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Jazmin Huerta　　　　Date

Understanding Hispanic and Latino Perceptions on Ancestry-Targeted Inherited Cancer Screening in Georgia via Democratic Deliberation

By

Jazmin D. Huerta

Master of Public Health

Behavioral, Social and Health Education Sciences

Yue Guan, PhD, ScM, CGC

Committee Chair

Emily Lemon, PhD

Committee Member

Don Operario, PhD

Department Chair

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B.A.

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An abstract of

A thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of

Master of Public Health

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Abstract

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By Jazmin D. Huerta

We used a democratic deliberation approach to gain informed community perspectives regarding targeting communities of Hispanic and Latino Ancestry for Hereditary Breast and Ovarian Cancer (HBOC) screening in Georgia. Our study seeks to address whether GA should target those of Hispanic and Latino ancestry for HBOC risk identification, identify perceived barriers and facilitators impacting genetic screening uptake, and explore concerns and recommendations regarding cancer prevention voiced by the community.

We recruited 33 Spanish-speaking Hispanic and Latino community members living in Georgia and conducted a half-day in person democratic deliberation exclusively in Spanish. We conducted thematic analysis guided by the empowerment theory framework to identify distinct concepts related to pros and cons participants highlighted and categorized each under the process arm factors. Participants were also asked to complete pre and post deliberation surveys. Survey data were analyzed using SAS to assess participant satisfaction with the deliberation process, and changes in participant community agency, self-efficacy to deliberate, perceived benefits of HBOC screening, and willingness to undergo genetic screening for HBOC.

Participants generated impeding and facilitating influencers across all process levels, including person/group factors, environmental factors, and empowerment capacity. Frequently discussed concerns included fear of test results, cost, and access to testing and treatments, while common facilitating factors included improved awareness of HBOC risk and prevention, increased support and funding for the Latino community, and early detection and treatment. Deliberation survey results display overall support for the program, high satisfaction with the deliberation process, and slight increases in community agency, perceived knowledge of HBOC risk and screening importance, and self-efficacy to deliberate post-deliberation.

Our study highlights the feasibility and effectiveness of DD for engaging Spanish speaking Hispanic/Latino community members in public health policy discussions. Study findings call for more efforts to address the community and societal level barriers and concerns.

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Acknowledgements

I would like to extend my sincerest gratitude to my committee: Dr. Guan and Dr. Lemon who provided invaluable feedback and support throughout the entirety of this project.

All the facilitators and individuals who dedicated their time and skills to carry out the democratic deliberation including Denise Martinez, Dayanna Ramirez, Susan Vadaparampil, Sheryl Gabram, Cynthia Snider, Jackie Bonilla, Nora Colemenares, Estefany Rivera Sanchez, Luccy Mercedes, Rose Olacklin, and Michele Gornick.

A special thanks to our shareholders, including Georgia Center for Oncology Research and Education (GA Core), Gwinnett Public Health Department, the NETT church, and the MOFFIT Cancer Center for their contributions and expertise.

Lastly, all the deliberation participants for their willingness to engage and share their insights on this important topic.

Table of Contents

Chapter I. Introduction

1.1 Background

Cancer has been the leading cause of death worldwide, accounting for 1 in 6 deaths (WHO, 2022). Globally, breast cancer is the most diagnosed cancer with over 2.3 million new cases in 2020 and a reported 685,000 deaths (Arnold et al., 2022). Ovarian cancer (OC) accounts for approximately 225,000 new cases each year and reported 140,000 deaths worldwide (Lynch et al., 2013). In the United States alone, cancer is the second leading cause of death, just behind heart disease, with 1 in every 5 deaths being due to cancer (U.S. Cancer Statistics Working Group, 2023). In 2020, approximately 240,000 new cases of female breast cancer were detected in the US and over 42,000 deaths were reported (U.S. Cancer Statistics Working Group, 2023). OC has a reported incidence of 22,280 new cases per year and accounts for 15,500 deaths (Lynch et al., 2013).

Hereditary Breast and Ovarian Cancer (HBOC) syndrome is characterized by pathogenic variants within the breast cancer 1 (*BRCA1*) and breast cancer 2 (*BRCA2*) genes and accounts for 5-10% of all breast cancers and 15-20% of all ovarian cancers (Yoshida, 2021; Campacci et al., 2017; Kukafka et al., 2022). Pathogenic variants in the *BRCA1* and *BRCA2* gene result in greater risk for associated hereditary breast and ovarian cancer in both males and females (Petrucelli et al., 1998). For example, a woman with a single first-degree relative diagnosed with OC has a threefold increase in OC risk (Andrews & Mutch, 2017). Similarly, males with BRCA1/2 pathogenic variants have increased absolute risk of breast and pancreatic cancer, with carriers being more likely to have faster growing and higher-grade prostate tumors (Peshkin et al., 2021).

Furthermore, pathogenic variants within the *BRCA1* and *BRCA2* genes have been associated with an increased lifetime risk of developing other cancers including fallopian tube cancer, melanoma, endometrial cancer, pancreatic cancer, and colorectal cancer (Lee et al., 2019; Paul & Paul, 2014). Women with HBOC syndrome have up to an 85% lifetime breast cancer risk and up to a 40% lifetime risk of ovarian cancer (Lee et al., 2005; Kukafka et al., 2022).

1.2 Problem Statement

Among the Latino and Hispanic community, those with family history of breast and ovarian cancers are at significantly greater risk of *BRCA1/2* pathogenic variants; Latinas have been found to have the second highest prevalence of *BRCA1/2* pathogenic variants (Gómez-Trillos et al., 2020). Aside from breast cancer being the leading cause of cancer death among Latinas, compared to non-Hispanic whites, Latinas are also diagnosed with breast cancer at younger ages and with tumor types (i.e., triple-negative breast cancer) linked to hereditary pathogenic variants (Gómez-Trillos et al., 2020; Boyle & McPadden, 2004; Lara-Medina et al., 2011). Despite these alarmingly high statistics, Latinas remain the racial/ethnic group with the lowest awareness of genetic testing when compared to non-Hispanic Whites and other minorities (Gómez-Trillos et al., 2020; Kaplan et al., 2006; Lynce et al., 2016). Additionally, men are ten times less likely to seek genetic counseling and testing due to misconceptions about associated cancer risks for men, psychological discomfort with being at-risk, and lack of awareness about how to access genetic counseling (Paeshkin et al., 2021).

Brief family history assessments serve as a new tool to identify families at high risk for these BRCA-associated HBOCs (Moyer, 2014; Owens et al., 2019). This form of cascade testing, where once a pathogenic variant is identified in an individual, genetic testing is expanded to at-risk relatives horizontally and vertically through a pedigree, has been found to be efficient in case identification (Peshkin et al., 2021). Screening and identifying individuals with *BRCA1/2* pathogenic variants at an early stage improves patient quality of life and overall survival rates through timely prevention and treatment. (Kuchenbaecker et al., 2017; Lynce et al., 2016).

Disparities in genetic cancer risk assessment uptake remain prevalent despite the implementation and endorsement of new low-cost population-based screening options (Moyer, 2014; Gómez-Trillos et al., 2019). Latinos in the US are more likely to be uninsured than other racial and ethnic groups, leading to limited access to medical providers who can provide genetic service referrals (Gómez-Trillos et al., 2019). Moreover, physicians have been noted to be less likely to recommend genetic testing to minority racial and ethnic communities (McCarthy et al., 2016). These disparities are further exacerbated within the Latino and Hispanic community due to a multitude of unique barriers to care including language, lack of insurance, immigration status, medical mistrust, and health illiteracy (Juckett, 2013; Vadaparampil et al., 2006). These barriers pose significant hindrances to accessing genetic cancer prevention and the slew of treatments required if patient is found to have positive screening results (Juckett, 2013; Gómez-Trillos et al., 2020; Zavala et al., 2021).

1.3 Significance Statement

This research aims to better understand the perceptions of the Latino and Hispanic community on expanding genetic cancer screening services in Georgia through a deliberative democracy approach. Deliberative democracy is a community-engaged research method that aims to gain informed community perspectives and allow members in the community to voice their invaluable opinions on the potential expansion of a targeted hereditary breast and ovarian cancer (HBOC) screening program in the state.

There is a clear gap in the existing knowledge concerning Latino cancer genetic risk screening in Georgia. Firstly, most biological discovery utilized to develop genetic risk assessment models are based on White populations with limited applicability to Latinos (Dutil et al., 2015; Lynce et al., 2016; Weitze et al., 2013). Lack of Latino representation in cancer genomic databases results in higher likelihoods of inconclusive genetic test results with no clear treatment recommendations (Caswell-Jin et al., 2018; Ndugga-Kabuye et al., 2019). Due to wide ranging and diverse genetic roots in the heterogenous Latino population, inherited cancer risk is greatly impacted by specific geographic regions (Belbin et al., 2021). Lastly, health literacy significantly impacts an individual's ability to comprehend risk and process complex and nuanced health issues; Latinos, even those with high English proficiency tend to prefer receiving health information in Spanish or a mix of Spanish and English (Kaplan et al., 2016; Quinn et al., 2011).

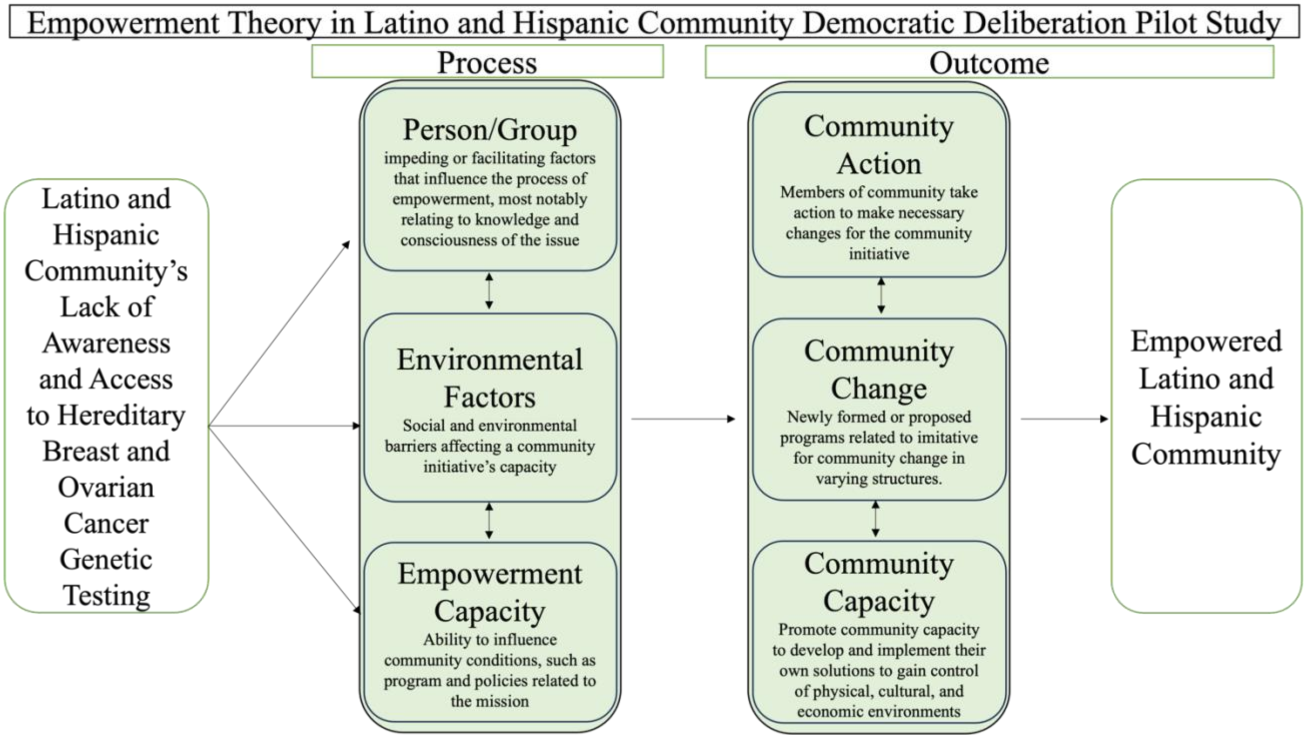
1.4 Theoretical Framework

Empowerment research focuses on the process of restoring power in individuals and communities attempting to gain greater influence and control over conditions that impact their quality of life and overall wellbeing (Fawcett, et al., 1995). Applying this framework in community interventions involves a deliberate approach in understanding and addressing the community's concerns and desires within the overarching socio-political climate influencing these outcomes (Perkins & Zimmerman, 1995). Underscoring the environmental influencers and social issues that affect these outcomes serves to further address misconceptions that communities bear sole responsibility for their loss of control over these issues and that they can easily regain their influence (Perkins & Zimmerman, 1995).

