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## **Evaluating Health Awareness in Cancer Genetics Amongst the Black and African American Community in South Carolina**

Annika Jaliya Gadson

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EVALUATING HEALTH AWARENESS IN CANCER GENETICS AMONGST THE  
BLACK AND AFRICAN AMERICAN COMMUNITY IN SOUTH CAROLINA

by

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Bachelor of Science  
Wofford College, 2021

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in

Genetic Counseling

School of Medicine

University of South Carolina

2023

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## ABSTRACT

Historically minoritized individuals are underrepresented in genomic research which limits the ability to fully understand genetic variation within the population (Sirugo et al., 2019). This creates bias that questions the effectiveness of guidelines for genetic testing, predictive risk values, and medical management. Disparities in cancer genetics may be attributed to historical events that have cultivated mistrust in research and medicine, institutional bias, provider skepticism in patient reporting of medical symptoms, and limited access to genetic testing (Saulsberry et al., 2013). More exploration is needed to better understand how to increase access and awareness of cancer genetic services to Black and African American patients. This study aimed to identify deficits in cancer genetics awareness within the Black and African American community in South Carolina through perspectives of individuals belonging to this population. Participants were invited to partake in an original online and paper survey. After quality control, 110 participants that self-identified as Black and African American, at or above the age of 18 years old, reported being either unaffected (defined as having no personal medical history of cancer) or affected (defined as having a personal health history of cancer), and a resident of South Carolina were included in data analysis. Quantitative and qualitative questions were utilized to assess health literacy, perception of cancer risk, participant experience in healthcare, and access to genetic testing. Overall, the study identified that most participants were interested in a genetics evaluation for hereditary cancer to learn personal or familial risks, but health awareness of cancer

genetics was limited. There was a statistically significant difference in health awareness scores between uninformed participants in comparison to informed participants ( $p = 0.010$ ). The findings highlight the need for community engagement and educational outreach to increase awareness of and access to genetic counseling and testing for the Black and African American community.

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## CHAPTER 1: BACKGROUND

Discriminatory practices in the healthcare system have contributed to higher mortality rates, lower survival rates, and increased diagnosis of more advanced disease stages, including cancer, in Black and African American communities in the United States (American Cancer Society, n.d.). Few studies have looked at the experiences and motivations of Black and African American individuals to pursue cancer genetic services or identified barriers individuals may face to access services. Some studies have researched the experiences and motivations of African American women with breast cancer to pursue genetic counseling (Henderson et al., 2021). What previous research has shown about their experiences, however, is that most genetic testing research is representative of individuals who identify as non-Hispanic White and further establishes the need for more research to assess whether Black and African American patients have access to genetic counseling services and to evaluate their medical experiences (Chapman-Davis et al., 2021). There is also a need for more research on patient perceptions of cancer to better understand how to address cancer health disparities in the Black and African American community. Many of the patterns described have been identified across this community regardless of age, gender, and socioeconomic status. Identifying perceived patient barriers to cancer genetic counseling and testing can provide more insight on strategies to reduce disparities in healthcare.

## 1.1 Cancer Genetics

The Black and African American community is one of the most medically underserved populations (Khan et al., 2022). Seigel et al. (2022) have reported on several rates of cancer frequency and mortality. Individuals belonging to this racially minoritized community disproportionately represent the highest death rates for most cancers. The expected death rate for new cancer cases amongst the Black population is approximately thirty-three percent. Although there is a lower incidence of breast cancer in Black women, they are forty-one percent more likely to die from the disease (Siegel et al., 2022.). African American men are more likely to die from prostate cancer in comparison to their white counterparts (American Cancer Society, n.d.). According to the American Cancer Society and National Cancer Institute, African Americans are more likely to be diagnosed with pancreatic, renal, and prostate cancer at earlier ages in comparison to other racial and ethnic groups. This emphasizes the need for heterogeneous data, which is representative of ethnically diverse populations, to establish accurate information for individuals who identify as Black and African American to improve their health outcomes related to cancer diagnoses.

Cancer is a group of diseases with the following characteristics: irregular growth of abnormal cells, uncontrolled growth due to a cell ignoring apoptosis or stop signals, local tissue invasion, and the ability to metastasize. Based on our current knowledge, there are over twenty thousand genes that encode instructions to make proteins, which are important for the body to function properly. All cancer is genetic because it is due to a disruption of genetic functions within a cell, but not all cancer is inherited. Cancer is due to a combination of factors including environment, genetics, personal medical history,

and family history. About 5-10% of cancer is estimated to be hereditary. Hereditary cancer is caused by a germline pathogenic variant, typically in a tumor suppressor gene or oncogene (American Cancer Society, n.d.).

There are over 100 cancer predisposition genes (CPGs) (Rahman, 2014). These genetic variants are typically inherited from one or both parents. Often, a family history displays a recognizable pattern of cancer that indicates the cancer may be hereditary. A family history indicative of hereditary cancer is often characterized by unusually young cancer diagnoses (typically younger than 50 years old), rare cancers such as male breast cancer, multiple family members having the same or related cancer types, and more than one primary in an individual. On the contrary, most cancer cases –about 75-85% – are considered to be sporadic. Sporadic cancer is caused by acquired genetic mutations which are influenced by environment, age, and lifestyle. Individuals who develop sporadic cancer will not have the same acquired genetic mutations as another individual who developed sporadic cancer. It is possible for multiple family members to develop cancer by chance because cancer is common, and anyone is at risk of developing cancer due to acquired mutations (American Cancer Society, n.d.).

In the United States, breast cancer is the most common type of cancer in women. There is a 12% general population risk of women developing breast cancer in their lifetime (American Cancer Society, n.d.). There is a forty percent higher mortality rate for breast cancer in Black women in comparison to White women (Riggin et al., 2022). In the United States, prostate cancer is the most common type of cancer in men. There is a twelve percent lifetime risk for men to develop prostate cancer in their lifetime (American Cancer Society, n.d.). Prostate cancer is more likely to occur at a younger age

in African American or African Caribbean men in the United States, and they are more likely to die from the disease in comparison to White men (McHugh et al., 2022). In general, racially minoritized populations are more likely to begin to receive care when their cancer is more advanced, which often means chances of survival are lower (Chapman-Davis et al., 2021). Access to genetic counseling and testing can be helpful to identify if these individuals are at a higher risk of developing cancer based on their genetics, hopefully leading to earlier detection or prevention of cancer or candidacy for additional treatment options for those with a cancer diagnosis.

### **1.2 Access to Genetic Testing and Knowledge of Cancer Risk**

Genetic counselors are a necessary and key component in adequate consenting to cancer genetic testing. Genetic testing uptake is limited in populations that have lower education levels, belong to minoritized racial or ethnic groups, and/or have limited access to healthcare (van der Giessen et al., 2021). The same study identified the need for communication and education about genetic testing to reduce disparities. Another study identified that healthcare providers were sixteen times less likely to discuss genetic testing with African Americans and were less likely to be referred for genetic counseling services (Khan et al., 2022). Without knowledge of specialty services like genetic counseling, patients are not educated or informed about opportunities to understand possible inherited risks.

In genetic counseling, family history is an important assessment tool for estimating a patient's cancer risk. In general, patients are unable to recall extensive family history, but this trend seems to be more common in Black and African American patients especially concerning paternal lineages (Khan et al., 2022). Both the maternal

and paternal family history can be beneficial for proper risk assessment. Incomplete family histories may be a contributing factor to reduced referral rates among Black and African American patients. Additionally, clinician deficits in family history inquiries, lack of access to care, and several other barriers may lead to inequities in eligibility for testing and underestimation of risk. Furthermore, many African American breast cancer patients do not receive routine genetic testing, even when they are eligible for testing. Currently, the National Comprehensive Cancer Network (NCCN) criteria for genetic testing is used nationally to identify individuals at-risk for an inherited cancer syndrome based on reported family and personal history. Peterson et al. (2020) identified that Black non-Hispanic women who meet NCCN criteria for genetic testing for breast cancer risks are less likely to undergo testing, due to significant differences in provider referral rates. Moreover, Ademuyiwa et al. (2019) conducted a study that showed nearly 5% of women with deleterious mutations do not meet NCCN criteria. This suggests a need to increase knowledge of cancer genetics and genetic testing amongst providers and patients.

