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Advancing Health Equity: A Qualitative Study Assessing Barriers and Facilitators of Implementing Hereditary Breast and Ovarian Cancer Risk Screening Tools in Community-Based Organizations

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Abstract

Genetic counseling and testing (GCT) inform cancer management for persons at risk for hereditary breast and ovarian cancer (HBOC). Community-based organizations (CBOs) may play a role in identifying at-risk Latinx individuals to connect them to GCT but data are lacking. Two academic centers and their four CBO partners planned to implement a validated questionnaire for HBOC risk screening ('HBOC risk screening tool'). This study aimed to assess CBO's preferences for HBOC risk screening tools, as well as the barriers and facilitators anticipated for future implementation. Pre-implementation focus groups were conducted with CBO's staff. Discussions centered on current practices to identify and refer at-risk patients. During the discussion, staff were asked to select one out of five validated HBOC risk screening tools to implement and to discuss anticipated barriers/facilitators for implementation. The four focus groups were coded and qualitative analyzed following the Consolidated Framework for Implementation Research (CFIR) Framework and Health Equity domains.

All CBOs chose the Family History Screen 7 (FHS-7). Participants (N=35) highlighted how the FHS-7 was easy to adapt to better fit the target population and changing guidelines. They had positive attitudes toward implementing the screening tool, stressed how the culture of the organization positioned them to reach the target population, and noted barriers in different CFIR domains (e.g., low knowledge about HBOC and GCT referrals; scarce available resources). Participants pointed to barriers related to health equity domains including limited access to GCT and follow-up care for uninsured and underinsured populations, challenges obtaining accurate family history, and immigration-related barriers. CBOs highlighted the importance of partnering with other stakeholders to overcome barriers.

Findings emphasize the need to develop multi-level implementation strategies to overcome barriers and leverage facilitators. This study can inform the development of implementation toolkits for CBOs to implement HBOC screening tools to advance health equity.

Key words: HBOC; Latina; Risk Assessment; Community; Disparities

1. What is known about this topic

- Latina women at-risk of hereditary breast and ovarian cancer (HBOC) are less likely to be screened and referred to genetic counseling and testing services.
- Community-based organizations may play a key role identifying and referring at-risk Latinas to genetic counseling and testing services.

2. What this paper adds to the topic

- Findings emphasize the need to develop multi-level implementation strategies, including adapting a short validated HBOC risk questionnaire ('HBOC risk screening tool') to the target population's needs and to changing guidelines, training CBO staff, fostering stakeholder partnerships, and promoting policy changes to improve GCT access and follow-up care.

Background

Pathogenic variants in the *BRCA1* and *BRCA2* genes remain the most strongly associated with hereditary breast and ovarian cancer (HBOC), although pathogenic variants in several additional genes are also associated with increased risk for HBOC (Reiko Yoshida 2021). Women with a pathogenic variant in *BRCA1/2* have a 38 to 87% risk of developing breast cancer and 17 to 63% risk of developing ovarian cancer up to 70 years of age (Reiko Yoshida 2021). Additionally, they have a higher risk of developing contralateral breast cancer or other types of cancer (e.g., pancreatic) (Reiko Yoshida 2021). Participation in genetic counseling and testing (GCT) can provide critical information to inform risk management in women with and without cancer and to inform cancer patients' treatment (e.g., PARP inhibitors) (Reiko Yoshida 2021).

To inform referrals to genetic counseling, the United States Preventive Services Task Force (USPTF) has recommended for over 15 years that primary care clinicians assess women with a personal or family history of breast, ovarian, tubal, or peritoneal cancer or who have an ancestry associated with *BRCA1/2* gene mutations with a brief validated familial risk assessment tool ('HBOC risk screening tool'). Women with a positive result on the screening tools should receive genetic counseling, and may consider genetic testing if appropriate (US Preventive Services Task Force and Owens D. 2019). The USPTF identified five validated HBOC screening tools (i.e. Ontario Family History Assessment Tool, Manchester Scoring System, Referral Screening Tool, Pedigree Assessment Tool, and the Family History Screening-FHS-7) and found insufficient evidence to recommend one over the other (Moyer 2014). The sensitivity across screeners ranged from 81%-95% (see Supplement 1), which is crucial given the potential implications of identifying individuals with a positive mutation. Given the lack of clear recommendation for one screener over the others based on their effectiveness, understanding the

preferences of the individuals who seek to implement it is key to maximize adoption and sustainability