Empowering a community through a theoretical lens can be delineated through a **processes** and **outcome** mechanism, wherein the actions and structures in place to promote empowerment and the operationalization of empowerment used to display the resulting level of empowerment created are highlighted (Perkins & Zimmerman, 1995). In the context of HBOC genetic testing among the Latino and Hispanic community, the empowerment theory underscores the importance of actively listening to members of the community regarding all the factors influencing their ability to engage in HBOC preventative care to identify key priorities for the community via the process mechanism. Utilizing this mechanism allows for the framing of impeding and facilitating factors influencing the process of empowerment for the community, especially those relating to spread of knowledge and consciousness of the issue, the social and environmental barriers affecting the community's capacity, and the empowerment capacity of the community defined as their ability to influence the community's conditions (Perkins & Zimmerman, 1995).

Therefore, this pilot study employs this theoretical framework to facilitate a deeper understanding of the processes that serve as both barriers and facilitators in awareness and access to HBOC genetic testing via deliberative democracy approach to amplify the voices of the Latino and Hispanic community, as well as serve as a steppingstone for future community empowerment. Through their recommendations and concerns, the community informs policy and practices in their region, promoting power restoration and influence over the conditions affecting them. The following conceptual model (**Figure 1**) highlights the main constructs under the process arm of the empowerment theory used to inform data analysis, as well as the constructs under the outcome arm used to operationalize the term empowerment which can be utilized to inform future study implications.

Figure 1. Conceptual Model Applying Empowerment Theory in Latino and Hispanic Community Democratic Deliberation Pilot Study



1.5 Purpose Statement

The primary aim of this study is to gain insight into the Latino and Hispanic community's perspective on the proposal of a targeted HBOC screening process in Georgia. A secondary aim is to better understand the factors that impede or promote the awareness and access of quality genetic cancer screening services for HBOC among the Latino and Hispanic community. By employing a Deliberative Democracy strategy, this study sought to actively engage members of the Latino and Hispanic communities living in Gwinnett County, Georgia. As a collective, participants thoroughly discussed this nuanced topic and ultimately highlighted the most prominent factors affecting their community's access to cancer screening and healthcare. Participants also proposed recommendations to enhance and promote their overall wellbeing. This research aims to foster a deeper understanding of the challenges and opportunities within the healthcare system for the Latino and Hispanic community leading to the promotion of equitable policies and practices in hereditary breast and ovarian cancer prevention.

1.6 Research Questions

A mixed-methods approach was utilized to better understand the perceived challenges that Latino and Hispanic communities face in the state of Georgia when attempting to engage with genetic cancer screening services for HBOC. Informed by the empowerment framework, this study seeks to answer the following questions:

- Should Georgia target all individuals of Hispanic and Latino Ancestry to identify those at risk for Hereditary Breast and Ovarian Cancer?
- What are the perceived barriers and facilitators that affect genetic cancer screening awareness and access within the Latino and Hispanic Community?
- What concerns and recommendations do Latinos and Hispanics engaging in a democratic group deliberation pose to promote health equity regarding cancer prevention?

1.7 Definition of Terms

Deliberative Democracy: public policy tool that seeks to elicit citizens' values and priorities to inform decision-making on complex, values-laden issues by 1) gathering members of the public in a forum or structures setting; 2) presenting information and arguments from multiple sides of the target issue or policy to increase members' understanding of the issue and available policy options; 3) allowing members to collectively discuss the information, options, and conflicting groups perspectives or opinions; and 4) obtaining public comments and recommendations to determine the most appropriate policy options (Subica & Brown, 2020)

Empowerment: an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources (Cornell Empowerment Group, 1998)

Health Equity: the attainment of the highest level of health for all people … achieving health equity requires valuing everyone equally with focused and on-going societal efforts to address avoidable inequities, historical and contemporary injustices and the elimination of health and health care disparities (Liburd, et al., 2020)

Chapter II. Review of the Literature

This study sought to investigate the Latino and Hispanic communities' response to a targeted cancer genetic screening approach in the state of Georgia, as well as the perceived barriers and facilitators to genetic testing awareness and access. The purpose of chapter two is to review literature relevant to this thesis. This chapter begins with a robust review of literature surrounding risk of Hereditary Breast and Ovarian Cancer (HBOC) among the Latino and Hispanic community, current Latino and Hispanic engagement with genetic cancer screening and disparities seen in HBOC prevention, as well as current strategies used to promote health equity in this field.

2.1 HBOC risk in the Latino population

Since 2000, Hispanics and Latinos have accounted for more than half (50.5%) of the overall population growth in the United States with a projected increase from 55 million in 2014 to 119 million by 2060 (PEW, 2008; Colby & Ortman, 2014). The Hispanic and Latino population is culturally and genetically diverse given that they originate from colonized North, Central and South America, and the Caribbean, entailing a range of indigenous, African and European ancestry that varies across geographic regions and country of origin (Lynce et al., 2016; Colby & Ortman, 2014). In 2020, the US Hispanic population became the nation's second largest racial/ethnic group, only behind the White American population, at approximately 62.1 million individuals (Funk & Lopez, 2022). According to the US Census Bureau, self-reported data reveals that 61.5% of all Hispanics identify with Mexican origin, 9.6% with Puerto Rican origin, 9.3% with Central American origin, 6.4% with South American origin, and 3.9% with Cuban origin further underscoring the rich diversity within this population (OMH, 2020; Lynce et al., 2016). Diversity of Hispanic origin has also been noted to vary by state; although

Mexicans are the predominant Hispanic origin group in most states, there are notable exceptions to this such as New York and New Jersey, where Puerto Ricans are the largest Hispanic group, and Florida where Cubans take precedence (Brown & Lopez, 2013). Given the ongoing and projected trends of growth within the community, as well as the sizeable impact on the nation's demographic trends, a comprehensive analysis of the HBOC risk in the Hispanic and Latino population is imperative (Sussner et al., 2015).

Hereditary Breast and Ovarian Cancer Syndrome is a heritable genetic condition that increases the likelihood of an individual developing breast, ovarian, and other cancers including prostate, pancreatic, and male breast cancers (CDC, 2016). HBOC is mostly attributed to genetic changes in the breast cancer 1 (*BRCA1*) and breast cancer 2 (*BRCA2*) genes (CDC, 2016). Approximately 15% of all breast cancers and 20% of all ovarian cancers in the general population are directly linked to hereditary factors, with 5-10% of all breast cancer cases being associated with *BRCA1/2* gene pathogenic variants (Sussner et al., 2015; Lynce et al., 2016; Kukafka et al, 2022; Pasick et al., 2016). Women with HBOC due to pathogenic variants in *BRCA1/2* genes face a high lifetime risk of breast and ovarian cancer, with risks as high as 85% and 45%, respectively (Joseph & Guerra, 2015; Lee et al., 2005; Pasick et al., 2016). Even more alarmingly, 300,000 US females are estimated to carry a *BRCA1/2* variant yet are unaware of their status due to lack of awareness and utilization of genetic screening tools (Conley et al., 2021; Lee et al., 2005).

Currently, breast cancer is the most commonly diagnosed cancer and leading cause of cancer death among Latina women (Conley et al., 2021; Sussner et al., 2015; Lynce et al., 2016). Initial studies examining the prevalence of deleterious pathogenic variants in *BRCA1/2* genes among Hispanics show a potential for accounting for a higher proportion of breast cancer in

Hispanics than other non-Ashkenazi Jews (Weitzel et al., 2013). Similarly, *BRCA1* 185delAG, a Jewish haplotype has been documented as a recurrent mutation in Hispanics (Weitzel et al., 2013). Pathogenic variants within these BRCA genes have increased lifetime risks of developing breast and ovarian cancer. Additionally, this population has been noted to be diagnosed at younger ages, at later stages, experience greater disruption in breast cancer treatment, and have worse prognostic features, such as triple negative disease and *HER2*-positive disease when compared to their non-Hispanic White counterparts (Conley et al., 2021; Lynce et al., 2016; Mette et al., 2016).

2.2 Latino engagement with screening practices and disparities in HBOC prevention

Further research has highlighted significant health disparities within these racial and ethnic groups. Structural inequities embedded within the healthcare system, as well as larger societal structures, significantly impact the disparities seen among Latinos receiving preventative treatments for hereditary breast and ovarian cancer (Zavala et al., 2021). Barriers to family history screening and genetic counseling include insufficient knowledge of HBOC, inability to estimate risk, lack of time and competing priorities, inadequate family history reporting in medical records, and limited access in low-income areas (Kukafka et al., 2022; Pasick et al., 2016; Joseph & Guerra, 2015). Furthermore, patients within this population are also more likely to experience the following barriers to genetic cancer risk assessment: language, lack of knowledge and awareness, low health literacy, time constraints and competing priorities, limited access to insurance, and cost of testing (Hass et al., 2000; Hurtado-de-Mendoza et al., 2020; Schonberg et al., 2020; Mette et al., 2016; Lee et al., 2005). Fear has also been found to be a significant barrier within this population as many individuals are weary to participate in genetic counseling services due to fear of discrimination, mistrust of the US medical system, fear of attention due to current immigration status, and cultural taboos about cancer diagnosis (Pasick et al., 2016; Lee et al., 2005; Kukafka et al., 2022)

Primary care providers have also noted numerous barriers to discussing breast cancer prevention and raising awareness to HBOC screening and genetic counseling during clinic visits such as lack of time, poor reimbursement, and lack of training; a call for interventions such as standardization of breast cancer risk assessment, risk communication, and risk-based management in primary care (Schonberg et al., 2020). Providers have also been noted to refrain from referring high risk Latinas in minoritized ethnic and racial groups, as well as those in with lower education and/or income levels for genetic counseling due to concerns about access, language, and cultural barriers (Conley et al, 2021; Kukafka et al., 2022). Hurtado-de- Mendoza et al., 2020 underscores that even when a patient is able to attend genetic counseling, significant gaps in risk communication result in misunderstandings, emphasizing the need for improved strategies to enhance the effectiveness of communication with the Hispanic and Latino population. Currently, in the US, 92% of genetic counselors are White, 86% do not speak a language other than English, and only 6% are fluent in the Spanish language, further underscoring the dire need for diversity and language representation within the profession (Conley et al., 2021; Joseph & Guerra, 2015).