Riggan et al. (2022) suggests that cultural factors contribute to patient perception of hereditary breast and ovarian cancer risk and uptake of cascade (familial) genetic testing. Cascade genetic testing occurs when an individual has a known pathogenic mutation so it is recommended that family members should receive genetic testing as well. It is most beneficial to understand and identify culturally sensitive themes that could promote referrals and uptake of education of cancer risk and genetic testing (Kurian et al., 2021; Riggan et al., 2022). Given that limited information may be known about family health history, it is less likely that at risk Black and African American individuals will

meet established NCCN criteria for uptake of genetic testing. This further emphasizes the need to promote health awareness.

### **1.3 Health Literacy**

Lui et al. (2020) defines health literacy as the extent to which individuals have the capacity to obtain, process, and utilize basic health information needed to make appropriate health decisions. Health literacy involves meeting the complex demands of modern healthcare as it relates to an individual's health needs. Health literacy skills allow patients to take control of their own well-being by making better meaningful healthcare choices, improving their communication with health professionals/providers, and equipping them with the tools and information to be an advocate for themselves in a medical setting. According to United States government reports, only twelve percent of Americans are proficient in health literacy skills. This means over eighty-seven million American adults have a low health literacy, which contributes to an increased inability to navigate health systems and advocate for high quality healthcare (Muvuka et al., 2020).

Health literacy is important for prevention and management of health issues. Health literacy improves patient outcomes because it allows the patient to take control of their healthcare. Improving health literacy requires both patients and providers to work cohesively to increase quality of life. Discriminatory practices and implicit biases contribute to the lack of health literacy in underserved communities, resulting in poorer health outcomes and reduced survival rates (Yearby et al., 2022). There is a need for understanding the patient's perspective to educate providers and other individuals in the healthcare community to reduce healthcare disparities. Promoting health literacy amongst

racially and ethnically minoritized patients assists with communication of genomic information.

The importance of assessing health literacy of cancer genetics is essential for understanding how health disparities contribute to poorer health outcomes within the Black and African American population. Analyzing patient responses from open-ended questions can initiate the development of themes that can be used to provide culturally safe and appropriate healthcare. Additionally, addressing healthcare disparities provides beneficial information for progressing towards equitable healthcare.

A lack of health literacy can have consequences, not just for the patient's personal health, but for their family's long-term health. Studies indicate that health literacy is less prevalent in racially minoritized populations, medically underserved individuals, older individuals, and individuals of lower socioeconomic status (Hickey et al., 2018; McDonald & Shenkman, 2018; Schillinger, 2021). Improving health literacy requires both patients and providers to work cohesively together. Research that explores the Black and African American patient experience can provide beneficial insight on how discriminatory and oppressive experiences contribute to low health literacy in cancer genetics (Liu et al., 2020). To properly combat the low health literacy rate amongst Black and African Americans, barriers like systemic racism must be acknowledged and dismantled to achieve health equity.

#### **1.4 Healthcare Disparities**

Healthy People 2020 defines health disparity as a particular type of difference that is closely linked with social, economic, and/or environmental disadvantage. The elimination of health disparities and promotion of culturally safe healthcare is necessary

to achieve health equity (Curtis et al., 2019). The term “race” is a social construct created to divide the human species into distinct groups based on physical and behavioral differences. In recognizing how this social construct has contributed to social and structural racism in the United States, we can research racism as an epidemic, which has contributed to healthcare inequalities in the United States (Borrell et al., 2021). The Center for Disease Control and Prevention (CDC, 2021) has declared racism as a “serious public health threat.” Racism contributes to maternal mortality, obesity, infant mortality, and many other poor outcomes within racially minoritized communities. In addition, race exacerbates implicit and explicit factors that overwhelmingly contribute to the misrepresentation and underrepresentation of racially minoritized individuals within the healthcare system (Khan et al., 2022). Words and phrases such as, “lynch”, when describing a hereditary cancer predisposition known as Lynch syndrome, or “less likely to feel pain”, invoke traumatic experiences formulated by racial terrorism in the United States and may contribute to increased medical mistrust amongst the Black and African American community. Systemic oppression and structural racism, such as food deserts, redlining, and lack of capital, has contributed to racially and ethnically minoritized groups experiencing greater obstacles to access healthcare.

Structural racism is an underlying system that reinforces historical ideologies, impedes health literacy, and contributes to health disparities in the Black and African American community (Williams et al., 2019). Structural racism exacerbates poorer health outcomes through discriminatory practices of healthcare professionals (Yearby et al., 2022). Current literature shows that Black populations are more likely to receive care when their cancer has spread, become more advanced, and are underrepresented in



hereditary cancer predisposition data (Frey et al., 2022). The lack of early access to cancer prevention, cancer management, and genetic testing to Black and African American patients is a healthcare disparity.

### **1.5 Medical Mistrust**

Personal and historical implications have led to mistrust in healthcare amongst the Black and African American population (Scharff et al., 2010). Biased research has contributed to recognizable healthcare disparities in the United States. The deliberate maltreatment of Black males with syphilis in the Tuskegee Experiment conducted by the United States Public Health Services, the unethical use of Henrietta Lacks cervical cancer cells in research, unconsented sterilization and other medical procedures for medical knowledge gain, Black genocide, segregation, prolonged limited access to healthcare, and dissatisfaction with care have all perpetuated Black and African Americans' medical mistrust and contributes to health disparities prevalent in modern society healthcare (Brandon et al., 2005). These historical events expose the traumatic experiences inherited by each generation of Black Americans. The legacy of maltreatment in research regarding Black and African Americans has instilled fear of partaking in other studies that may be beneficial for cancer prevention, treatment, and management (Hostetter & Klein, 2021). As a result, this mistrust has further contributed to poorer health outcomes within this specific racially minoritized population. Community engagement and educational outreach could be utilized to increase trustworthiness amongst the Black and African American community.

Most of the current data about genetic variation has been collected from individuals of European ancestry (Sirugo et al., 2019). This suggests possible selective

bias amongst providers when assessing family history for referral to genetic services. Pre-existing notions about Black and African Americans may contribute to poorer patient-provider relationships and communication. According to previous research, seven out of ten Black Americans reported being treated unfairly and 55% reported mistrust in healthcare (Hostetter & Klein, 2021). This reinforces how challenging it is for this community to create trust in healthcare in addition to the provider's ability to dispel misconceptions about medicine.

Recent studies have shown that effectively recruiting African Americans into genetic studies requires efforts from genetic counselors, physicians, and community members (Ewing et al., 2015). Additionally, utilizing medical professionals that identify as African American has shown to be beneficial. In this sentiment, "representation matters". Representation essentially promotes validation of concerns and opinions for individuals belonging to racially minoritized populations in a comfortable manner. Subsequently, when all medical professionals learn how to communicate to diverse audiences, then minoritized patients may be more willing to comfortably share personal information. As we become more knowledgeable about Black and African American patient's health, then individuals within this community can make informed decisions about their healthcare management.

### **1.6 Gaps in Access to Genetic Services**

There is limited research utilizing patient testimonials to identify barriers to access genetic services. Utilizing patient testimonials allows for the identification of implicit and explicit factors contributing to the gap in access to genetic counseling and testing. Genetic testing has not benefited racial minorities equitably, in comparison to

their White/European ancestry counterparts (Khan et al., 2022). Disparities in testing criteria are a result of data which mostly represents non-Hispanic Whites. Inequitable data and inclusion criteria are examples of explicit systematic biases that contribute to the disparities in cancer healthcare amongst the Black and African American community. Even for the individuals within this subpopulation who are aware of and want to undergo genetics evaluation, more research is needed to identify limited racial and ethnic diversity in research data. Additionally, limited research has been conducted to gain insight on Black and African American patient health literacy.

Yee et al. (2020) found that women who identified as African American had a significant delay between their diagnosis of suspected breast cancer and a follow up visit to a clinic. Yee et al. (2020) emphasized how patient demographics impact early access to screening, diagnosis, and management of breast cancer diagnosis. Implications from previous studies emphasize that education and prevention programs must be implemented. Prior to the implementation of these programs, it is important to assess patient health literacy to identify gaps in knowledge. In addition, implicit and explicit factors that contribute to limited access to genetic services need to be analyzed from the patient's perspective. Tailoring information specific to the Black and African American population in addition to community outreach can initiate a necessary process to reduce healthcare disparities. The downstream effects of this intentional approach will ultimately promote reliable, high-quality care for racially minoritized patients.