Despite the longstanding existence of evidence-based guidelines to implement HBOC risk screening tools, research outside cancer specialty settings is scarce (Guan et al. 2021). A recent systematic literature review that aimed to characterize strategies to identify at-risk individuals outside oncology specialty settings found that only 16 studies focused on non-specialty settings, such as community practices and community-based organizations (CBOs) (Guan et al. 2021). In the United States, CBOs serve a large portion of the medically underserved, who also tend to belong to racially/ethnically diverse communities. Therefore, the CBOs are often the main venues to access healthcare for these populations. Given the health disparities Latina women encounter in accessing GCT for hereditary cancer risk, including lack of referrals, (Williams et al. 2019), CBOs have the potential to serve as bridges between Latinas at risk for HBOC and GCT services by identifying potentially at-risk women through screening tools (Almeida et al. 2021; Reyna et al. 2022; Vadaparampil et al. 2021). Thus, implementing these validated screening tools to assess HBOC risk for patients served at CBOs can be a key first step to reduce disparities in GCT utilization by Latinas. Indeed, findings from the systematic literature review (Guan et al. 2021) suggest that implementing HBOC risk screening tools at settings that serve minoritized populations, such as CBOs, can successfully enhance the reach of genetic services for underserved populations. Despite these promising findings, this review highlighted the need for more research in this nascent area, especially research that integrates Implementation Science to understand implementation barriers and facilitators to scale up effective strategies at non-specialty settings (Guan et al. 2021).

Implementation Science, as the scientific study of strategies to integrate evidence-based interventions and guidelines into routine clinical practice (Eccles and Mittman 2006), provides an excellent framework to assess barriers and facilitators to implementing routine HBOC risk screening tools at CBOs. Yet, significant gaps remain in the use of Implementation Science in the fields of translational genomics and health equity (Senier et al. 2019). A systematic review of 283 genomic medicine studies found that only five used Implementation Science frameworks and that community-based studies and ethnic/racial minorities were severely underrepresented (Roberts et al. 2017). This highlights the urgency to integrate health equity determinants in Implementation Science frameworks to ensure that the field contributes to reducing health disparities (Chinman et al. 2017; Senier et al. 2019; Woodward et al. 2021).

The Consolidated Framework for Implementation Research (CFIR) is one of the most widely used frameworks to assess implementation barriers and facilitators in five different domains: characteristics of the intervention, inner setting, characteristics of individuals, outer setting, and process (Damschroder et al. 2009). Recent expansions of CFIR strive to link the barriers and facilitators to actionable implementation strategies and include constructs that impact health equity (Senier et al. 2019). Practical guidelines have been proposed to facilitate the integration of health equity domains into Implementation Science frameworks (Woodward et al. 2021). Guided by an expanded CFIR framework (Senier et al. 2019), this study conducted focus groups with staff from CBOs that provide services to underserved Latinos to (1) assess preferences for HBOC risk screening tools to implement and to (2) examine anticipated barriers and facilitators for implementation to inform implementation strategies.

Methods

Participants

Two academic centers partnered with four CBOs in the Washington DC metropolitan area and Virginia. All of the CBOs provide health related services to underserved Latinos including patient navigation, community health promotion, and health care services. Individuals were eligible to participate in focus groups discussions if they were full-time, part-time, or volunteer staff at one of the CBOs, were 18 years old or older, were fluent in English or Spanish, and were able to provide informed consent.

Study Procedures

Focus groups were conducted between February 2020 and May 2021. One focus group was conducted at each CBO. The number of participants at each CBO ranged from 7-13 participants. The research team coordinated a date and time for the focus group with the respective CBO's director and invited their staff to discuss barriers and facilitators to implementing HBOC screening at their organization. Participation was voluntary. Research Assistants (RAs) obtained verbal informed consent from participants prior to the scheduled focus group either by phone or in person and shared a copy of the informed consent form with each participant. All study procedures were conducted in the participant's preferred language (English or Spanish).