Patients, regardless of race or ethnicity, must navigate a complex and confusing healthcare system when receiving care in the United States (Zavala et al., 2021). Most Americans can cover their medical expenses via private insurance from their employers or public programs such as Medicaid and Medicare, however, Hispanics and Latinos are currently reported to have the highest uninsured rate in the nation at 17.7% (Zavala et al., 2021; US Census Bureau, 2022). Even with insurance, Medicaid and Medicare provide only a limited amount of assistance as

Medicaid covers genetic counseling and testing for hereditary cancers in only 26 states and Medicare can only cover genetic testing for breast cancer leaving genetic counseling without pay coverage (Joseph & Guerra, 2015; Kaplan et al., 2006). Within this system, patients are also required to coordinate their own care and must navigate these private and public systems and programs leaving racial and ethnic minorities disproportionately affected due to limited language and cultural proficiency (Zavala et al., 2021; Lee et al., 2005).

When analyzing HBOC prevention service uptake, it is important to consider the multitude of barriers to awareness and access among the Hispanic and Latino community. Numerous studies show that as a result, when compared to their white counterparts, Hispanics have lower levels of awareness of genetic testing for breast cancer risk which in turn results in significantly lower levels of genetic testing uptake and worse morbidity and mortality rates (Mette et al., 2016; Kaplan et al., 2006; McGuinness et al., 2019). A national study of approximately 650 patients who received genetic testing in community-based setting between 1998 and 2000 revealed that only 1% of participants were of Hispanic origin underscoring a significant underrepresentation of this demographic group in genetic testing uptake and highlighting the lack of genetic and genomic information available for this population (Vadaparampil et al., 2006; Lynce et al., 2016). Kaplan et al., 2006 also reports disproportionate differences in awareness of genetic testing by race and ethnicity such that only 19.4% of Latinas had been exposed to this topic compared with 59.4% of Whites, 26.1% of Asian Americans, and 31.0% of Black women. Despite relatively low personal and community knowledge regarding BRCA genetic counseling, a study investigating Latinas' beliefs and attitudes about BRCA genetic counseling reveled women felt positive about the topic with the main motivator serving as ensuring family members were not at risk (Sussner et al., 2015).

2.3 Current strategies to promote health equity in HBOC cancer screening

McGuinness et al., 2019 highlights that despite the United States Preventative Service Task Force's recommendation for women who are at a high hereditary risk for *BRCA1/2* to receive counseling and testing, uptake for these high-risk populations remain low (McGuinness et al., 2019). To address this low uptake of genetic cancer screening among the Hispanic and Latino population, various health promotion strategies have been explored, particularly focusing on overcoming barriers related to awareness and access to preventative services for HBOC (Ramirez et al., nd).

Cost can be one such deterrent to testing in these populations. In a study by Nogueira et al., a PDCA (Plan, Do, Check, and Act) method was used for the implementation of an oncogenetics service in Brazil for at risk patients and was found to effectively reach over 300 families, particularly those in lower-income regions within one year. This four-step method consisted of planning and raising funds, hiring professionals for a multidisciplinary team, checking patient referrals, and ensuring all clinical staff are properly trained in taking family history and appropriately referring at risk patients (Noguerira et al., 2021). Utilizing this methodology for the implementation of further oncogenetics services can ensure cost-effective, efficient, and sustainable programs are in place to identify those at risk of hereditary syndromes and improve the overall uptake of genetic counseling. Another study in Brazil assessed the effectiveness of a short and comprehensive primary screening questionnaire for showed that utilization of this questionnaire via in person, by telephone, or by letter was a cost-effective strategy to expand accessibility of cancer genetics services and improve the overall identification of individuals at risk for HBOC (Campacci et al., 2017). In areas where healthcare delivery systems are underdeveloped or are unable to reach the entire population, primary screening questionnaires are a great alternative screening method that reduces number of excluded at-risk individuals living in secluded areas without burdening the healthcare system (Campacci et al., 2017). Mette et al., 2016 also demonstrated the advantages of cancer genetic risk assessment and counseling delivered through telemedicine to remote Hispanic populations living near the Texas-Mexico border. Participants expressed a high level of satisfaction with the telemedicine program and reported overall benefits to counseling, including a reduction of cancer worry, anxiety, and depression (Mette et al., 2016).

Aside from cost, another major deterrent to testing among the Hispanic and Latino population is lack of knowledge and comprehension of HBOC risk in the community. In a study assessing the effectiveness of a culturally targeted educational booklet intervention aimed at increasing genetic counseling and genetic testing uptake among Latina breast cancer survivors, participants in the intervention demonstrated a higher likelihood of completing genetic counseling and genetic testing (Conley et al., 2021). Additionally, they exhibited a more substantial and sustained increase in knowledge when compared to participants in the control group who only received a factsheet about breast cancer survivorship (Conley et al., 2021). In another study focused on creating a culturally targeted narrative video to inform participants about HBOC risk factors and addresses barriers to attending genetic counseling, findings indicated that participants who engaged with the film experienced a notable increase in knowledge and demonstrated greater uptake of cancer screening (Hurtado-de-Mendoza et al., 2020). The use of culturally relevant narrative films proved beneficial for minority populations with low literacy and English proficiency, serving as a valuable tool in mitigating screening disparities between Mexican Americans and non-Hispanic Whites (Hurtado-de-Mendoza et al., 2020; Thomas et al., 2004).

In an in-depth scoping review analyzing the body of evidence on interventions aimed at addressing current racial/ethnic disparities in genetic databases, numerous gaps regarding current promotion strategies were highlighted and underscored for future targeted interventions (Ramirez et al., n.d.). Current literature regarding primary interventions reporting cancer genomic service interventions among Latino communities revealed to be extremely limited and lacking comprehensive promotion strategies. Of the 2,344 publications reviewed, only 16 published interventions fit inclusion criteria, as it required evidence-based interventions informed by acculturation measures such as language fluency, immigration status, and country of origin (Ramirez et al., n.d.). Furthermore, none of these published interventions were written in Spanish or identified through LILACS, or the Latin American and Caribbean Literature on Health Sciences database emphasizing disparities in genetic counseling promotion and utilization across and within Latin and North America (Ramirez et al., n.d.). Analysis of reported promotion strategies revealed a concentration in interventions implementing family-history based screening tools within clinical settings, focused primarily on the patient level (75%) (Ramirez et al., n.d.). Despite measures of language preference, language fluency, nativity, and country or origin being well documented within these strategies, there was no documentation of immigration status and time/generations in the US, which serve as important factors affecting access to genomic services and overall health (Ramirez et al., n.d.).

2.4 Community engagement in cancer genomics

Understanding current community engagement approaches toward genomics-informed application uptake among racial and ethnic minorities is crucial in ensuring cancer related disparities across these populations are minimized (Guan et al., 2023). The success, acceptability, and relevance of health promotion programs and policies is contingent on a culturally relevant approach that weighs the concerns and priorities unique to the community (Guan et al., 2023). Due to elevated cost and increased time commitments in strategies requiring greater public engagement, most efforts utilize focus groups and cross-sectional surveys as the main methodology (Guan et al., 2023). Information processing theories have revealed these methodologies to have low impact in motivating participants to provide thoughtful insight, consider the complexities of the new discourse, or feel empowered to believe they can make a change (Chaiken & Ledgerwood., 2012). Shifting towards newer methods like democratic deliberation, where targeted audiences are actively engaged and viewpoints extending beyond personal implications, serves as a steppingstone towards engaging racial and ethnic minorities in the creation of cancer genomic interventions (Guan et al., 2023).

2.5 Conclusion

In conclusion, this study aimed to investigate the Latino and Hispanic communities' response to a targeted cancer genetic screening approach in the state of Georgia, as well as the perceived barriers and facilitators to genetic testing awareness and access. The comprehensive literature review highlights the risk of HBOC in the Latino population, as well as the cultural and genetic diversity within the Hispanic and Latino community. Additionally, disparities in engagement with genetic cancer screening and current health equity promotion strategies are addressed to better understand the necessity for future actions.

Rapid growth and diversity in the US Hispanic and Latino population coupled with the high prevalence of HBOC and disparities in outcomes underscores the dire need for target interventions. There are a multitude of barriers to awareness and access, ranging from structural inequities in the healthcare system to cultural factors, language proficiency, and limited health literacy. Healthcare providers also experience challenges in providing patients with adequate service due to communication gaps and a lack of diversity in the field. Further review of the healthcare system highlights the impact of insurance status, with Hispanics having the highest uninsured rate in the nation, as well as limited coverage for genetic counseling and testing services.

Despite the identified disparities and barriers, there is a strong emphasis in ongoing efforts to promote health equity in HBOC cancer screening. Strategies such as telemedicine, culturally targeted educational interventions, and narrative videos can greatly improve knowledge and uptake of genetic counseling and testing among the community. Additionally, screening alternatives that are more cost-effective and able to reach individuals in more secluded areas demonstrate a potential for mitigating HBOC risk. It is imperative to recognize the need for continued research, community engagement, and the implementation of targeted interventions to address the unique needs of the Hispanic and Latino population.

Chapter III. Student Contribution

Conceptualization

Once the community discussion audio recordings were transcribed by GMR transcription services, Ms. Huerta carefully read and performed a preliminary analysis of each transcription to develop the research question for her thesis. The question was informed by community members' input and a theoretical foundation in empowerment theory constructs. The student's positionality as a first-generation Mexican American with difficulty navigating the US healthcare system for her family and friends played a role in further conceptualizing this project. The student conceptualized this project as a means of exploring the diverse lived experiences of members of Latinos and Hispanics within the scope of hereditary cancers and the prevention tools available to this community in Georgia. Her objective was to garner their insights on the factors that either hinder or facilitate access to genetic cancer screening for individuals of Hispanic or Latino heritage, as well as the perceptions of these prevention tools within the community to increase uptake and better target this community. As an aspiring medical practitioner, she intends to emphasize these findings and adapt her healthcare approach with a comprehensive understanding of these obstacles and enablers, to cater to Hispanic and Latino communities more effectively and enhance their health outcomes.

Student Role

Ms. Huerta served as a Graduate Research Assistant (GRA) to support the Latino Community Engagement project. As a GRA, she was responsible for attending research training and project meetings as well as facilitating a small group discussion in Spanish for a half-day in-person community discussion group in Gwinnett County, Georgia.