Previous studies examining the effect NCCN guidelines on African American breast cancer patients with deleterious mutations identified that these patients do not receive routine genetic testing, even when they are eligible for testing (Ademuyiwa et al.,

2019). More research is needed to identify barriers to data availability on racially minoritized populations, which can be beneficial for assessing cancer risk. Increasing knowledge of cancer genetics within the Black and African American community allows for an improvement in clinical outcomes for all patients and their family members. It is through the patient's perspective that allows for informing healthcare providers about the gap in access to genetic services.

### **1.7 Purpose of Study**

This study aimed to identify deficits in cancer genetics awareness within the Black and African American community, address patient knowledge of cancer risks, access to genetic testing, and patient comfortability level with healthcare. We assessed participant access to genetic services and evaluated participant experiences to analyze disadvantages and inequitable practices within the healthcare system that affect the Black and African American community in South Carolina. The study aimed to achieve the following objectives:

1. Assess the Black and African American patient experience with healthcare in South Carolina; and
2. Assess participant health literacy in cancer genetics; and
3. Identify patient perspectives about cancer genetics.

We predicted that patient experiences and trustworthiness in the healthcare system in the United States have both historical and personal implications. We hypothesized that health literacy of cancer genetics and perception of cancer risk contribute to patient willingness to uptake genetic services and comfort with care. Additionally, we

hypothesized that participants' healthcare awareness is dependent on personal, familial, and environmental factors.

CHAPTER 2: EVALUATING HEALTH AWARENESS IN CANCER GENETICS  
AMONGST THE BLACK AND AFRICAN AMERICAN COMMUNITY IN SOUTH  
CAROLINA<sup>1</sup>

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## 2.1 Abstract

Historically minoritized individuals are underrepresented in genomic research which limits the ability to fully understand genetic variation within the population (Sirugo et al., 2019). This creates bias that questions the effectiveness of guidelines for genetic testing, predictive risk values, and medical management. Disparities in cancer genetics may be attributed to historical events that have cultivated mistrust in research and medicine, institutional bias, provider skepticism in patient reporting of medical symptoms, and limited access to genetic testing (Saulsberry et al., 2013). More exploration is needed to better understand how to increase access and awareness of cancer genetic services to Black and African American patients. This study aimed to identify deficits in cancer genetics awareness within the Black and African American community in South Carolina through obtaining perspectives of individuals belonging to this population. Participants were invited to partake in an original online or paper survey. After quality control, 110 participants that self-identified as Black and African American, at or above the age of 18 years old, reported being either unaffected (defined as having no personal medical history of cancer) or affected (defined as having a personal health history of cancer), and a resident of South Carolina were included in data analysis. Quantitative and qualitative questions were utilized to assess health literacy, perception of cancer risk, participant experience in healthcare, and access to genetic testing. Overall, the study identified that most participants were interested in a genetics evaluation for hereditary cancer to learn personal or familial risks, but health awareness of cancer genetics was limited. There was a statistically significant difference in the health awareness scores between uninformed participants in comparison to informed participants ( $p = 0.010$ ). The findings highlight the need for community engagement and

educational outreach to increase awareness of and access to genetic counseling and testing services for the Black and African American community.

## **2.2 Introduction**

Cancer is a common disease in the United States. According to the American Cancer Society (2022), there were 1.9 million new cancer cases diagnosed in the country and an estimated 33,440 new cancer cases diagnosed in South Carolina. Among the new cancer cases in South Carolina, breast and prostate cancer were the most common diagnoses. Cancer genetic counseling and testing can be utilized to identify whether individuals and their families have a higher-than-average risk of certain types of cancer. Criteria derived from the National Comprehensive Cancer Network (NCCN, 2022) is utilized to identify individuals and families with a suspected inherited risk for cancer. Most of the data utilized to formulate these criteria were obtained from individuals who identify as non-Hispanic White and report predominantly European ancestry (Kulkarni, 2022). The lack of representative data for minoritized populations poses a disadvantage for identifying cancer predisposition genes in individuals belonging to these populations.

Historical events in the United States that have promoted segregation and discrimination against minoritized individuals contribute to healthcare disparities that persist today. For example, many founding medical procedures and groundbreaking treatments were created through the unconsented use of Black slave bodies (Hostetter & Klein, 2021; Scharff et al., 2010). In the process, this contributed to misleading interpretations of pain perception in Black and African American patients resulting in poorer health outcomes. These discriminatory practices fostered medical mistrust in the Black and African American community and has



remained a factor in willingness to partake in research (Hostetter & Klein, 2021).

Institutionalized racism in the United States healthcare system has encouraged discriminatory practices and created medical disadvantages that have affected health outcomes of Black and African American patients. Persistent racism within the healthcare system contributes to provider bias, which has been shown to affect the referral rates of Black and African American patients for genetic counseling services (Ademuyiwa et al., 2021).

One of the most significant racial disparities in oncology is that Black women have a higher prevalence of triple negative breast cancer diagnoses (TNBC) and have poorer clinical outcomes in comparison to their European counterparts (Prakash et al., 2020). Previous studies have identified that both biologic and nonbiologic factors contribute to significant cancer healthcare disparities affecting the Black and African American community (Prakash et al., 2020). In addition to understanding the biological factors contributing to disparities, genetic counselors have the unique ability to understand and assist with reducing non-biological factors such as, access to healthcare, health literacy, and psychosocial situation factors. Educational interventions can be beneficial for increasing health literacy by providing a patient with knowledge and skills that increase healthcare advocacy and familiarity with maneuvering the health system. In short, health literacy is health awareness.

Other studies have primarily researched the experiences and motivations of African American women with breast cancer (Henderson et al., 2021). Assessing the experiences and motivations of all Black and African American individuals regarding all cancer types is necessary for identifying barriers to cancer genetic services. Additionally, there is a need to research patient perceptions of etiologies of cancer to better understand how to address health

disparities. Limited research has been conducted to gain insight on Black and African American patient health literacy. Previous studies examining the effect of the NCCN guidelines on African American breast cancer patients with deleterious mutations identified that these patients do not receive routine genetic testing, even when they are eligible for testing (Ademuyiwa et al., 2019). Additionally, it has been found that there were deleterious mutations identified in African American breast cancer patients who did not meet NCCN guidelines (Ademuyiwa et al., 2019). A generalized perception of cancer risk amongst affected and unaffected Black and African American patients is necessary for initiating educational opportunities in addition to potential guideline recommendations regarding cancer genetics evaluation. Understanding the concerns of Black and African American individuals is important for reducing mistrust in healthcare and increasing the uptake of genetic testing (Saulsberry et al., 2013).

Genetic counselors have a unique role in healthcare which allows them to create interpersonal relationships with patients; however, racial discordance and implicit bias may limit the ability to create strong and meaningful connections with minoritized patients and contribute to disparities in healthcare (Lowe et al., April 2020). Additionally, shared in-group identity between patient and provider potentially cultivates a higher satisfaction with care. According to the National Society of Genetic Counselors Professional Status Survey (PSS) executive summary (2022), 89% of the profession identifies as White. The minimal racial and ethnic diversity suggests the presence of inconsistencies in client-centered communication and care when interacting with minoritized patients (Hostetter & Klein, 2021; Lowe et al., June 2020). Previous studies have also identified a lack of exposure to diverse patient populations throughout genetic

counseling training (Pollock et al., 2022). These findings support the idea that there is limited awareness of and access to genetic counseling and testing amongst minoritized populations.

By surveying participants that belong to the Black and African American community in South Carolina, we aimed to understand barriers to genetic counseling services and evaluate patient experiences to identify ways to promote increased uptake of education concerning cancer risk and genetic testing.

## **2.3 Materials and Methods**

This study was approved by the University of South Carolina Institutional Review Board (Pro00122727).

### *2.3.1 Participants and Recruitment*

Participants in this study were required to meet the following inclusion criteria: (1) all individuals that self-identify as Black and/or African American; (2) women, men, transgender, gender-non-conforming, non-binary, genderqueer; (3) adults, defined as individuals at or above the age of 18 years old; (4) unaffected, defined as having no personal medical history of cancer, or affected individual, defined as having a personal health history of cancer; and (5) resident of South Carolina. Exclusion criteria included: (1) children, defined as individuals under the age of 18 years old and (2) individuals that did not identify as Black or African American.

Participants were sent an invitational flyer containing either a link or QR code to participate in this study or were provided a paper survey in-person. Participants either completed an anonymous online survey or an anonymous paper survey. Participants were recruited via church congregations, community centers, special interest groups, social media, and snowball

sampling. Participation in this study was voluntary; therefore, completion of the survey served as participant consent.