The Principal Investigator (PI) (AH) and the Project Coordinator (SG) moderated the focus groups. Both the PI (Ph.D) and the Project Coordinator (M.S) are Latina bilingual female psychologists who have extensive expertise in qualitative data collection. Two focus groups were conducted in Spanish and two in English, according to the predominant language of each CBO's staff. Two focus groups were conducted in person (one in Spanish and one in English) and two online via a HIPAA compliant platform (one in Spanish and one in English). Each focus group

lasted between 1 and 1.5 hours. Focus groups were audiotaped with participants' permission and transcribed verbatim in the recorded language.

Participants completed a short survey (either online or in paper) that captured sociodemographic factors and information about their roles. Participants received \$20 as compensation. The IRB from the Principal Investigator's institution approved the study protocol.

Measures

Sociodemographic Data. The survey captured age, education, race, ethnicity, and sex.

Work experience data. The survey assessed the participant's roles, the time they had worked at the CBOs, and the time they had been in their specific roles.

Focus Group Guide. CFIR was used to guide the development of focus group prompts. The focus group started by examining participants' awareness about HBOC, prior screening practices, and GCT referrals at their organization. Next, the moderator presented the five brief validated HBOC screening tools recommended by the USPSTF, asked participants to select one that could best be integrated into their practice, and prompted them for their rationale (e.g., why do you think this one would fit better?) (Moyer 2014). The remaining discussion focused on anticipating potential barriers and facilitators for implementing the selected screening tool and discussing potential implementation strategies that could help overcome the barriers and leverage facilitators. Supplement 1 includes the interview guide that tapped into selected CFIR constructs.

Validated HBOC Screening tools

The five screening tool options were: the Ontario Family History Assessment Tool (Gilpin et al. 2000), Manchester Scoring System (Evans et al. 2004), Referral Screening Tool (Bellcross et al. 2009), Pedigree Assessment Tool (Teller et al. 2009), and Family History Screen 7 (FHS-7) (Ashton-Prolla et al. 2009). All screening tools include a series of questions about

family history of cancer. Some also capture personal history of cancer. Four of the five screening tools require scoring to inform referral. (Supplement 1 includes each of the screening tools and their sensitivity and specificity).

Analysis

Quantitative. We used descriptive statistics to characterize the study sample. We used counts and percentages to describe categorical variables and measures of center (mean) and dispersion (standard deviation) for continuous variables.

Qualitative. Bilingual RAs translated the Spanish transcriptions into English for the analysis. We developed the codebook using a deductive approach guided by an expanded CFIR (see Supplement 2 for exhaustive codebook). The codebook included codes and definitions from CFIR constructs in four domains: 1) innovation characteristics (attributes of the HBOC screening tools that can affect the success of its implementation), 2) inner setting (structural, political, and cultural context in which the implementation of HBOC screening takes place), 3) outer setting (economic, political, and social context in which the CBOs are embedded), and 4) characteristics of individuals (personal attributes of the CBOs staff such as knowledge and beliefs that can impact implementation) (see Figure 1) (Damschroder et al. 2022).

Each CFIR construct was additionally coded as either a barrier or a facilitator. For instance, if CBOs mentioned that they were concerned about the time it would take to administer the HBOC screening tool, it was coded as both “inner setting-available resources” and “barrier.” To integrate health equity constructs, we followed Woodward and colleagues’ (Woodward et al. 2021) guidelines to integrate health equity domains in Implementation Science Frameworks and added a “health equity” code with three sub-codes: doctor-patient communication, culturally relevant factors of recipients, and social context. Lastly, an implementation strategies code

captured the actions or strategies that participants suggested to successfully implement and sustain HBOC screening. The study PI (AH) and a genetic counseling Masters candidate (AB) conducted the qualitative analysis. Both had training in qualitative data analysis and the PI had training in Implementation Science. Since only one of the coders was bilingual (AH), the English translations of the Spanish transcripts were used for the analysis. They independently coded all of the focus group transcripts and then met to reconcile the coding. Disagreements were solved by consensus, as recommended by the Consensual Qualitative Research Framework (Hill et al. 1997). A third researcher (GC) with extensive expertise in Implementation Science contributed to resolving disagreements. We used Dedoose, a qualitative analysis software for coding. We report on the themes that were mentioned at least ten times during the focus group discussions within the intervention characteristics, inner setting, characteristics of individuals, and outer setting domains.

Results

Community-based Organizations

Participants (N=35) had an average age of 49.66 years (SD=15.31), 82.9% were female and 48.6% self-identified as Hispanic or Latino. All participants worked or volunteered at a CBO that served the Latino community. Participants held diverse roles including nurses (20%), patient navigators (20%), community health workers (20%), healthcare providers (8.57%), directors (8.57%), and administrators (5.71%) (see Table 1).