Study Population and Recruitment

Our target population included Hispanics and Latinos who were living in the surroundings of Gwinnett County in Georgia (31 miles northeast of Atlanta), the location of our community partnering organization Hispanic Health Coalition of Georgia and Nett Church. Participants were eligible if they: 1) self-identified as Hispanic or Latino, indicating Hispanic or Latino ancestry; 2) spoke Spanish; and 3) were 25 or older (i.e., the age when risk-reducing intervention for BRCA mutation carriers are typically recommended to begin) (Petrucelli et al., 2016). Participants were recruited by Emory's research team and the Georgia Center for Oncology Research and Education (GA Core), as well as other local Latino community partners (e.g., the NETT church) via flyers, community partner outreach, and word-of-mouth outreach.

Those interested were directed to complete a recruitment screener in person or online through Emory Qualtrics. The screening questions were developed based on a study recruitment rubric we developed to maximize the diversity of the participants in the deliberation conference. Individuals who were invited and agreed to participate in the study were emailed or mailed a detailed consent form to review before the session. Participants were then asked to sign the consent form during registration on the day of the community discussion group.

Deliberation Conference Procedures

On Saturday, June 10th, 2023, we engaged 33 community members of Hispanic or Latino ancestry living in Northeast Georgia to take part in an in-person deliberation conference at the Nett Church in Gwinnett County. The research team assigned participants to five small groups that were balanced in the number of males and females, age, and levels of education. A trained Spanish-speaking facilitator moderated the discussion in each group. Upon completion of the half-day conference, participants were compensated with $200 in the form of a gift card. All study activities were approved by Emory University IRB (IRB01302023).

The half-day deliberation conference was solely conducted in Spanish and included: 40-minute introduction to HBOC via a pre-recorded lecture, 60-minute breakout group discussion regarding deliberation question, and 30-minute full group presentation of breakout group pros and cons. Participants were provided with structured materials defining and explaining the need for balanced scientific and ethical viewpoints in Spanish, as well as information about interests and experiences related to HBOC population screening. Following that, participants were asked to generate and prioritize pros and cons related to the question group members. These discussions culminated in participants voting on whether they believed Georgia should target all individuals of Hispanic or Latino descent in order to identify those at risk for HBOC. All group sessions were audiotaped and transcribed.

Prior to beginning the HBOC democratic deliberation, participants were allocated an hour to register, enjoy breakfast, and complete a pre community discussion group survey. Survey questions assessed participants' baseline awareness of Georgia's HBOC screening initiatives, as well as their perceptions of trust in the healthcare system, community agency, self-efficacy, and perceived benefits of HBOC screening. Concluding the half-day deliberation, participants were invited to complete a post community discussion group survey, similar to the pre community discussion group survey. This aimed to assess changes in perceptions and awareness, and to gather feedback on their overall participant experience. After completing the survey, participants were asked to sign-out and received their compensation. Participants were made aware that all questions in the surveys were optional and all feedback would remain anonymous.

Data Analysis

After receiving transcribed and Spanish to English translated audio recording from GMR transcriptions services, we conducted thematic analysis to identify distinct concepts and categories related to pros and cons of targeting Hispanic and Latino communities. We developed an inductive codebook based on careful reading of the transcripts and study team member (JH, DM, YG) discussion (**Appendix, Table 3**). **Qualitative analyses** of group transcripts were conducted using MAXQDA Software. Three study team members (JH, DM, YG) read through all small group deliberations transcripts (n=5) and coded one small group session to ensure accuracy of coding, as well as to ensure the clarity and completeness of the coding scheme. To increase the reliability of the coding process, two coders (JH, DM) coded each transcript independently and met to resolve discrepancies. After coding was completed, each transcript was systematically reviewed for the most commonly occurring themes and representative quotes were identified.

Quantitative descriptive analyses of survey data were conducted using SAS Software to characterize the participant's demographics. Changes in awareness and attitudes toward population based HBOC screening, trust toward the health care system, community agency, self-efficacy, and perceived benefits of HBOC screening were calculated based on pre- and post-deliberation surveys. Overall perceptions regarding deliberation satisfaction and deliberation effectiveness were quantified via post-discussion survey responses.

Deliverables

Ms. Huerta will publish a manuscript in a peer-reviewed journal with guidance from Drs. Guan and Lemon. The manuscript will contribute to the body of knowledge surrounding hereditary breast and ovarian cancer prevention services among racial and ethnic minority populations with an emphasis on the perceived barriers and facilitators to genetic testing and counseling provided by members from the Latino and Hispanic community in a community discussion group.

Chapter IV. Journal Article

ABSTRACT

Objective: Guided by the Community Empowerment Theory, this study utilized the Democratic Deliberation (DD) approach to gather informed opinions from communities of Hispanic and Latino ancestry on targeted screening for Hereditary Breast and Ovarian Cancer Syndrome (HBOC) screening in Georgia, and to identify and understand the barriers and facilitators associated with this approach.

Design: We recruited 33 Spanish-speaking Hispanic and Latino community members living in Georgia and conducted a half-day in-person democratic deliberation in Spanish. Following the viewing of pre-recorded expert testimonies, participants were asked to generate and prioritize pros and cons related to the question with group members. All group sessions were audiotaped and transcribed. We conducted thematic analysis following the empowerment theory framework to identify distinct concepts related to pros and cons. Participants were also asked to complete pre and post deliberation surveys. Survey data were analyzed using SAS to assess participant satisfaction with the deliberation process, and changes in participant community agency, self-efficacy to deliberate, perceived benefits of HBOC screening, and willingness to undergo genetic screening for HBOC.

Results: Participants generated impeding and facilitating influencers across all process levels, including person/group factors, environmental factors, and empowerment capacity. Frequently discussed concerns included fear of test results, cost, and access to testing and treatments, while common facilitating factors included improved awareness of HBOC risk and prevention, increased support and funding for the Latino community, and early detection and treatment. Deliberation survey results display overall support for the program, satisfaction with the deliberation process, and slight increases in perceived knowledge and attitudes post-deliberation.

Conclusion: Our study highlights the feasibility and effectiveness of DD for engaging Spanish speaking Hispanic/Latino community members in public health policy discussions. Study findings call for more efforts to address the community and societal level barriers and concerns.

BACKGROUND

Hereditary Breast and Ovarian Cancer syndrome (HBOC) is characterized by pathogenic variants within the breast cancer 1 (*BRCA1*) and breast cancer 2 (*BRCA2*) genes and accounts for 5-10% of all breast cancers and 15-20% of all ovarian cancers [1,2,3]. Women with HBOC syndrome have up to an 85% lifetime breast cancer risk and up to a 40% lifetime risk of ovarian cancer, in addition to increased risk of other cancers including fallopian tube cancer, melanoma, endometrial cancer, pancreatic cancer, and colorectal cancer [3,4]. Similarly, males with BRCA1/2 pathogenic variants have an increased absolute risk of breast and pancreatic cancer, with carriers having a higher likelihood of faster growing and higher-grade prostate tumors [5]. Screening and identifying individuals with *BRCA1/2* pathogenic variants at an early stage improves patient quality of life and overall survival rate through timely prevention and treatment [6,7].

Among the Hispanic and Latino community, Latinas have been found to have the second-highest prevalence of BRCA1/2 pathogenic variants and are diagnosed with breast cancer at younger ages and with tumor types (i.e., triple-negative breast cancer) linked to hereditary pathogenic variants [8,9,10]. Despite these alarmingly high statistics, Hispanics and Latinos remain the racial/ethnic group with the lowest awareness of genetic testing when compared to non-Hispanic Whites and other minorities [8,11,6]. Additionally, men are ten times less likely to seek genetic counseling and testing due to misconceptions about associated cancer risks for men, psychological discomfort with being at-risk, and lack of awareness about how to access genetic counseling [5].

Disparities in genetic cancer risk assessment uptake remain prevalent despite the availability of low-cost population-based screening options [8,12]. Latinos in the US are more likely to be uninsured than other racial and ethnic groups, leading to limited access to medical providers who can provide genetic service referrals [8]. Moreover, physicians have been noted to be less likely to recommend genetic testing to minority racial and ethnic communities [13,8]. These disparities are further exacerbated within the Latino and Hispanic community due to a multitude of unique barriers to care including language, lack of insurance, immigration status, medical mistrust, and health illiteracy [14,15].

Several complexities must be considered in deciding how best to encourage cancer genetic risk screening for Latinos in Georgia. First, biological discovery used to develop genetic risk assessment models are derived from White populations, and their applicability to Latinos is not well understood [6,16,17]. Second, because Latinos are underrepresented in cancer genomic databases, they are more likely to receive indeterminant genetic test results with no clear course of action [18,19]. Third, the Latino population is heterogenous with genetic roots tracing back to multiple continents and regions [20] Thus, characterizing population inherited cancer risk can vary greatly for Latinos in specific geographic locales. Fourth, issues of risk comprehension must be considered. Studies show that persons with low health literacy have difficulty processing complex information [11,21]. Even Latinos who are highly proficient in English may prefer receiving health information in Spanish or a mix of Spanish and English [11,21].

Exemplar culturally targeted interventions have been developed to facilitate communication about cancer genetic risk and genetic service uptake among Latino populations [22,23] However, many of these interventions have been tested among largely Cuban-ancestry Hispanics living in Florida [22,23]. The Latino population in Georgia largely comprises people of Mexican and Puerto Rican ancestry [24,25]. Evidence-based interventions have yet to be adapted for these large segments of Latino communities who face unique challenges related to cancer genetic risk.

Obtaining informed community perspectives toward genomics-informed application is crucial in reducing cancer related disparities [26]. Information processing theories have revealed current methodologies concentrated in focus groups and cross-sectional surveys as having low impact in motivating participants to provide thoughtful insight, consider the complexities of the new discourse, or feel empowered to believe they can make a change [27]. Our prior work and the empowerment theory suggest active community engagement has benefits for empowering minority communities to consider genetic risk screening more thoughtfully [26]. Empowerment research focuses on the process of restoring power in individuals and communities attempting to gain control and influence over conditions impacting their overall wellbeing and quality of life [28]. Empowering a community through a theoretical lens can be delineated through a process mechanism, as displayed in our conceptual framework (**Figure 1)**. In the context of HBOC screening among the Latino and Hispanic community, the empowerment theory underscores the importance of actively listening to members of the community regarding all the factors influencing their ability to engage in HBOC preventative care to identify key priorities for the community via the *process mechanism*.

Democratic deliberation (DD) could enhance the community empowering process by first providing individuals with balanced and unbiased information about various, often conflicting, viewpoints on the topic. Participants can then use this knowledge to engage in thoughtful discussions with others, aiming the reach a consensus on the best actions for the community at large [26,29,30]. DD has been used in numerous health policy context internationally [31]. Prior studies show that DD is particularly useful in the case of complex and new health topics, and when considering health promotion programs for marginalized populations [32]. Shifting towards more in-depth community engagement approaches like democratic deliberation, where targeted audiences are actively engaged and viewpoints extending beyond personal implications, serves as a steppingstone towards engaging racial and ethnic minorities in the creation of cancer genomic interventions [26].

