. Having culturally tailored decision-making tools with representatives of older individuals of color may make it more accessible to address communication gaps during the cancer treatment decision-making experience. Materials can be translated into various languages to convey culturally appropriate messaging to make it easier for patients and providers to understand the shared decision making. Finally, the recruitment of older minority participation into aging research studies needs to evaluate effective interventions for specific populations living with cancer.

Implications for Social Change

The findings from this study has the potential to affect social change for underserved men and women aging populations. The findings may contribute to body of knowledge about the lived experiences of racial and ethnic minorities regarding cancer interventions to improve patient-provider communications among aging Baby Boomers. In addition, the study may lead to future research to identify important factors to advance the field of cancer epidemiology. Additionally, the findings have the capability to inform public health approaches that correlate to poor health outcomes for cancer diagnosis and treatment relevance to minority aging and health disparities in the United States. The results of the study suggest a need to bring awareness to community-based organizations serving aging minorities and may reduce access barriers to cancer treatment when faced by cancer survivors.

Summary

In conclusion, based on data analysis from this qualitative, phenomenological study incorporated in-depth interviews with 10 cancer patients currently in treatment. Often when adult patients confronted with a cancer diagnosis, the health care professionals must be accountable to needs of the individuals during the transition from diagnosis to treatment decision making. The findings from this study may add to limited knowledge on cancer treatment decision making in aging racial ethnic minorities can improve cancer disparities and health equity among vulnerable populations.

Research Question 1 explored the participants' experience with cancer treatment decision making with patient-provider communication. It was determined, that communication is essential to trust between the patients and providers to help cancer patient understand complex information, cope with uncertainty and emotional impact of the cancer experience, and make appropriate and timely cancer treatment decisions. Significant findings identified barriers related to the provider's miscommunication, needing more time with the cancer doctor, and mistrust of the medical professor. Poor interpersonal communication as a lack of understanding cancer treatment decision making when discussing cancer treatment options with their providers.

Research Question 2 explored facilitators for post cancer treatment, the importance of spiritual and social networks and barriers accessing quality cancer care. All participants indicated the strongest influence on their cancer treatment decisions and follow up care was the loving support of family, friends, faith in God, and prayer. These are all essential for helping cancer survivors cope with cancer. Additionally, the financial burden for underinsured participants through out of pocket cost to cover coinsurance, deductibles, and prescription drugs for cancer treatment impacts quality of life. Reducing long wait-times at public or teaching health systems is a barrier when navigating follow up cancer care services.

Lastly, Chapter 5 discussed the conceptual framework of the study based on the Social Ecological Model (SEM) focused on multi-level approaches of patient-provider communication from a public health perspective. The recommendations and findings of this study may contribute to the existing literature of minority Baby Boomers perception of patient-provider communication when making cancer treatment decisions. To reach the aging minority population health care providers should strengthen access and improve communication strategies may reduce mortality and morbidity of certain cancers. Additionally, the results of the study may bring awareness to care givers and cancer survivors among area aging organizations servicing racial ethnic minorities.

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Appendix A: Letter of Cooperation

Letter of Cooperation from (Insert Community Health Center Partner)

Community Health Center

Address

Date

Dear Patrice L. Kemp,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Cancer Treatment Decision Making in Aging Minorities within the (Community Health Center). As part of this study, I authorize you to conduct up to 15 semi-structured in-depth interviews with individuals born between 1946 and 1964, diagnosed with a cancer such as breast, cervical, colorectal, prostate or other diagnosed form of cancer. Proper names will not be used and participants will be assigned a pseudonym to protect their identity. Interviews can last up to 1 hour. Individuals' participation will be voluntary and at their own discretion.

To ensure validity, Ms. Kemp may audio record the interview of consent form study participants. A structured interview note taking for consistency with study participants will follow all interviews. If requested, (Community Health Center) will receive an electronic copy of the study.

We understand that our organization's responsibilities include permission to interact with participants for completing this research. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

Authorization Official
Contact Information

Walden University policy on electronic signatures: An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically. The Uniform Electronic Transactions Act regulates electronic signatures. Electronic signatures are only valid when the signer is either (a) the sender of the email, or (b) copied on the email containing the signed document. Legally an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. Walden University staff verify any electronic signatures that do not originate from a password-protected source (i.e., an email address officially on file with Walden).

Appendix B: Interview Guide

Personal Interview Guide

Cancer Treatment Decision Making in Aging Minorities

Code ID #: ___________

Date: ________________ Place/Time of Interview:

____

Participant Sociodemographic

1. **Age:** ____

2. **Gender:**
   Male ____ Female ____

3. **Race/Ethnicity:**
   Asian ___ Black or African American ___ Indian/Alaska Native___
   Hispanic/Latino ___ Hawaiian or Pacific Islander ___White ___ Other __

4. **Marital Status:**
   Single ____ Divorced ____ Married____ Widowed ____

5. **Educational level:**

Less than high school	_____
High school/GED	_____
Some college	_____
College graduate	_____

6. **Income:**

Below - $25,000	_____
$25,000 - $35,000	_____
$35,000 - $50,000	_____
$50,000 - $75,000	_____
Above - $75,000	_____

7. Health insurance status:

Campus/Tricare/VA ______
Indian Health Service ______
Medicare ______
Medicaid ______
Private / Employer ______
Self-Pay ______
Other ______
No insurance ______

8. Type of cancer:

Breast ______
Prostate ______
Colon/rectal ______
Cervical/Ovarian ______
Leukemia ______
Lung ______
Other ______

9. Stage of cancer at diagnosis:

Stage I ______
Stage II ______
Stage III or IV ______

10. Type of Cancer treatment:

Surgery ______
Chemotherapy ______
Radiation ______
Hormone therapy ______
Immune therapy ______

11. Length of time (years) with cancer treatment provider:

≤ 2 ______
3-4 ______
≥ 5 ______

12. Other medical condition(s):

____

Interview Questions

1. Describe how you first learned about your cancer diagnosis?

2. Describe how your cancer doctor discussed treatment options you can understand in making decisions about your cancer treatment process?

3. Please tell me how long was your cancer treatment decision made after the cancer diagnosis?

4. Please describe how your cancer doctor encouraged your involvement to ask important questions about your cancer treatment options?

5. Did your doctor encourage you to voice your opinion (agree or disagree) about your cancer decision test or specific treatment recommendation?

6. Please describe how family members or significant individual(s) influenced your cancer treatment decision.

7. What ways have the family member or significant individual(s) communicated with your doctor about your cancer treatment options?

8. In what ways do you feel your age plays a role in your cancer treatment decision making?

9. In what ways do you feel your financial resources play a role in your cancer treatment decision making?

10. Did your spiritual beliefs and religion engagement influence your cancer treatment decisions? If so, explain how you dealt with this serious physical illness?

11. In looking back, what things do you think the medical care team can do to improve quality cancer care with patients?

12. Are there any additional comments you would like to provide about your cancer treatment decision experiences?

Thank you for participating in this interview. The confidentiality of all responses will be maintained.