### *2.3.2 Procedure*

A questionnaire was designed and administered on an online questionnaire platform, Qualtrics.com. A total of 17 items made up the questionnaire which consisted of multiple-choice items, Likert scale items, yes or no items, true or false items, and open-ended questions. The survey included items regarding cancer genetic health literacy, genetic testing, perception of cancer risks, health awareness and advocacy, and familial communication. Participants were given the opportunity to skip or leave questions blank at any point during the survey. Demographic questions were placed at the end of the survey to obtain participant's age, gender identity, medical history, educational history, socioeconomic status, and current insurance status. All demographic categories were derived from previous research studies. Gender identity categories were derived from the publication manual of American Psychological Association, seventh edition. This survey was used to obtain qualitative and quantitative data to evaluate health literacy in cancer genetics, analyze comfort with care, and assess perception of cancer risk and how it may contribute to patient willingness to uptake genetic services. Upon completion of the survey, participants were prompted to partake in a voluntary raffle that included an opportunity to win one of six Visa gift cards. Participants were taken to a different survey questionnaire which prompted them to voluntarily input their email addresses to be included in the raffle drawing.

Survey responses were collected from August 2022 to January 2023. There were 117 total responses. Ninety-six electronic questionnaires were collected utilizing Qualtrics.com.

Twenty-one paper surveys were collected. Two participants that completed the paper survey were not eligible for data analysis based on inclusion criteria. The remaining nineteen paper surveys were uploaded onto Qualtrics.com. Of the 117 respondents, 115 submitted responses that were eligible for data analysis based on inclusion criteria. Five participants began the questionnaire but did not complete the entire questionnaire and were therefore excluded. The final data analysis included 110 total responses.

### 2.3.3 Data Analysis

Quantitative analysis was performed by utilizing Microsoft Excel and Statistical Package for Social Sciences (SPSS) to formulate descriptive statistics. Health awareness questions were compacted and categorized into composite measures to score survey responses (Appendix C). This scoring system was utilized to rate the number of correct (composite measure=1) and incorrect (composite measure=0) surveys. The correct response for general information assessment included: *causes of cancer was all of the above*; correct response for *there are ways to reduce your risk of getting cancer was True*; and *most cancer cases run in the family was False*. Participants were required to answer all three health literacy questions correctly to receive a survey composite measure of one. Participant interest in genetic testing services was assessed utilizing qualitative explanations. Descriptive statistical analysis was utilized to interpret the frequency of the qualitative explanations to evaluate participant interest in genetic testing. Perception of risk was assessed using Likert scales and interpreted using descriptive statistics (frequency count). Chi square analysis was utilized to compare health literacy with participant awareness of genetic services, experience with healthcare, and perception of cancer risk. Statistical significance was determined by a *P* value of less than 0.05.

Tables and figures were assembled using Microsoft Excel and Microsoft Word software. Participant interest in genetic testing services was assessed utilizing qualitative explanations. Descriptive statistical analysis was utilized to interpret the frequency of the qualitative explanations to evaluate participant interest in genetic testing. Descriptive statistical analysis was utilized to identify participants that had an experience that led to mistrust in healthcare. Excerpts of open-text quotations were extracted to provide brief explanations of participant mistrust.

## **2.4 Results**

### *2.4.1 Demographic Information*

All participants included in this data analysis were self-reported Black and African American. Gender, socioeconomic status, highest level of education obtained, and age were reported for 110 participants (Table 2.1). The majority of participants self-reported “woman” as their gender identity (66%), with the average age range of participants primarily being between 50 to 59 (31%). Most participants reported having a bachelor’s degree (23%) and making between \$50,000 to \$74,000 a year (34%). Participants were given the opportunity to select, *prefer not to respond*, for all demographic questions. Only 7% of respondents reported a personal history of cancer with 96% reporting insurance coverage.

### *2.4.2 Assessment of the Black and African American Patient Experience and Trustworthiness in Healthcare in South Carolina*

Patient experience and trustworthiness were assessed through open response questions. Participants were asked about their experience at a doctor’s visit. Each response was categorized based on the tone of the participant’s response (Table 2.2). Tone classification was defined by common words utilized in participant responses. Tone responses were then categorized into three

main groups: positive tone, neutral tone, and negative tone. A positive tone response was indicated by an emotional and productive patient experience. Most participants (n = 50) reported a positive tone when asked about their experience at a doctor's visit. Some participants described their experience as "good", "great", or "pleasant." Some participant responses portrayed outstanding positive toned experiences at a doctor's visit:

*"My doctor is very attentive and provides education about cancer and other health care issues."*

*"It is usually a pleasant and educational experience because my doctor discusses my current health and preventative options."*

*"I have a good relationship with my current health care provider."*

However, one participant that reported a positive tone experience, followed the statement with "...when I had an African American doctor, there were things she taught me to be aware of that I have had to share with my present doctor who is not of color." Another participant stated, "I feel it is a good experience, but not sure if they have my best interest at heart." A negative tone response elicited feelings of discomfort and abjection. Of the participants, 34 (31%) reported a negative tone with their experience at the doctor. The patients that reported a negative tone experience indicated feeling "hurried", "overwhelmed", and "nervous". A few participants clearly stated their doctor was "dismissive of the concerns of African Americans" and "listens but does not seem concerned about the concerns I have about my health and test results." Neutral tone responses were indicated by facts with absent emotion in patient experiences. Response examples included: "normal", "fair or fine", "okay", "basic", "typical", or "brief." The least number of participants (n = 26) indicated a neutral tone experience at a doctor's visit.

Participants were asked if they ever had an experience that led to mistrust in healthcare. Most participants (n = 73) denied an experience of mistrust in healthcare (Table 2.3). Those who responded yes (n = 28) were prompted to provide a brief explanation of their experience. Some of the participants indicated a lack of attentiveness, lack of empathy, and inadequate health education (Figure 2.1). Lack of attentiveness was conveyed as a provider being inconsiderate and careless about patient care. Lack of empathy was conveyed as the inability to understand patient experiences and emotions. Inadequate health education was conveyed as poor communication and discrepancies in care.

*“I was diagnosed with intracranial hypertension but never referred to neurology. I was given medication and when I was told my symptoms were worsening the PA ignored me. I sought a second opinion and learned I had an AVF Cognard III that could have led to my demise.”* (lack of attentiveness)

*“I was hospitalized, and the doctors offered me no explanation of what was wrong. Even when I begged and pleaded for answers”* (inadequate health education)

*“A physician with extremely poor bedside manner [who] made a generalization based on my appearance. He assumed that I could not read and stated his opinion without proper knowledge about what I had been asked to do by his colleague.”* (lack of empathy)

#### *2.4.3 Assessment of Participant Health Awareness (Literacy Scores) in Cancer Genetics*

Health awareness (literacy scores) was measured by asking three questions about cancer genetics including the causes of cancer, the availability of ways to reduce cancer risk, and to identify whether most cancer cases run in the family. Participant health awareness scores were



then compared with knowledge of genetic services, reported personal history of cancer, and experiences that led to mistrust in healthcare (Table 2.3). Eighty percent of participants indicated that they had never been informed of genetic services, and 20% selected they had been previously informed of genetic services. There was a statistically significant difference in health awareness scores between participants that were informed of genetic services in comparison to participants who were not informed ( $p = 0.010$ ). Of the 21 individuals that were informed of genetic services, 14 had correct health awareness scores while seven had incorrect health awareness scores. There was not a statistically significant difference in health awareness scores between individuals who had a reported personal history of cancer and individuals who did not. Most participants ( $n = 99$ ) that denied a personal history of cancer had an incorrect health awareness score. There was not a statistically significant difference in health awareness scores between participants who had mistrust in healthcare in comparison to participants that did not report an experience that led to mistrust in healthcare. Supplemental health awareness questions asked participants to rate their agreeability with risk for cancer based on maternal history of cancer, absent family history of cancer, and overall risk perception of cancer based on family history (Table 2.4; Table D.2). There was a statically significant difference in health awareness scores and risk perception scores based on an absent family history of cancer.

#### *2.4.4 Identification of Participant Perspectives of Cancer Genetics*

Participants were asked about their experience with cancer (Table 2.5). Each response was categorized based on reported experience. The experience categories were defined by frequent phrases utilized in participant responses. There were four categories identified: little to no experience, personal experience, family history or friends, and general knowledge of cancer.