To this end, this study used a DD approach to gain informed community perspectives regarding targeting communities of Hispanic and Latino Ancestry for HBOC screening in Georgia. We aim to answer the following research questions: Should Georgia target all individuals of Hispanic and Latino Ancestry to identify those at risk for Hereditary Breast and Ovarian Cancer? What are the perceived barriers and facilitators that affect genetic cancer screening awareness and access within the Latino and Hispanic Community? What concerns and recommendations do Latinos and Hispanics engaging in a democratic deliberation pose to promote health equity regarding cancer prevention?

METHODS

Study Population and Recruitment

The target population for this study included Hispanics and Latinos living in Gwinnett County Georgia. Participants were eligible if they: 1) self-identified as Hispanic or Latino, indicating Hispanic or Latino ancestry; 2) spoke Spanish; and 3) were 25 or older (i.e., the age when risk-reducing intervention for BRCA mutation carriers are typically recommended to begin) [33]. Participants were recruited by Emory's research team and the Georgia Center for Oncology Research and Education (GA CORE), as well as other local Latino community partners (e.g., the NETT Church) via flyers, community partner outreach, and word-of-mouth outreach.

Those interested were directed to complete a recruitment screener in person or online through Emory Qualtrics. The screening questions were developed based on a study recruitment rubric we developed to maximize the diversity of the participants in the deliberation conference. Individuals who were invited and agreed to participate in the study were emailed or mailed a detailed consent form to review before the session. Participants were then asked to sign the consent form during registration on the day of the community discussion group. All study activities were approved by Emory University IRB (IRB01302023).

Data Collection

Consenting participants (n=33) engaged in an in-person deliberation conference at the NETT Church in Gwinnett County. The research team assigned participants to five groups that were balanced in the number of males and females, age, and levels of education. A trained facilitator moderated the discussion in each group. Upon completion of the half-day conference, participants were compensated with $200 in the form of a gift card.

The half-day deliberation conference included: 40-minute introduction to HBOC via a pre-recorded lecture, 60-minute breakout group discussion regarding deliberation question, and 30-minute full group presentation of breakout group pros and cons. Participants were provided with structured materials defining and explaining the need for balanced scientific and ethical viewpoints, as well as information about interests and experiences related to HBOC population screening. Following that, participants were asked to generate and prioritize pros and cons related to the question with group members. These discussions culminated in participants voting on whether they believed Georgia should target all individuals of Hispanic or Latino descent to identify those at risk for HBOC. All group sessions were audiotaped and transcribed.

Prior to beginning the HBOC democratic deliberation, participants were asked to complete a pre discussion survey. Survey questions assessed participants' baseline awareness of Georgia's HBOC screening initiatives, as well as their perceptions of trust in the healthcare system, community agency, self-efficacy to deliberate, and perceived benefits of HBOC screening. Concluding the deliberation, participants were invited to complete a post community discussion group survey, similar to the pre community discussion group survey. This aimed to assess changes in perceptions and awareness, and to gather feedback on their overall participant experience. Participants were made aware that all questions in the surveys were optional and all feedback would remain anonymous. All study materials were developed in English and Spanish, and the deliberations were conducted in Spanish.

Data Analysis

After receiving the transcribed and Spanish-to-English translated audio recording from GMR Transcription Services, we conducted thematic analysis to identify distinct concepts and categories related to pros and cons of targeting Hispanic and Latino communities. We developed an inductive codebook based on careful reading of the transcripts and study team member (JH, DM, YG) discussion. The empowerment theory guided both our codebook development and data analysis. The *process* arm of the framework identifies impeding and facilitating factors across three levels - person/group, environment, and policy - impacting the community's awareness and access to HBOC genetic testing.

Qualitative analyses of group transcripts were conducted using MAXQDA. Three study team members (JH, DM, YG) read through all small group deliberations transcripts (n=5) and coded one small group session to ensure accuracy of coding, as well as to ensure the clarity and completeness of the coding scheme. To increase the reliability of the coding process, two coders (JH, DM) coded each transcript independently and met to resolve discrepancies. After coding was completed, each transcript was systematically reviewed for the most commonly occurring themes and representative quotes were identified (**Table 3**).

Quantitative descriptive analyses of survey data were conducted using SAS to characterize the participant's demographics, satisfaction with the deliberation, as well as deliberation impacts on participants' perceived knowledge, community agency, self-efficacy to deliberate, and willingness to undergo genetic screening for HBOC.

RESULTS

Participant Characteristics

Participants included both males (12%) and females (88%), between 20 to 69 years of age, with the majority being 30-39 years old (36%) (**Table 1**). Participants had a wide range of education levels and employment statuses, with half of the sample being college graduates (52%) and employed (46%). Most participants reported their country of origin as Mexico (28%), followed by Colombia (21%), with other participants coming from other countries in South America, Centra America, or the Caribbean. The majority of participants (85%) reported Spanish as their preferred language. Nearly half of respondents reported being a member of a church (49%), while the other did not report any church membership.

Community Perceptions of Targeted HBOC Screening

Applying the empowerment theory as a guiding framework for understanding the concerns and perceptions of the Hispanic and Latino community regarding targeted HBOC genetic screening, themes for impeding and facilitating influencers emerged across all community empowerment process levels, including person/group factors, environmental factors, and empowerment capacity (**Figure 1**). Person/group factors refer to all impeding or facilitating factors affecting the community's empowerment goals. Environmental factors included all social and environmental factors affecting the community's empowerment goals Lastly, elements recognized as empowerment capacity refer to the community's capacity to shape their conditions.

Person/Group Factors

Impeding Influencers. When asked about potential concerns regarding the implementation of Hispanic and Latino Ancestry-targeted HBOC screening, participants expressed concerns, both for themselves and other members of the community. The prevailing concern voiced by participants was fear associated with an individual's current immigration status. Participants noted that lack of legal documentation and fear of legal implications plays a major role in an individual's mentality and approach towards seeking and accessing health related services, as one noted:

> "Fear has a lot to do with it. I have a lot of relatives who have refused to go and get checked, just for a check-up, because of fear. The fear of money and legal status. I'm going to get deported. They're going to see my information."

Another highlighted influencer includes fear of genetic screening test results and outcomes, with one participant describing this fear by stating "sometimes the word cancer means death." Several participants expressed a preference for not knowing their results, citing heightened stress attributed to the challenges associated with seeking treatment and navigating barriers to access. Other concerns regarding targeted screening included fear of being ethnically profiled if Hispanics and Latinos were found to have high rates of pathogenic variants and heightened fear of diagnosis due to stigma surrounding cancer in the community. Lastly, many participants noted feelings of not belonging and not feeling worthy of support from the United States government mentioning "we are in a country that is not ours. The priority here will always be the American citizen."

Facilitating Influencers**.** The main facilitating influencers mentioned underscore the potential improvement of awareness and knowledge of HBOC risk, prevention, and treatment, as well as available HBOC resources. They noted wanting more workshops and talks to expand on HBOC prevention and to help educate the Latino community and combat any misinformation. Overall, they expressed that through such education, the perceived importance of testing among the community will improve and help the overall health of the Hispanic and Latino community.

Participants also highlighted two potential facilitating factors that could impact their emotional, communicative, and relational abilities if targeted genetic screening was implemented. They note an improved sense of self-advocacy and overall improved detection of HBOC and treatment at earlier stages. Participants note an increased opportunity to "set an example for others," and "knowledge to talk to a friend, a wife, a contact, or a partner, and then it spreads." They state that genetic screening "would help families detect the risk that they have and help develop plans to take better control of [their] health".

Environmental and Social Factors

Most concerns raised by participants were categorized under environmental and social impeding factors. Participants voiced having difficulty accessing healthcare services due to high cost, lack of insurance, transportation, language comprehension, and culturally competent care and representation within the field. For example, one participant expressed: "We open up more with, with doctors or with people who speak Spanish, for the same reason that we can engage better." Another participant said:

> "If I'm going to look for a doctor, I want to find a Hispanic woman for my care. I think a lot of times we find a doctor, maybe its, you know, a white man, or a male, and they don't give us the attention we need. So, if they check us, and we find that we have it, and they refer us to a doctor, lets say for chemo or to treat that cancer, and they're not giving us the

> care we need, then maybe it wouldn’t be the right care. I’m going to want a doctor who will pay attention to me and meet my needs.”

Others noted cultural aspects such as religious beliefs, machismo, and stigma associated with women’s health as deterrents to seeking HBOC prevention and care. One participant highlighted the particular taboos around sexual and reproductive health, saying “When you talk about the reproductive system and the problems that a woman or a man can have, you have to be very careful with religious beliefs.” Another also highlighted gender expectations and machismo expressing:

> “It’s something cultural because Latinos, that mentality that unfortunately highlights the Latino; I say unfortunately because I am very Latino and at the same time, I accept that our culture suffers from that ego of machismo. So, men don’t get sick.”

Many individuals highlight social and political factors like racial and/or ethnic discrimination, legal status implications and immigration laws as social determinants of access and healthcare seeking behaviors. For instance, a participant highlighted how political shifts in the country escalate certain fears and acts as deterrent remarking “now in Florida with the new governor, you have to state your immigration status, now people are going to be much more afraid to go for an exam, because they have to inform if they are undocumented in the country.”

The most prominent impeding social and environmental factor mentioned was cost and access to follow-up treatment. When considering the effectiveness of this program, participants highlight that without proper access and cost coverage to treatment, members of the Hispanic and Latino community will not benefit as intended. Others cite a lack of trust in the medical system and scientific community among the Latino community, noting that they don’t feel supported by the US medical system and stating that "if [this initiative is] done for the purpose of acquiring data for public health and not to help us, we are not interested." Participants also note that a lack of awareness of available resources and ability to navigate the healthcare system play a major role in the community's ability to participate in this initiative and receive proper follow-up care. Another concern raised focuses on the potential violation of autonomy and privacy underscoring that not everyone in the community wishes to participate and may feel forced to participate.

Empowerment Capacity

Participants voiced important factors that would facilitate their capacity to shape and improve their HBOC prevention practices. They underscore the importance of targeted genetic cancer screening as it will advance scientific knowledge of Latino genetic profiles and potentially increase research grants and funding for the Latino community, as one participant notes, "this is going to open the doors to providing these types of programs with more funding to our community."

They also note that programs like this serve as an opportunity for the state to acknowledge and act on the lack of past support they have given the community underscoring the potential to promote the economy with healthier inhabitants as well as reduce the cost burden on the state and healthcare system. For example, one participant expressed "by truly focusing on us, there's the possibility that the economic contribution is greater," and another stated "if all these diseases are prevented, it would also mean the reduction of costs in the health system, and the government."

Furthermore, participants note that for this program and any future interventions to be most effective, cultural competency must be fostered, as well as health equity within the genetic counseling field. The community emphasized the significance of cultural understanding, as expressed by one participant: “all those details that usually come with the culture of Hispanics, they need to be taken into account when they want to do this kind of project. They have to take those details into account because if not, it won’t be of any use.”

Impacts of Deliberation

Prior to deliberation, only 9 out of 33 participants were aware of Georgia’s statewide HBOC family history screening program. Trust in the healthcare system was moderately rated (M=8.87, SD=1.93, range: 3-15). Nonetheless, a strong willingness to engage in family screening, consult genetic counselors, and undergo blood testing was evident both before and after the deliberation (**Table 2**).