The four CBOs differ in size, types of services provided, and the extent to which they focus on cancer-related services. Site 1 (Latina cancer navigation site) provides support and navigation for Latina cancer survivors and promotes early cancer detection through community outreach to over 1,300 Latinas annually. Site 2 (Academic-community cancer navigation site) is

part of an academic medical center and provides education and navigation to cancer screening services to about 750 underserved women annually (49% are Latina). Site 3 (Latino health promotion site) facilitates access to local preventive care and services through community health workers (e.g., diabetes, hypertension, cancer screening) and delivers health education to the Latino community. Site 4 (Free clinic site) is a community based, volunteer driven clinic that provides free health care to low-income, uninsured adults, serving approximately 1,600 patients per year (80% Latinos).

CFIR Domains

Participants shared ideas and perspectives that fit into each of the CFIR domains (referred to as bolded text). Table 2 presents CFIR definitions and additional quotes from the domains included in the focus group guide.

Innovation Characteristics.

Two themes that were repeatedly connected were **relative advantage** and **complexity** (the perceived difficulty of implementing the HBOC screening tool). CBO staff perceived that using a short screening tool would represent a facilitator and serve as an advantage over prior screening practices given that the CBOs either did not collect family history, did not collect enough information about family history to issue a referral, or collected it in open fields that were difficult to retrieve. Thus, systematically implementing a short screening tool that captured enough information with actionable referral guidelines was perceived as an improvement of the CBOs services. CBOs favored screening tools that used specific questions (e.g., short, clear, yes/no answers) because they were perceived to be easier for patients. Many participants repeatedly expressed not wanting a screening tool that required a scoring system to determine if

a patient needs a referral to GC, as scoring was perceived to be confusing and time consuming.

As explained by a participant:

“For our population and for our volunteers to have a screening tool that requires someone to score, it is probably not very realistic. We do a lot of things during that initial intake part, right. So, to have a scoring system - I don't think that is probably very feasible.”

Participants strongly preferred screening tools with a fast, clear method for determining if the patient meets criteria for a GC referral (e.g., if a patient answers yes to any question, they need a referral). All of the sites independently elected to use the FHS-7 based on its simplicity. Site 1 initially chose the RST, but later changed to the FHS-7 given difficulties integrating the RST into their electronic system.

Regarding complexity as a barrier, participants thought that patients might not have all of the information about their family history of cancer, which could make the screening more complex and time consuming. Additionally, some participants highlighted the complexity of referring patients to GCT due to access barriers for uninsured populations and logistic barriers (e.g., needing a physician's signature on the test order) (see needs and resources of those served by the organization).

The CBOs identified the screening tool's **adaptability** (the degree to which the HBOC screening tool could be adapted, tailored, refined to meet local needs) as a facilitator to implementation. Participants expressed the importance of screening tools being adaptable to account for rapidly changing referral guidelines and to meet the needs of their patient populations (e.g., health literacy). For instance, many expressed concerns about some medical jargon or unfamiliar terms included in the screening tools (e.g., bilateral, Ashkenazi, first-degree relative). One participant asked to: *“define what a second and third degree relative is. Many*

people don't know what that means.” Participants suggested specific adaptations to ensure that words were comprehensible to patients and that key HBOC clinical information was captured.

For example, one participant explained:

“The bilateral one, yes...cancer in both breasts. We change those things to make them easier. And then we also add colon cancer and pancreatic cancer, which are related to hereditary cancer.”

Inner Setting

CBOs perceived that the implementation of HBOC screening tools was **compatible** with their norms and values, which was coded as a facilitator. CBOs expressed motivation to use the screening tool, confidence that their previous experience would enable them to use it smoothly, and overall positive sentiments towards use of the screening tool. Staff from the academic-community cancer navigation site (Site 2) noted that the screening tool would also fit easily into their current workflow, community outreach efforts, and tracking. One of them said:

“We have a system for it, right? We have a screening system that requires multiple layers of referral, and we have been successful in keeping track of treatments, too. So, it won't be that much of a big issue. I think the proportion of cancers we see is about five to ten a year. This would be like 10 to 15 a year maybe. It won't be that much more.”