Little to no experience with cancer (n = 34) was indicated by a “none” or minimal response.

Most participants (n = 66) indicated an encounter with cancer based on a family member(s) or friend(s) with cancer.

*“I’ve watched someone lose a teenage daughter to cancer while trying to make sure the other teenage daughter recovers.”*

*“Helping take care of my grandmother and both daughters is so painful for the patient.”*

*“I have lost several loved ones to cancer and know many survivors. My wife carries the BRCA2 gene.”*

When a family history of cancer was mentioned, most participants disclosed the type of cancer that affected their family member. The reported cancer types included: breast, colorectal, lung, prostate, pancreatic, multiple myeloma, esophageal, endometrial, leukemia, and bladder cancer (Table 2.5). Participants that reported a personal experience with cancer (n = 5) mentioned a diagnosis or survivorship. Five participants indicated their experience with cancer in terms of general knowledge. These participants’ experiences with cancer were indicated by alternative medicine treatment options and knowledge of disease statistics and symptoms.

*“The pain that the person suffers like losing hair, losing taste, vomiting or nausea, medicine.”*

*“I was extremely scared of cancer until I learned about alternative medicines.”*

*“I don’t know too much about cancer. All I know is it’s one of the leading causes of death.”*

Participants were asked about their interest in genetic testing and could select up to three options (Figure 2.2). Thirty-two percent of participants indicated an interest in genetic testing to

inform them of their own risks. The second most common reason for interest in genetic testing was for children or future children's health (21%). Although 80% of individuals previously indicated that they had never been informed of genetic services, only 5% of participants indicated that they had never heard of genetic testing when asked about their interest. Of the participants that indicated no interest in genetic testing, 3% stated this because they either did not think insurance would cover it or could not afford genetic testing. Three participants indicated no interest in genetic testing because they were afraid of their DNA being utilized for research. While most participants indicated an interest, few individuals indicated an overall lack of interest but were aware that genetic testing was available (n = 23).

## **2.5 Discussion**

This study aimed to gain insight on barriers contributing to minimal cancer genetics awareness within the Black and African American community by assessing knowledge of cancer risks, access to genetic testing, and patient experience with healthcare. Previous research examined disparities in genetic testing criteria and cancer diagnoses, but limited research has explored the patient's perspective on barriers to access cancer genetic counseling and testing. The unique perspective of Black and African Americans allows for better educating providers on how to communicate in a culturally competent and sensitive way to reduce healthcare disparities affecting this community. The primary findings of this study indicated that most Black and African American individuals were interested in genetic testing to understand their cancer risk for proper health management, and that there is a lack of information and education being provided to this community.

When given the opportunity to counsel racially minoritized individuals, many testimonials describe the lack of awareness of genetic counseling services and the desire to gain more knowledge to better manage their personal and family health (Henderson et al., 2021.) Through these minimal experiences, it has shown how effective genetic counseling can be in increasing knowledge (Ademuyiwa et al., 2019). Proper health education promotes patient advocacy, which in turn increases better health outcomes. A key finding in this study indicated that being informed of genetic services was associated with a better health awareness of cancer genetics. Despite this finding, there were few participants that reported being informed of genetic services that had an incorrect health awareness of cancer genetics score. Additionally, health awareness was correlated with personal, familial, and environmental factors. Given the findings in this study, we can assume that the knowledge barrier contributes to the decreased uptake of genetic services and lack of diversity in cancer genomic research. We can infer that health awareness of cancer genetics and perception of cancer risk contribute to patient willingness to uptake genetic services and comfort with care. An educational framework can promote knowledge acquisition amongst Black and African American individuals to stimulate uptake of genetic testing and standardization of cancer genomic research data.

Across racial groups, Black and African American women and men have the highest death rates and shortest survival rates for cancer (American Cancer Society, n.d.). The poorer health outcomes amongst this minoritized community can be attributed to multiple factors. This study identified that at least a portion of Black and African American participants have negative toned experiences when visiting the doctor. These experiences were described by participants as inattentive, impersonal, hurried, overwhelming, nerve-racking, dismissive, and inadequate in

addressing patient concerns and health education and communication. Given this finding, we can infer that these experiences may contribute to the poorer health outcomes of Black and African American individuals. A nuance that can affect patient experiences is provider bias. One patient stated, *“I have felt that my request was not taken seriously, and assumptions were made about everything being mental instead of getting tested.”* The dismissive behavior of the provider in this encounter is a continuation of how misconceptions are promoted about Black and African American patient biology in comparison to their European counterparts (Hostetter & Klein, 2021).

Provider bias has been shown to affect the number of Black and African American patients being referred to genetic counseling services (Ademuyiwa et al., 2019; Peterson et al., 2020; Rodriguez et al., 2023). When asked about experiences with cancer, a significant proportion of participants indicated a family history of cancer. According to NCCN genetic testing criteria, individuals with certain family histories of cancer are eligible for a genetics evaluation. This finding suggests that Black and African American patient family history may not be adequately assessed to identify a need for genetic services referral. Additionally, this finding further suggests that Black and African American patients may not receive the same educational opportunity from their providers about genetic services as an option to assess cancer risk. Due to limited knowledge of genetic counseling services amongst the participants in this study, it is possible that provider bias leads to reduced identification of individuals appropriate for referral for a genetics evaluation.

An important finding in this study indicated that Black and African Americans endure experiences that generate medical mistrust. Several participants reported experiences that led to

mistrust due to lack of attentiveness and compassion and being inadequately educated about health information by a provider. Furthermore, although only three participants selected, *I will not do genetic testing because I am afraid of my DNA being used for research*, there is a level of mistrust that should not exist. Concerns for privacy and poor medical experiences not only affect a patient's health outcome, but also their willingness to uptake future beneficial health services. Even when participants reported their experiences and trustworthiness in healthcare, there was a perceived sense of caution in their healthcare experiences amongst the study cohort. Individuals that report an unpleasant experience or mistrust in healthcare are more likely to have poorer health outcomes and dismiss medical advice (Hostetter & Klein, 2021).

Identifying and understanding the experiences of medical mistreatment and mistrust amongst Black and African Americans provide a step towards combating the downstream effects of negative healthcare encounters. Diversifying the genetic counseling workforce through higher education awareness and scholarship programs, in addition to establishing networks within the Black and African American community can bridge gaps, build trust, and promote informative educational interventions. Another beneficial approach could be the implementation of equity scorecards to analyze differences in medical care and promote accountability (Brachio & Reichman, 2022). This framework and data tool creates measurable disparity statistics to identify the needs of marginalized communities in order to be able to stimulate beneficial bidirectional communication between patients and providers (Brachio & Reichman, 2022). Utilizing this could ultimately identify disparities in assessing family history and identifying genetic risk within the Black and African American community. An additional method encourages the

reassessment of institutional policies and algorithms through a diversified lens to ensure patient safety.

Many participants expressed an interest in genetic testing. With the increase in population screening there is hope that genetic data can become more inclusive and allow for greater identification of those with a hereditary risk. However, education is essential to combat misconceptions, reduce medical mistrust, and encourage patient advocacy. Genetic counselors serve a unique provider role and are well-trained in presenting detailed education of risks and genetics to patients. However, previous studies have indicated that genetic counselors' interpersonal relationships and shared in-group racial identities influence their counseling and delivery of educational information to minoritized patients (Lowe et al., April 2020). Implicit bias contributes to healthcare disparities. Awareness of one's implicit bias is not enough to combat inequitable medical practices (Pollock et al., 2022). A multidisciplinary approach is necessary to better serve minoritized communities to promote equitable healthcare through engagement and education programs. In addition to incorporating patient testimonials in bias training, well researched communication skills and interventions should be included. Furthermore, alterations in didactic coursework and intervention protocols that address racial indifference, and exposure to more diverse patient populations would be beneficial as a part of genetic counseling training.

## **2.6 Limitations**

Due to the small sample size, the participant perspective may only be generalized to the experiences of Black and African American individuals in South Carolina and not to other areas of the United States. However, this study and previous studies indicated a generalized consensus

that Black and African Americans are interested in genetic testing to identify personal and familial risk for cancer. Additional limitations include potential confirmatory bias given that few individuals reviewed and confirmed derived themes from data analysis. Finally, use of validated items on the questionnaire would lead to more impactful results, analysis, and generalization.