Participants showed an increase in community agency to influence HBOC screening policies and programs from a baseline mean of 20.38 (SD=4.79) to 22.03 (SD=3.32) post-deliberation (p=0.217). Self-efficacy to deliberate improved significantly, increasing by 2.38 points to 28.35 (SD=2.21, p=0.0002). Perceived knowledge of HBOC risk and screening importance increased (M=22.53, SD=4.21, p=0.107), although benefits perceived from targeted genetic cancer screening among Hispanics and Latinos showed a slight decrease post-deliberation (M=17.86, SD=1.95, p=9.839).

Satisfaction with the Deliberation

Participants expressed high satisfaction with the deliberation process, rating their facilitators' attentiveness and the fairness of the decision-making process highly (M=9.95, SD=0.10). They also rated the effectiveness of various sessions activities positively - including Q&A, expert video presentation, and discussions (M=9.26, SD=1.08). Furthermore, 67% of participants were willing to engage in an online version of the session, and 82% were open to participating in a similar conference in the future.

DISCUSSION

Our study furthers the discourse pertaining to the potential benefits of utilizing democratic deliberation as a tool for community engagement among communities often excluded from public health policy decisions [26]. Consistent with previous studies, participants displayed understanding and active engagement with the deliberation process by providing reasoned justifications of their pros and cons using information and concepts provided to them during the lectures and upholding the concept of "common good" to explore perspectives beyond their personal opinions [26,34]. Deliberation satisfaction and efficacy were rated highly by participants indicating they felt comfortable with the discussion and final decision made by the group, as well as the overall usefulness of each activity conducted during the session. Additionally, perceptions of perceived knowledge on the topic, community agency to influence public policy, and self-efficacy in their ability to converse on the topic increased post deliberation underscoring the potential to foster positive change within communities through this process.

Moreover, research samples in studies focused on HBOC among the Hispanic and Latino community predominantly consist of English-speaking and bilingual Latina women with higher levels of education, income, and insurance coverage [35,36,15]. Consequently, study findings do not reflect the entire community and fail to address barriers others in the community may face. Conducting the democratic deliberation exclusively in Spanish fostered engagement from members of the community who would typically be excluded with the overall aim of creating a diverse study sample reflective of the Hispanic and Latino community in Georgia. Study findings displayed a wide range of perspectives including both males and females with various levels of education and employment status, as well as various countries of origin. This is particularly significant when considering the Hispanic and Latino population, given that it is both culturally and genetically diverse across geographic regions [6,37].

Analysis of deliberation results was guided by the empowerment theory as it emphasizes the promotion of self-development and awareness among both individuals and communities. The use of this framework ensured our study identified multi-level factors that the community deemed as impeding or facilitating for their overall empowerment in HBOC genetic screening awareness and access [38,28]. Moreover, using the empowerment theory ensured the political nature surrounding this topic remained at the forefront emphasizing the voices of the community regarding public policy and the potential implications of implementing targeted screening in Georgia [39]. This HBOC democratic deliberation and study serves as the initial steps of the empowerment theory as it only captures and focuses on the process arm. Future interventions or the continuation of this research, if and when Georgia begins targeted HBOC genetic screening for the Hispanic and Latino community, can focus on the outcome arm of the empowerment theory to produce a comprehensive picture of the intervention's effects on the community.

Members in the deliberation voiced their support for Ancestry-targeted screening in Georgia highlighting its potential to not only advance scientific knowledge of Latino genetic profiles but also increase research grants and funding to help combat the barriers they noted of most concern. When considering the common good, community members recognize the positive impact a healthier Hispanic and Latino community can have on the nation. This includes promoting the economy with greater contributions and reducing costs within both the healthcare system and government expenditures.

Findings underscored the need to focus research and interventions on both the community and societal level. Most concerns raised by participants were categorized as environmental and social impeding factors. At this level, participants voiced having difficulty accessing genetic counseling services due to high cost, legal status implications, and lack of insurance, transportation, language comprehension, culturally competent care, and representation within the field. These barriers are commonly observed in studies examining barriers and facilitators to screening uptake among the Hispanic and Latino community, however participants also highlighted how these barriers affect their attitudes towards the medical and research community subsequently impacting their healthcare-seeking behavior [40,41,36,35]. In order for the community to truly benefit and feel supported by the US, the program must ensure continuity of care with proper access and cost coverage to treatment if an individual is found to have positive results; awareness is not sufficient. Participants expressed a strong desire for greater cultural understanding and representation within the field, a sentiment supported by current research which notes only 6% of genetic counselors in the US speak Spanish [23,42]. Moreover, policymakers and researchers must prioritize open communication and transparency with the community as participants cited that they would not be interested in a program solely aimed at collecting data for public health without efforts to truly help the community.

Several limitations were identified in this study. The data collection was restricted to a single county within the state, which may limit the applicability of the findings in other areas of the state. Additionally, our study did not observe many significant changes in attitudes towards HBOC cancer screening. Potential reasons for this lack of detection include the relatively small sample size or the participant’s initial high ratings at baseline.

In conclusion, our study underscores the feasibility and effectiveness of democratic deliberation as a method to engage community members on public health policies. There is also a call to shift research and intervention focus to the community and societal level as most concerns and barriers highlighted by participants fell within this category. Furthermore, it is crucial for policymakers and researchers to prioritize open communication and transparency with community members to not only uplift their voices but also to ensure sustainable change and foster trust with the community.

Appendix. Figures and Tables

Figure 1. Conceptual Model Applying Empowerment Theory in Latino and Hispanic Community Democratic Deliberation

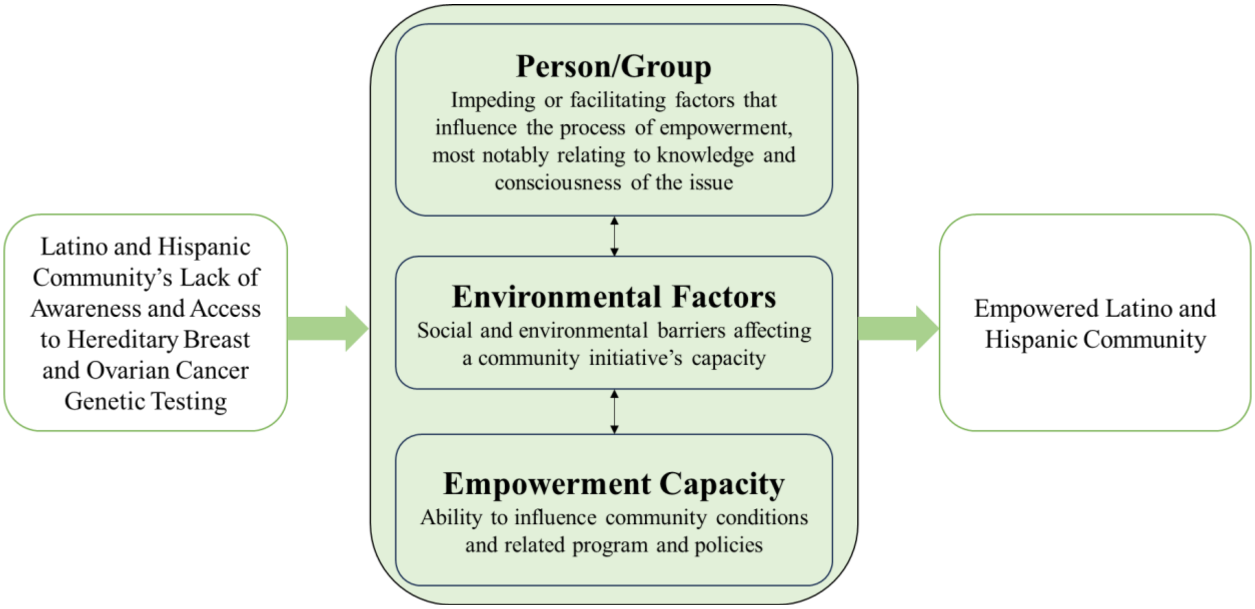


Table 1. Participant characteristics from community deliberation group (n=33)

Member Characteristics	**Total** (n=33)
Gender	
Female	29 (88%)
Male	4 (12%)
Age	
20-29	5 (15%)
30-39	12 (37%)
40-49	8 (24%)
50-59	5 (15%)
60-69	3 (9%)
Education	
Some High School	2 (6%)
High School Graduate	5 (15%)
Some college	3 (9%)
College graduate	17 (52%)
Postgraduate work	3 (9%)
Prefer not to respond	3 (9%)
Employment status*	
Unemployed	11 (33%)
Self-employed	7 (21%)
Employed	15 (46%)
Retired	0 (0%)
Time living in Gwinnett County	
Less than 1 year	8 (24%)
1-5 years	11 (33%)
More than 5 years	14 (43%)
Race	
Black or African American	5 (15%)
White	15 (46%)
Other	12 (36%)
Country of Origin	
Brazil	1 (3%)
Colombia	7 (21%)
Dominican Republic	4 (12%)
Guatemala	2 (6%)
Honduras	1 (3%)
Mexico	9 (28%)
Nicaragua	2 (6%)
Peru	2 (6%)
Puerto Rico	1 (3%)
Venezuela	4 (12%)
Preferred Language at Home	
English	3 (9%)
Spanish	28 (85%)
Other	1 (3%)

Primary care in FQHC	
Yes	5 (15%)
No	27 (82%)
Don’t Know	1 (3%)
Member of church	
Yes	16 (49%)
No	17 (51%)
Prior experience with Committees	14 (42%)
Yes	19 (58%)
No	
Experience voting in Local & National Elections*	
Always	8 (24%)
Sometimes	7 (21%)
Never	17 (52%)

*****Missing 1 response

Table 2. Deliberation Impacts on Participants

Survey Measures	**Baseline**				**Post-Deliberation**				**Overall**	**P-Value**
	N	Mean	STD	Max	N	Mean	STD	Max	Mean Diff	Alpha=0.05
Community agency	30	20.83	4.79	30	31	22.03	3.32	30	1.2	0.217
Self-efficacy to deliberate	31	25.97	4.28	30	31	28.35	2.21	30	2.38	0.0002*
Perceived HBOC Knowledge	31	20.39	5.59	25	32	22.53	4.21	25	2.14	0.107
Perceived benefit of HBOC screening	31	18.35	2.3	25	28	17.86	1.94	25	-0.49	0.839
Willingness to…										
Complete a 6-question HBOC family screening form	33	4.55	0.87	5	33	4.82	0.53	5	0.27	0.0831
Meet with a genetic counselor if screening identifies a risk for HBOC	33	4.79	0.48	5	33	4.88	0.42	5	0.09	0.4138
Undergo genetic testing through blood sample	33	4.76	0.56	5	33	4.79	0.48	5	0.03	0.8007

Table 3. Qualitative Analysis Codebook

Qualitative Codebook guided by Empowerment Theory Process Mechanism			
Code/Subcodes	**Definition**	**English Quote (translated)**	**Spanish Quote**
1. Impeding Person/Group Factors			
Fear related to current immigration status	Participant highlights fear relating to current immigration status as an impeding factor towards seeking care	"Fear has a lot to do with it. I have a lot of relatives who have refused to go and get checked, just for a check-up, because of fear. The fear of money and legal status. I'm going to get deported. They're going to see my information."	"El miedo tiene mucho que ver. Tengo muchos familiares que no han querido ir ni a checarse, nada más un chequeo, por el miedo. El miedo de el dinero y estatus legal. Me van a deportar. Van a tener mi información."
Fear of test results	Participant is fearful of a positive HBOC genetic test, and the consequences associated with this result, as well as inaccurate results and the potential implications that can arise from these results	"Sometimes the same fear, not only financial. I think also fear of knowing that they might find something." / "The fact also that, from the seven tests, even though they told you it was negative, it could be that it was positive."	"A veces el mismo miedo no solamente a lo financiero. Yo creo que también miedo a saber que puedan encontrar algo." / "El hecho también de que, de las siete pruebas, aunque te hayan dicho que es negativo, puede ser que era positivo."
Perceived stigma associated with cancer	References to negative perceptions, beliefs, and attitudes surrounding individuals with cancer and notes being fearful of judgement	"They prefer to stay with the doubt, than to know the results and go to treatment, because sometimes the word cancer means death. So they are afraid of, of doing that and being certain that they have cancer."	"Prefieren quedarse con la duda, que saber los resultados y ir a tratamiento, porque a veces la palabra cáncer significa muerte. Entonces ellos tienen miedo de hacer eso y estar en certeza de que tienen cáncer."