However, compatibility was also perceived as a barrier. CBOs mentioned that capturing the information from the HBOC screening tools in electronic medical records (EMR) could be potentially challenging due to the difficulty of modifying the EMR and retrieving the appropriate information. Site 3 (Latino health promotion site) specifically reported that they did not have an EMR system.

The CBOs' **culture**, including the norms and values was mainly brought up as a facilitator. Participants noted how their organizations were highly motivated to serve the Latino community. They reported that engaging staff members who belong to the community enabled the CBOs to build trust with community representatives to identify their needs. This in-depth knowledge of the patients' culture allowed the CBOs to provide culturally sensitive services, which could facilitate the implementation of HBOC screening. One participant said:

“The greatest strength is knowing the culture, we know that this is a great barrier to access health services. Many [of our] health promoters are associated to churches or groups in the community. And of course, the affinity in terms of geography, country of origin, is one of the factors that contribute a lot to this approach and credibility especially in the community for what we do in that sense.”

Even though the CBOs perceived that implementing HBOC screening tools was mostly compatible with their norms, values, and workflow and that their culture could facilitate implementation, the limited **availability of resources** was a prominent implementation barrier. All of the sites reported having overburdened staff with limited time to take on additional tasks. This could limit the CBOs ability to implementing the HBOC screening tools and navigate patients to GCT, especially in the face of competing priorities/needs. In the words of one provider:

“We have more than 100 women waiting right now for screening mammograms... We cannot cover the need for which they called here. They call me about a mammogram, not to know about genetics or anything. You first have to give them the basics. Nothing moves...without money unfortunately.”

Characteristics of Individuals (CBOs staff).

A theme that emerged as both a barrier and a facilitator was the CBOs' staff **knowledge and beliefs about HBOC screening**. Many CBO staff had positive attitudes toward genetic counseling in general, expressing that they felt it was an important cutting-edge service. In the words of a CBO staff: "*We know this is very important.*" However, some participants noted difficulties stemming from a lack of physician/staff knowledge about how to administer HBOC screening tools, and how to make appropriate genetic counseling referrals. They also underscored how the limited number Spanish-speaking counselors compounded this limitation. Furthermore, many participants expressed difficulty knowing where to refer patients with financial hardship for care, and they explained that some providers lack knowledge on how patient financial assistance programs work. They also feared screening tools would not consider all relevant risk factors, especially non-genetic cancer risk factors, and that screening tools may miss patients who are not forthcoming with their family history. Notably, most participants from two of the four CBOs reported having limited knowledge about HBOC and GCT, as shown in this excerpt:

“Moderator: I don’t know if you have ever heard of genetic testing and counseling services. Have you heard?

Participant 1: No

Participant 2: Not me.”

Outer Setting

Cosmopolitanism, understood as the degree to which an organization is networked with other external organizations, was mostly discussed as a facilitator. The participants explained how their connections to other institutions (e.g., government health initiatives, other clinics, research initiatives, and universities) could facilitate genetic screening and referral. Specifically,

they cited the organizations providing grants, educational training, and services to refer patients. The participants also cited connections with laboratories that have generous patient assistance programs as very helpful. For instance, one participant expressed,

“I think that genetic counseling is easier to get for breast cancer patients, for those who are diagnosed because they go to [hospital name] (...) and then they take care of that (...) but I don't think that we have any resources to refer those patients who have a history of cancer.”

CBOs described their connections with other community organizations like churches and support groups. They explained how these partnerships could help bridge the gap between patients and larger health institutions. As stated by a participant:

“We work by being the bridge between organizations. The mission is to contribute to the improvement of the health and well-being of the Latino community. We serve as a bridge in facilitating access to health services and other resources through health promoters. We also have relationships with some organizations to carry out joint projects in the community.”

A few barriers were reported. CBOs that depended on larger health care organizations to access resources could have limited ability to use their clinical priorities to inform decision-making or could be limited in their capacity to change EMR. In addition, the participants explained that while receiving funding from a research grant could be helpful for a short time, it was not a sustainable method to increase healthcare access.