## **2.7 Future Directions**

While the majority of participants expressed interest in genetic testing, further research is needed to identify whether Black and African American patients are being asked about their family history of cancer and if sharing family history increases the uptake of genetic counseling and testing within the Black and African American community. Many participants indicated not being informed of genetic services; therefore, future research is necessary to analyze the effectiveness of community engagement and educational interventions. Future research could include analysis of effectiveness of educational advancement opportunities.

One participant expressed a better health experience and more trustworthiness when there was a shared racial identity between the patient and provider; *“My experience is very positive. However, when I had an African American doctor, there were things she taught me to be aware of that I have had to share with my present doctor who is not of color.”* Differences in satisfaction rates should be analyzed when the patient does or does not share the same racial identity as the provider. This could potentially identify comfortability barriers that can be incorporated into bias training for healthcare providers. Additionally, experiences of medical mistrust could be incorporated into annual bias training to highlight how prejudice and systemic racism affects health outcomes and perspectives of the healthcare system. Future research beyond this study may be able to create educational models that increase health literacy in all



patient populations, promote cultural sensitivity amongst healthcare professionals, and initiate a higher volume of minoritized patients to advocate for equitable healthcare.

**Table 2.1 Participant demographic information**

Variable	Total (N=110)	
	Count	Percentage
<b>Gender</b>		
Man	35	32
Woman	72	66
Prefer not to respond	3	3
<b>Socioeconomic Status</b>		
\$20,000-\$34,000	7	6
\$35,000-\$49,000	12	11
\$50,000-\$74,000	37	34
\$75,000-\$100,000	21	19
Less than \$20,000	6	6
More than \$100,000	22	20
Prefer not to respond	5	5
<b>Education</b>		
Associate degree (e.g. AA, AS)	9	8
Bachelor's degree (e.g. BA, BS)	25	23
Doctorate or professional degree (e.g. MD, DDS, PhD)	10	9
High school degree or equivalent (e.g. GED)	23	21
Less than a high school diploma	1	1
Master's degree (e.g. MA, MS, MEd)	22	20
Some college, no degree	18	16
Prefer not to respond	3	3
<b>Age</b>		
18 - 20	1	1
21-29	8	7
30-39	13	12
40-49	24	22
50-59	34	31
60-69	13	12
70+	14	13
Prefer not to respond	3	3
<b>Insurance Coverage</b>		
YES	106	96
NO	4	4
<b>Personal History of Cancer</b>		
YES	8	7
NO	99	93

**Table 2.2 Tone of participant response when asked about experience at doctor’s visit**

Category	Response Example	Count (%)
Positive Tone	Pleasant Positive Awesome Good Informative Attentive Comfortable Strong Relationship Conversational	50 (45)
Neutral Tone	Normal Fair/Fine Okay Basic Typical Brief	26 (24)
Negative Tone	Lack of attentiveness Hurried Impersonal Overwhelming Nervous Inadequate health education Dismissive Poor communication	34 (31)

**Table 2.3 Comparison between health awareness and participant knowledge of genetic service availability, reported personal history of cancer, and experiences that led to mistrust in healthcare**

		Participant Responses		P value
	Health Awareness Score (Composite Measure)	NO	YES	
<b>Knowledge of genetic services</b>	<i>Incorrect (0)</i>	54	7	0.010
	<i>Correct (1)</i>	31	14	
<b>Reported Personal history of cancer</b>	<i>Incorrect (0)</i>	58	4	0.307
	<i>Correct (1)</i>	41	4	
<b>Experiences that led to mistrust in healthcare</b>	<i>Incorrect (0)</i>	46	12	0.090
	<i>Correct (1)</i>	27	16	

**Table 2.4 Comparison between health awareness scores and participant perceived likelihood of cancer risk based on an absent family history**

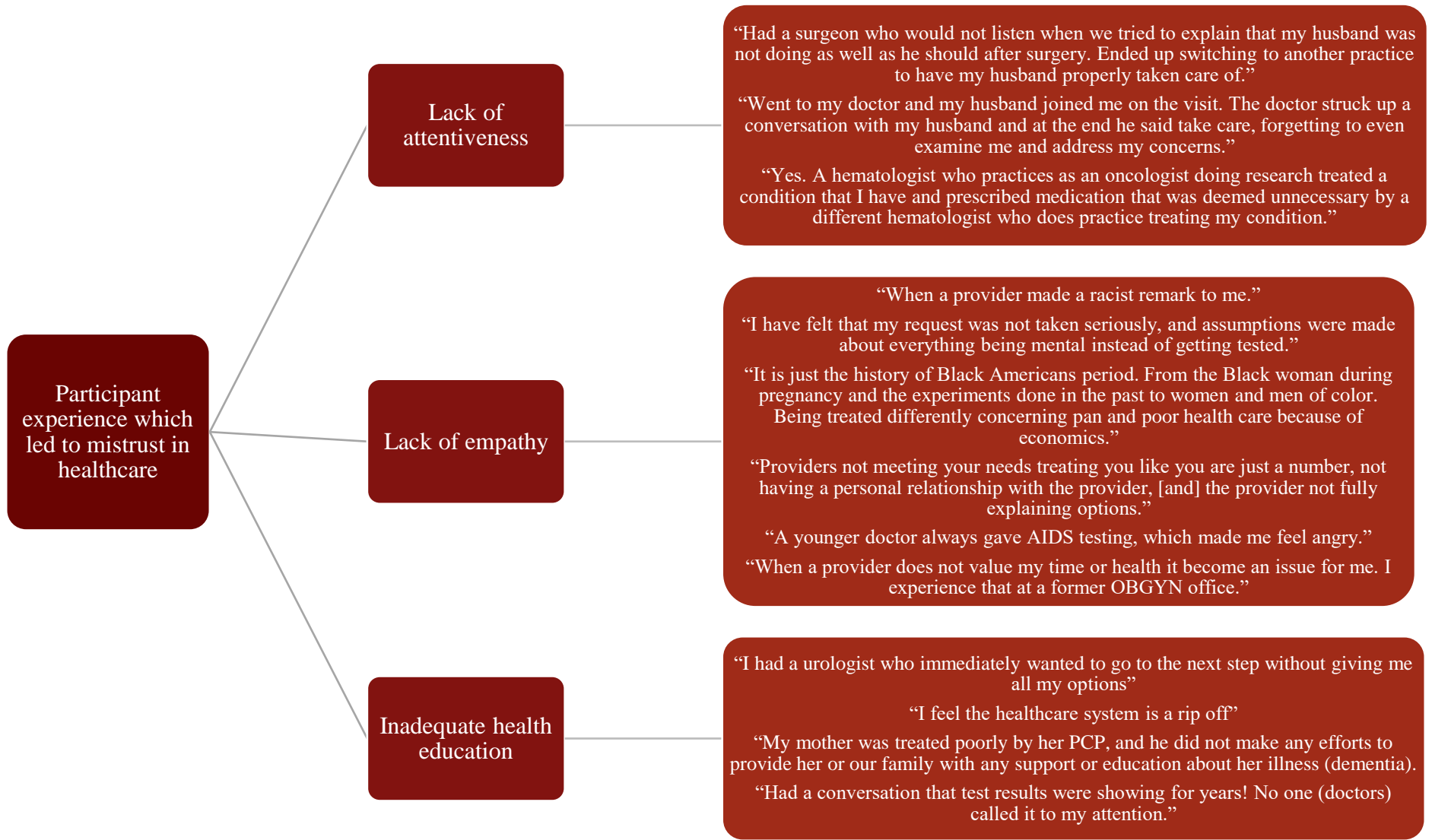
Health Awareness (Composite Score)	1 (strongly disagree)	2 (disagree)	3 (agree)	4 (strongly agree)	<i>P</i> value
Incorrect (0)	19	35	9	2	.036
Correct (1)	21	23	0	1	