Concerns related to ethnic profiling	Any mention of being treated negatively due to their ethnicity within the field or as a result of widespread testing	"It's funny, but you had a reaction that many people have regarding Jews. They are the highest group, uy, stay away. So that's called profiling … So, if they do the study on us and we turn out - that we're above Jews, then nobody wants - is going to want anything to do with us."	"Y es chistoso, pero, tú tuviste una reacción que muchas personas tienen. Ellos son el grupo más alto, uy, aléjate. Entonces eso en inglés se llama profiling. Entonces, si nos hacen el estudio y resultamos - que somos sobre los judíos, entonces van a querer nada que ver con nosotros."
Lack of belongingness/worthiness	Participant notes a sense of worthiness connected to HBOC prevention access and notes feelings of not being worthy of receiving support as a social barrier affecting the community's ability to improve HBOC prevention	"Unfortunately, in our community it is very - they have the taboo of not asking for help, that because they are not in their country and they are just working; they may be very sick with - they have, they know they may have cancer, this and they don't ask for help, why? Because they say no, they are not going to help us because - we don't belong. It is not your right."	"Lastimamente, en nuestra comunidad es muy - tienen el tabú de no pedir ayuda, que porque no están en su país y se dedican nada más a trabajar; pueden estar muy enfermos de - que tienen, saben que tienen a lo mejor cáncer, esto y no piden ayuda, ¿por qué? Porque dicen no, no nos van a ayudar porque no tengo derecho. No pertenecesmos. No es su derecho."
2. Facilitating Person/Group Influencers			
Improve knowledge of HBOC risk, prevention, and treatment	Any mention of increasing education in the community to raise overall awareness and understanding of HBOC prevention and treatment	"Educating ourselves, uh, well, we can educate others, it's that simple. And, having that education, which gives me the, the prevention, will be more treatment."	"Educandonos, eh, pues podemos educar a otros, es así de sencillo. Y, teniendo esa educación, que me da la, la prevención, será más tratamiento"

Improve self-advocacy	References to education acting as a promoter for self-advocacy amongst individuals in the community and the community as a whole	"We have check ourselves, review ourselves, and – and we have to set an example for others who – who have critiques and beliefs that are rooted, and they don't, how do I say this, don't go see a doctor until they feel really bad."	"Tenemos que checarnos, revisarnos, y – y tenemos que ser un ejemplo para las demás que – que tienen criterios que son muy arraigados, que no quieren, como les digo yo, hasta que ya se sienten mal es cuando van al doctor"
Improve early detection and treatment	Participant notes the program's importance in improving treatment of HBOC with early detection	"It would help families to detect the risk that they have to help develop plans to control that."	"Ayudaría a las familias a detectar el riesgo que tiene para poder desarrolar planes para controlar eso."
Improve awareness of available HBOC resources	Participant highlights a need to raise awareness of HBOC resources available to the community	"They don't know the services available for prevention. They don't know the services available for treatment; uh, people that, that simply don't take care of their health because they don't know the risks they have."	"Desconcen los servicios disponisbles para prevención. Desconocen los servicios disponibles para tratamiento; eh, gente que, que simplemente no atiende su salud porque no conoce los riesgos que tiene."
3. Environmental and Social Factors			
Cost	Any mention of cost acting as a barrier to seek or access healthcare services.	"I think that another reason why they don't, they don't do it, is because of the costs, because they don't have medical insurance and the costs are very high."	"Creo yo que también otra parte por la que no, no se lo hacen, es por los costos, porque no tienen un seguro médico y los costos son muy altos."

Insurance Status	Any mention of insurance or lack thereof acting as a barrier to seek or access healthcare services.	"Unfortunately, if you don’t have insurance, if you don’t have health insurance, they can’t take care of you. So, the health system, when it comes to a problem like this one, is going to have to look for where it’s going to have those resources to be able to support you."	"Desgraciadamente, si no tienes aseguranza, si no tienes un seguro médico, no te pueden atender. Entonces, el sistema de salud, cuando se trata de un problema como este, va a tener que buscar de dónde va a tener esos recursos para poder apoyar."
Transportation	Any mention of transportation or lack thereof acting as a barrier to seek or access healthcare services.	"I tell them "Come get your Pap smear free, mammogram, and STDs." And they respond, "They're going to ask me for information, and I'm going to have to give my name. And how do I drive there?" They don't have transportation."	"Les digo “Vengan, para que se hagan el Papanicolau gratis, mamografías, y STDs. Y ellas dicen “Y me van a pedir información, y voy a tener que dar mi nombre. ¿Y cómo manejo hasta allá?” No tienen transporte."
Language Comprehension	Any mention of language differences or lack of language comprehension acting as a barrier to seek or access healthcare services.	"A very big part of the reason why a lot of Latino people don't search, is because they don't speak the, the same language. Because there are no translation services in many places. There are no people to help you translate."	"Una parte muy grande de la razón por la que mucha gente latina no busca, es porque no hablan el, el mismo idioma. Porque no, no hay traducción en muchos lugares. No hay personas que te, te ayuden a traducir."

Lack of culturally competent care and representation	Any mention of culturally incompetent care of lack of representation in the field acting as a barrier to seek or access healthcare services.	"If I'm going to look for a primary doctor, I want to find a Hispanic woman for my care. I think a lot of times we find a doctor, maybe it's, you know, a white man, or a male, a man, and they don't give us the attention we need. So, if we're going to say, if they check us, and we find that we have it, and they refer us to a doctor let's say for chemo, for whatever, to treat that cancer, and they're not giving us the care we need, then maybe we don't – it wouldn't be the right care. Do you understand me? I'm going to want a – a doctor who will pay attention to me and meet my needs and not someone who treats me like just another patient."	"Si yo voy a encontrar un doctor primario, yo quiero encontrar a una mujer hispana por la atención. Yo creo que muchas veces, encontramos a un doctor, quizás sea, tú sabes, un – un blanco, o un male, un hombre y no nos dan la atención que necesitamos. So, si vamos a decir, si nos chequean, y encontramos que tenemos eso, y nos refieren a un doctor a ver for chemo, para lo que sea, para tratar ese cancer, y no están dando la atención que necesitamos, también nosotros quizás que no – que no sería bien. ¿Me entiende? Yo voy a querer un – una doctora que me ponga la atención a mí y lo que yo necesito; no alguien que me trata como un paciente más."
Religious beliefs	Any mention of religious beliefs acting as a social barrier affecting the community's ability to improve HBOC prevention	"So much taboo also includes religion. There are religions that don't let people go to check their health."	"Tanto los tabú también incluye la religión. Hay religiones que no dejan que las personas vayan a ver – a chequearse la salud."

Machismo	Any mention of 'machismo', or strong and aggressive masculine pride as a social barrier affecting the community's ability to improve HBOC prevention	"It's something cultural, because Latinos have that mentality, that unfortunately highlights the Latino; I say unfortunately because I am very Latino and, and at the same time I accept that our culture suffers from that ego of machismo. So, men don't get sick. So, I am not like that, I go to the doctor five times a year. Here I have been treated for that"	"Es algo cultural, porque los latinos tienen esa mentalidad, que destaca desafortunadamente al latino; digo desafortunadamente porque yo soy muy latino y, y a la misma vez acepto de que nuestra cultura sufre de ese ego de machismo. Entonces, que los hombres no se enferman. Entonces, yo no soy así, yo voy cinco veces al doctor al año. Aquí me han tratado de eso."
Stigma associated with women's health	Any mention of women's health as a stigmatized topic acting as a social barrier affecting the community's ability to improve HBOC prevention	"They should not be ashamed to, uh, examine their breasts, examine their vagina, open their labia, and wash themselves, and touch themselves properly. Why? Because some of them were not taught from an early age."	"Que no les de pena, eh, examinarse sus senos, examinarse su vagina, abrirse sus labios y lavarse, y tocarse bien. Hacer el aseo. ¿Por qué? Porque algunas no les enseñaron desde pequeñitas. "
Racial/Ethnic discrimination	Any mention of a discriminatory event due to race or ethnicity acting as a barrier to seek or access healthcare services.	"If an American arrives and you arrive, they give priority to the American because he has insurance, because he has everything."	"Si llega un americano y llegas tú, le dan la prioridad al americano porque él tiene su seguro, porque tiene todo."

Legal status implications	Potential repercussions of immigration status are noted as a barrier to seeking care, such as deportation.	"Why it would not be good, could be because, the means that would be used to identify these people at risk, could scare the population because of their immigration status."	"Por la que no sería bueno, podría ser porque, los medios que se utilicen para identificar a estas personas en riesgo, podrían asustar la población debido a su estatus migratorio."
Immigration laws	Any mention of immigration status acting as a barrier and determinant of eligibility and access to insurance	"When they say target the Hispanic or Latino community, what about people who have a negative immigration status, that is, who are not legal? Are they also offered part of the program or are they only people who are legally...?"	"Cuando dicen target la- la comunidad hispana o latina, ¿qué pasa con las personas que tienen un estatus migratorio negativo, o sea, que no son legales? ¿A ellos también se les ofrece parte del programa o solamente son personas que son legalmente…?"
Cost and access to follow-up treatment	Individual highlights fear of being unable to receive follow-up treatment due to lack of access or inability to cover cost	"Not everybody has the ease or the means or the tools to be able to afford this type of exams. Uh, and, therefore, if you are diagnosed, uh, and you cannot afford to pay for treatment, then you are also in limbo"	"No todo el mundo tiene la facilidad o los medios o las herramientas como para poder costearse este tipo de exámenes. Eh, y, por lo tanto, si lo diagnostican, eh, y no tiene cómo pagar un tratamiento, pues entonces ahí queda también en el limbo."
Lack of trust in medical system and scientific community	Any mention of unethical research or negative past experiences leading to a lack of trust of the medical community	"You're going to find doctors who don't care about anything and just want the money. Worse, if you have like state insurance."	"Te vas a encontrar doctores que no les importa nada y que solo quieren el dinero. Peor, si uno tiene como seguranza del estado."