**Table 2.5 Responses when asked about experience with cancer**

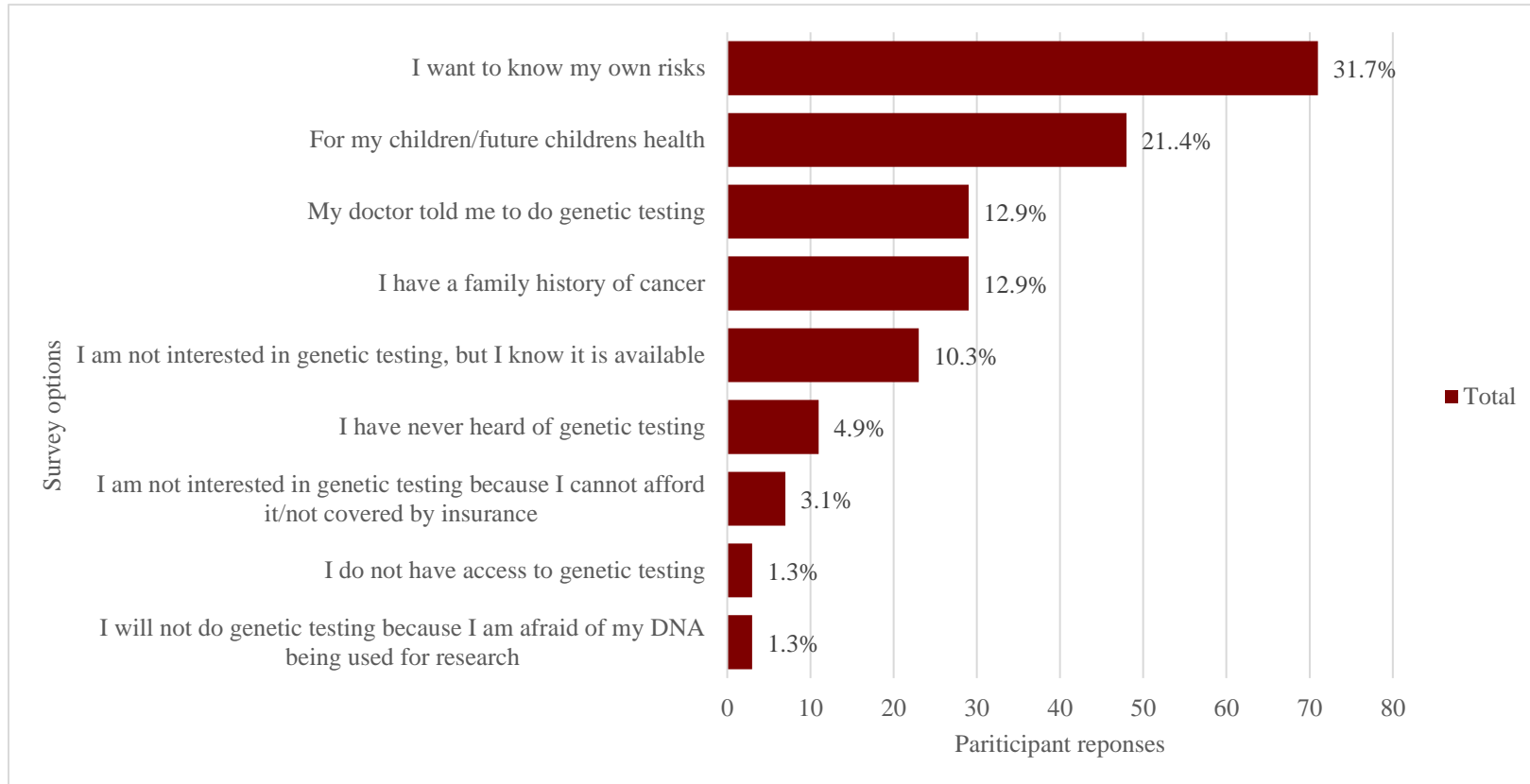
<b>Category</b>	<b>Response Example</b>	<b>Count</b>
Little to no experience	N/A or None Minimal	34
Personal experience	Diagnosis Survivorship	5
Family history or friend	Family history of cancer <sup>1</sup> Family survivors Death by cancer Cancer predisposition Caretaker of family member Role of a supportive friend	66
General Knowledge	Fear Symptoms of treatment Awareness	5

<sup>1</sup>types of cancer included: breast, colorectal, lung, prostate, pancreatic, multiple myeloma, esophageal, endometrial, leukemia, bladder

**Figure 2.1 Brief explanation of participant experiences which led to mistrust in healthcare**



**Figure 2.2 Participant reported interest in genetic testing**





## CHAPTER 3: CONCLUSION

We sought to identify barriers that contribute to the lack of awareness of cancer genetics amongst the Black and African American community by assessing access to genetic services and evaluating medical experiences. Minoritized individuals endure healthcare inequities and disparities which contribute to poorer health outcomes. Specifically, Black and African Americans have the highest mortality rates for most cancers in comparison to other racial or ethnic groups in the United States. Furthermore, the landscape of cancer predisposition gene data primarily reflects individuals of European descent leaving more uncertainty in results amongst patients with African ancestry. In addition to the findings in this study, other research identified an overall interest in genetic testing amongst Black and African American individuals. Despite previous research, the perspectives of Black and African Americans has not been thoroughly explored to identify barriers to access. Responses from participants indicated that health awareness is essential for making informed decisions and advocating for equitable care. The unique role of genetic counselors allows for advocacy of equitable healthcare across a variety of medical specialties that can stimulate the change necessary to reduce stigmatization and marginalization of historically underserved communities. Acknowledgement of bias alone is not enough to combat disproportionate healthcare and health outcomes. The findings in this study provide a baseline framework for the development of educational interventions to increase awareness and opportunity to advance health literacy. Additionally, the reported experiences of Black and African

American patients should be utilized to cultivate cultural awareness training programs to reduce provider bias and inequity.

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## APPENDIX A

### PARTICIPANT RECRUITMENT LETTER

#### Letter to Participants

Hello!

My name is [Annika Gadson](#), and I am a graduate genetic counseling student at the University of South Carolina School of Medicine. You are invited to participate in this survey because you identify as:

- Black/African American
- Adults (defined as individuals 18 years or older)
- Unaffected (no personal medical history of cancer) and Affected (personal health history of cancer)

The purpose of this research is to gain insight on healthcare disparities within the Black/African American community. This study addresses patient knowledge of cancer risks, access to genetic testing, and patient comfortability level with advocating for equitable healthcare of cancer risk and genetic services.

If you decide to participate in this survey, then it will take approximately 7-10 minutes to complete. Your responses are anonymous and voluntary and will not be able to be traced back to you. If you do not feel comfortable completing a question, then you may choose the option, “prefer not to answer.” and continue the survey. By completing this survey, you are consenting to participate in this study.

Each participant has the option to participate in a voluntary and optional raffle that includes the opportunity to win 1 of 5 \$25 gift cards. The raffle will be held at the end of Fall of 2022. **You can only participate in this raffle opportunity once.** If you would like to participate in the raffle, **you must complete the entire survey.** Participants will be notified if they win the raffle.

If you have any further questions please contact me at [annika.gadson@uscm.edu](mailto:annika.gadson@uscm.edu), or my faculty advisor, Shandrea Foster ([shandrea.foster@prismahealth.org](mailto:shandrea.foster@prismahealth.org)). If you have any questions about your rights as a participant, please contact the University of South Carolina’s Office of Research Compliance at 803-777-7095.

Thank you in advance for your willingness to participate. The following link will take you to the survey: [https://uofsc.co1.qualtrics.com/jfe/form/SV\\_9zSupR0Z84qaOgK](https://uofsc.co1.qualtrics.com/jfe/form/SV_9zSupR0Z84qaOgK)

APPENDIX B  
PARTICIPANT FLYER



Scan code NOW!



**Complete a 7-10 minute survey and be entered into a raffle to receive a \$25 gift card**

**For learning more about health disparities within the Black/African American community**



- Only 1 entry is permitted per person
- You must complete the entire survey to participate in the raffle
- The survey and raffle are voluntary and optional

If you have any further questions please contact me at [annika.gadson@uscmed.sc.edu](mailto:annika.gadson@uscmed.sc.edu), or my faculty advisor, Shandrea Foster ([shandrea.foster@prismahealth.org](mailto:shandrea.foster@prismahealth.org)). If you have any questions about your rights as a participant, please contact the University of South Carolina's Office of Research Compliance at 803-777-7095.

## APPENDIX C

### PARTICIPANT SURVEY

# **Evaluating Health Awareness in Cancer Genetics Amongst the Black/African American Communities in South Carolina**

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**Start of Block: Block 1**

Thank you for beginning this survey. The purpose of this research is to gain insight on healthcare disparities within the Black/African American community. This study addresses patient knowledge of cancer risks, access to genetic testing, and patient advocacy for equitable healthcare of cancer risk and genetic services. This survey will take approximately 7-10 minutes to complete. Your responses are anonymous and voluntary and will not be traced back to you. If you do not feel comfortable completing a question, then you may choose the option, “prefer not to answer.” and continue the survey. By completing this survey, you are consenting to participate in this study which has been approved by the University of South Carolina Institutional Review Board.