Lack of awareness of available resources	Participant notes lack of awareness among the Latino community regarding available resources and programs aimed at HBOC prevention	"Sometimes people don't have orientation, where to go, where to look for information."	"Aveces no tienen orientación, dónde ir, dónde buscar información."
Lack of awareness in navigating healthcare system	Any concerns related to challenges in navigating healthcare within the American system, due to its intricate nature and lack of proper resources to raise comprehension	"I think one of the things I’ve also seen in my community, this, is the ignorance of a lot of – a lot of Latin groups, especially in a lot of women. Uhm. We come here, and well, we don’t – we don’t know the system. So, as I say, uh, sometimes we won’t go to a doctor up until we’re really in pain."	"Creo que una de las cosas también que yo he visto en mi comunidad, este, es la ignorancia de muchas – de muchos grupos latinos, de muchas mujeres, principalmente. Em. Llegamos aquí, y, pues, no – no conocemos el sistema. Entonces, como le digo, eh, a veces hasta que nos duele algo es cuando vamos al doctor."
Health negligence due to conflicting priorities	Participant highlights conflicting priorities such as work, school, or familial roles as a major social barrier affecting the community's ability to improve HBOC prevention and a major contributor to being negligent of one's health	"The rent that has gone up, the food, that is, everything; one as a Hispanic, as a mother you see, this for light, for rent, for food. You have nothing left for health."	"La renta que ha subido, la comida, o sea, todo; uno como hispano, como madre tu ves, esto para la luz, para la renta, para la comida. No te queda nada para la salud."

Violation of autonomy and privacy	Participant voices concerns relating to the potential violation of autonomy and privacy if members in the community feel forced to participate in state-wide genetic testing	"We're in a country where people are very sensitive to the issue of violation of rights. Ah, don't violate my rights, my privacy. I have my right, first amendment of the United States. So people say, no, I don't want to be forced to do anything I don't want to do."	"Estamos en un país donde la gente es muy delicada con el tema de violación de derechos. Ah, no me violes mis derechos, mi privacidad. Yo tengo mi derecho, primera enmienda de los Estados Unidos. Entonces la gente dice, no, yo no quiero que me forcen a hacer nada que yo no quiero hacer."
4. Empowerment Capacity			
Advance scientific knowledge	References to the potential of improving HBOC genetic understanding to improve health outcomes	"Focusing on the Hispanic community. You can develop a deeper understanding of our genetics and our individual factors."	"Enfocarse en la comunidad hispana, um. Se puede desarrollar un entendimiento más profundo de nuestra genética y nuestros factores individuales."
Increase research grants and funding for Latino community	Any mention of strategies to secure additional financial support to improve HBOC preventative services and resources	"Focusing more on the Hispanic community. This, its going to open to doors to providing these types of programs with more funding. That's going to facilitate that for people. To educate more people within our culture."	"Enfocándose más en la comunidad hispana. Este, va a abrir las puertas a que le brindan a estos tipos de programas más fondos. Eso va, este, a facilitar que, este, busquen a – a gente. Para que se eduque más gente dentro de nuestra cultura."

Acknowledge and act on lack of past support	Participant notes the lack of support from the research community and highlights the potential to amend these past wrongs through this program	"They've always focused on American citizens, that, it's their right because it's their country, but that they give that importance to us as Latinos, to give us that right, to have health, of that right to be able to check us, to be able to live; because in our countries sometimes, because of the same that they do not support us, that is why we come here, to seek- to get ahead, to be able to have check-ups; so I think it is excellent that they focus on us, that they give us priority that, also because we Latinos make the United States strong."	"Siempre han estado enfocados en los ciudadanos americanos, que, es su derecho porque es su país, pero que nos den esa importancia a nosotros como latinos, darnos ese derecho, de tener salud, de ese derecho de poder chequearnos, de poder vivir; porque en nuestros países a veces, por lo mismo de que no nos apoyan, por eso venimos acá, a buscar a poder salir adelante, poder tener chequeos; entonces a mí me parece excelente que se enfoquen en nosotros, que nos tomen como prioridad que, también porque nosotros los latinos hacemos fuerte a Estados Unidos."
Promote economy	Participant underscores the potential benefit economic advantage associated with improving and focusing on Latino health	“By truly focusing on us, there’s the possibility that the economic contribution is greater.”	"Al tener un enfoque especial con nosotros, pues sería – habría la posibilidad de que el aporte económico sea mayor."
Reduce cost burden on state and healthcare system	Any mention of the implication this program holds regarding cost burden reduction	“If all these diseases are prevented, it would also mean the reduction of costs in the health system, and the government.”	"Si se previenen todas estas enfermedades, sería la reducción también de los costos en el sistema de salud, y, y pues, y pues, eh, al gobierno."

Foster cultural competency in future programs	Individual underscores the importance of culturally relevant programs to reach to the Latino and Hispanic community and mentions increasing representation and culturally appropriate care for Latino community	"It would be nice if our face is seen, and, also they have our interests as a priority. Then, that’s opening the doors for those some people to look for others like us to start doing - like you said, the workshops, the education, to disseminate information."	"Seria bien que se vea nuestra cara, y también, este, ellos tengan nuestros intereses, ya, este, en – en – a la – en frente. Luego, eso va abriendo las puertas para que esa misma gente busque a otros como nosotros para empezar a hacer – como habías dicho, los talleres, la educación, a propagar y diseminar información."
Promote health equity in field	Discussions aimed at reducing health disparities and ensuring equal opportunities for genetic testing access	"Having equal access to medical care for all. And it's not that Latinos want to get it for free, but it should be a budget that is accessible to all of us."	"Tener igualdad al servicio médico de todo. Y no es que los latinos estamos queriendo que nos lo den gratis, sino que sea un presupuesto accesible para todo el bolsillo de nosotros."

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Ch V. Public Health Implications

The empowerment theory serves as a major framework in current social work practices as it guides their core tenants of promoting self-development and awareness among individuals and communities. Research projects are highlighted as a macro-level tool in social work courses when they aim to identify factors contributing to social inequities or measure the effects of discrimination and other oppressive forces on specific populations (VCU, 2021). The term empowerment is complex with roots tracing back to civil rights and feminist movements, the self-help movement, and community psychology (Cavalieri & Almeida, 2018). It's power and meaning has transcended into the political realm, underscoring a hierarchical status of communities within society, and focusing on the various factors that work towards further oppressing marginalized communities (Cavalieri & Almeida, 2018; VCU, 2021). Furthermore, empowerment can serve as an operational tool for monitoring outcomes of social interventions and the process of gaining influence in areas important to a community (Cavalieri & Almeida, 2018; Fawcett et al., 1995).

In asking participants to voice their perspectives on the potential implementation of a state-wide ancestry targeted HBOC genetic screening intervention in their community, it became clear that the direction of this research required a framework grounded in the concepts and ideologies of the empowerment theory. Using this theory as a guide for data analysis ensured there was a clear breakdown of the various factors that the community deemed as impeding or facilitating for their overall empowerment in HBOC genetic screening awareness and access. Moreover, using the empowerment theory ensured the political nature surrounding this topic remained at the forefront, which was particularly important for the Hispanic and Latino community as they raised concerns about immigration status and its impact on overall access.

This HBOC democratic deliberation and study serves as the initial steps of the empowerment theory as it only captures and focuses on the process arm. Future interventions or the continuation of this research, if and when Georgia begins targeted HBOC genetic screening for the Hispanic and Latino community, can focus on the outcome arm of the empowerment theory to produce a comprehensive picture of the intervention's effects on the community.

Major strengths in this study were the use of an innovative public engagement strategy and ensuring the entire HBOC democratic deliberation was conducted in Spanish. The democratic deliberation process includes three steps: 1) expert testimony, 2) deliberation, and 3) consensus. Participants first gained balanced and unbiased knowledge of different (often conflicting) viewpoint relating to the topic, then deliberate with co-participants to reach consensus on what is best for the community at large. Democratic deliberation has been shown to be useful in the case of complex and new health topics, and when considering health promotion programs for marginalized populations. Shifting towards more in-depth community engagement approaches like democratic deliberation, where targeted audiences are actively engaged and viewpoints extending beyond personal implications, serves as a steppingstone towards engaging racial and ethnic minorities in the creation of cancer genomic interventions. Furthermore, being able to conduct the HBOC democratic deliberation entirely in Spanish, was crucial in ensuring information was accurately disseminated. All facilitators trained in leading the small group and larger group discussions were Spanish-speaking and from the Hispanic and Latino community to help gain the community's trust and evoke honest opinions on the topic.

When working with the Hispanic and Latino community, it is also important to ensure a variety of voices and perspectives are included. This means having both male and female perspectives with a variety of ages, education backgrounds, and employment statuses since previous studies for HBOC in the community primarily involved women and well-educated individuals. Furthermore, when focusing on the Hispanic and Latino community, it is crucial to represent various Latin American countries as each country possesses unique cultural nuances that can impact their perspectives. Research samples in studies focused on HBOC among the Hispanic and Latino community predominantly consist of English-speaking and bilingual Latina women with higher levels of education, income, and insurance coverage (Lumpkins et al., 2023; Sussner et al., 2015; Vadaparampil eg al., 2022). Consequently, study findings do not reflect the entire community and fail to address barriers others in the community may face. Conducting the democratic deliberation exclusively in Spanish fostered engagement from members of the community who would typically be excluded with the overall aim of creating a diverse study sample reflective of the Hispanic and Latino community in Georgia.

Study results illuminated on a myriad of impeding and facilitating factors the community deemed important to address when discussing the potential implementation of Hispanic and Latino targeted HBOC genetic screening in Georgia. Members in the deliberation voiced their support for Ancestry-targeted screening in Georgia highlighting its potential to not only advance scientific knowledge of Latino genetic profiles but also increase research grants and funding to help combat the barriers they noted of most concern. When considering the common good, community members recognize the positive impact a healthier Hispanic and Latino community can have on the nation. This includes promoting the economy with greater contributions and reducing costs within both the healthcare system and government expenditures.

Findings underscored the need to focus research and interventions on both the community and societal level. Most concerns raised by participants were categorized as environmental and social impeding factors. At this level, participants voiced having difficulty accessing genetic counseling services due to high cost, legal status implications, and lack of insurance, transportation, language comprehension, culturally competent care, and representation within the field. These barriers are commonly observed in studies examining barriers and facilitators to screening uptake among the Hispanic and Latino community, however participants also highlighted how these barriers affect their attitudes towards the medical and research community subsequently impacting their healthcare-seeking behavior. In order for the community to truly benefit and feel supported by the US, the program must ensure continuity of care with proper access and cost coverage to treatment if an individual is found to have positive results; awareness is not sufficient. Participants expressed a strong desire for greater cultural understanding and representation within the field, a sentiment supported by current research which notes only 6% of genetic counselors in the US speak Spanish (Conley et al., 2021; Jospeh & Guerra, 2015). Furthermore, policymakers and researchers must prioritize open communication and transparency with the community as participants cited that they would not be interested in a program solely aimed at collecting data for public health without efforts to truly help the community.

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