**End of Block: Block 1**

---

**Start of Block: General Information Assessment**

1. For the following questions, choose the best answer. What causes cancer?

- Environmental exposures (i.e., tobacco, radiation)
  - Weakened immune system
  - Family genetics
  - Viruses (i.e., human papillomavirus (HPV))
  - All of the above
- 

2. Most cancer cases run in the family.

- TRUE
  - FALSE
- 

3. There are ways to reduce your risk of getting cancer.

- TRUE
- FALSE

**End of Block: General Information Assessment**

---

**Start of Block: Perceptions of Risk**



4. For the following questions please rate your level of agreement. (1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree)

	1 (strongly disagree)	2 (disagree)	3 (agree)	4 (strongly agree)
I am more likely to develop cancer because my mother had cancer:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not have a risk for cancer because it does not run in my family:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a high risk of developing cancer because it runs in my family:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Perceptions of Risk

---

Start of Block: Access to Genetic Testing

5. For the following question, please choose up to three options most important to you. I am interested in genetic testing because:

- I want to know my own risks
- For my children's/future children's health
- I have a family history of cancer
- My doctor told me to do genetic testing
- I am not interested in genetic testing, but I know it is available
- I am not interested in genetic testing because I cannot afford it/not covered by insurance
- I will not do genetic testing because I am afraid of my DNA being used for research
- I do not have access to genetic testing
- I have never heard of genetic testing

**End of Block: Access to Genetic Testing**

---

**Start of Block: Healthcare Awareness and Advocacy**

6. For the following questions, please provide a brief explanation of your experiences. What is your experience with cancer?

\_\_\_\_\_

-----

7. When you go to the doctor, what is your experience like?

\_\_\_\_\_

-----

8. Were you ever informed of genetic services being available to you? If so, what were you told?

YES \_\_\_\_\_

NO

---

9. Have you ever had an experience that led to mistrust in healthcare? If so, please provide a brief explanation.

YES \_\_\_\_\_

NO

**End of Block: Healthcare Awareness and Advocacy**

---

**Start of Block: Demographics**

Page Break \_\_\_\_\_

Ethnicity Are you of Hispanic, Latino, or Spanish origin?

Yes

No

---

Ethnicity How would you describe yourself? Please select all that apply.

Black or African American

American Indian or Alaska Native

Native Hawaiian or Pacific Islander

White

Asian

Other \_\_\_\_\_

---

Age What is your age?

- 18 - 20
  - 21-29
  - 30-39
  - 40-49
  - 50-59
  - 60-69
  - 70+
  - Prefer not to respond
- 

Gender What is your gender identity?

- Man
  - Woman
  - Gender Non-Conforming
  - Non-Binary
  - Genderqueer
  - Other \_\_\_\_\_
  - Prefer not to respond
-

Personal History I have a personal health history of cancer:

- YES
  - NO
- 

Education What is the highest degree or level of school you have completed?

- Less than a high school diploma
  - High school degree or equivalent (e.g. GED)
  - Some college, no degree
  - Associate degree (e.g. AA, AS)
  - Bachelor's degree (e.g. BA, BS)
  - Master's degree (e.g. MA, MS, MEd)
  - Doctorate or professional degree (e.g. MD, DDS, PhD)
- 

Socioeconomic Status:

- Less than \$20,000
  - \$20,000-\$34,000
  - \$35,000-\$49,000
  - \$50,000-\$74,000
  - \$75,000-\$100,000
  - More than \$100,000
-

Insurance I currently have some form of health insurance:

YES

NO

**End of Block: Demographics**

---

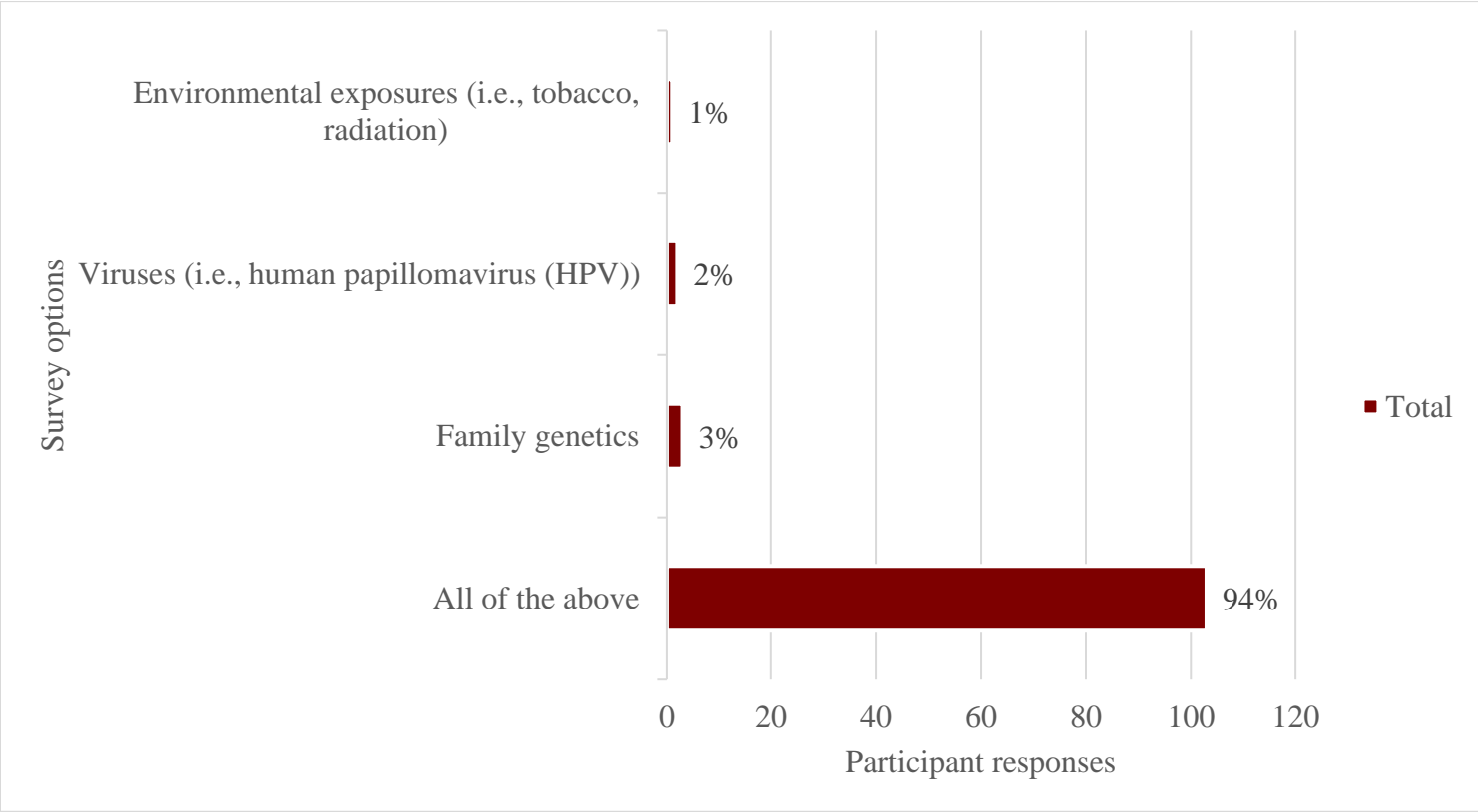
**Start of Block: Raffle Opportunity**

Survey Information Each participant has the option to participate in a raffle that includes the opportunity to win 1 of 5 \$25 gift cards. This raffle is voluntary and optional to all participants. To participate in the raffle, you must complete the entire above survey and only participate in the raffle once. The raffle will be held at the end of Fall of 2022. Participants will be notified if they won the raffle via email. If you would like to participate in the following raffle, please proceed to the end of the survey to enter your email into the raffle.

**End of Block: Raffle Opportunity**

APPENDIX D  
SUPPLEMENTAL DATA

Figure D.1 Participant reported knowledge of causes of cancer





**Table D.2 Comparison between health awareness scores with participant perception of the likelihood to develop cancer based on a maternal history of cancer**

Health Awareness (Composite Score)	1 (strongly disagree)	2 (disagree)	3 (agree)	4 (strongly agree)	<i>P</i> value
Incorrect (0)	10	24	22	9	.183
Correct (1)	8	24	11	2	