“Our EMR is not flexible. So we are actually not able to make any changes to our EMR really that are substantial like that we could not add a screening set of questions to our prevention screening tool right now. It is not a possibility”

Needs and resources of those served by the organization. CBOs were highly aware of their patients' needs and resources as well as the barriers and facilitators to meet those needs. Given that these needs were tightly related to health equity domains, we included the health equity domains within patient needs and resources. A prominent barrier reported was a lack of patient awareness of hereditary cancer. For instance, participants explained that many patients could find vocabulary on the screening tools unfamiliar or they may lack information on the importance of preventative medicine or why one's family history is medically important. CBO staff identified several potential challenges to obtaining accurate family history. First, they highlighted how some of their patients feel that cancer is taboo making them uneasy or embarrassed to share cancer family history information. One participant shared this poignant example:

“I had a 42-year-old person who died of ovarian cancer, and she didn't say anything to the family, not even to the husband. The doctor told her, ‘If you had come three months earlier, we would have been able to help you, but not anymore. Right now, there is no cure for you.’ And the young woman passed away, but due to lack of communication. There are taboos...people think that cancer is a bad thing. And they worry about how they are going to be criticized.”

Second, CBO staff mentioned that many patients confuse certain types of cancer diagnosis (e.g., cervical vs. ovarian) or label “stomach cancer” for any type of abdominal cancer. Third, given that some relatives live outside of the U.S and have limited access to the healthcare system, information about diagnoses and causes of death is often unknown. CBO staff were concerned that this limited knowledge of family history could result in a lengthy and complex

screening process that may require multiple calls and follow-ups to complete (see available resources). For instance, one participant recounted:

“Back home it is more difficult. Because they live in a village in El Salvador where there is no formal hospital but maybe there is a health center where a doctor only comes once a week (...) so, it is not so feasible to have the specific information of which disease they died of.”

CBO staff highlighted potential challenges to navigate patients to GCT resources due to access barriers (see knowledge and beliefs and available resources). They mentioned that the financial hardship encountered by their patients was a prominent barrier as this could limit patients’ ability to cover the costs of GCT and to take time off from work to attend appointments. Compounding this barrier, they reported that many patients do not have medical insurance, and some patients who did have insurance were unaware they had it. Additionally, they perceived that immigration status could further economic barriers because patients may not be able to use some patient assistance programs that require them to submit tax information. In the words of a participant: *“When the patients go to get testing, they have to provide the taxes for them to get eligible. They don’t want to do that, so they don’t get a test.”*

Implementation Strategies.

When asked what strategies they would find useful to implement the HBOC screening tools, the vast majority of comments from the CBOs focused on the need for training. Participants wanted education on hereditary cancer and genetic testing in general, training in how to ask clear and culturally sensitive questions about family history, how to explain HBOC risk, and where to refer patients for free/low-cost GCT services. Participants expressed that these

trainings would empower the staff who implement the screening tools to answer questions and aid with navigation. In particular, one participant said:

“A lot of times as a culture we teach people to be very guarded about their health information. This [information] stays in the family. And so when we’re asking these questions about what runs in the family, you see these red flags automatically go up. I think training would be helpful in just knowing how to address those concerns and how to put people at ease.”

CBOs also noted the importance of adapting the HBOC screening tools to fit the population’s health literacy needs and the changing guidelines. The participants also stressed the importance of providing outreach education about HBOC and GCT to their wider community. This could be especially helpful for people to understand the importance of knowing their family history. The CBOs recommended integrating these trainings into established educational events and repeating them periodically to accommodate the rapidly changing guidelines. Additionally, they mentioned the need for patients to have available Spanish-language education materials. See Table 3 for a summary of barriers and facilitators by the CFIR domain and proposed implementation strategies.

Discussion

National guidelines to implement evidence-based genomic recommendations have not been implemented equally across groups (Green et al. 2019; Khoury et al. 2022). Underserved ethnically/racially diverse populations are less likely to be screened for HBOC and to be referred to GCT (Cragun et al. 2019; Jagsi et al. 2015; Peterson et al. 2020; Williams et al. 2019). Given that CBOs play a key role in connecting underserved populations to health services (Shelby et al. 2002; Wilson et al. 2012), implementing HBOC screening tools at CBOs is an important first

step to identifying underserved individuals at risk for HBOC so they can be referred and navigated to GCT. This study used an expanded CFIR to examine barriers and facilitators to implementing HBOC screening tools in CBOs. Our findings underscore the need to develop multi-level implementation strategies to overcome barriers and leverage facilitators.

In this study, CBOs unanimously thought that the FHS-7 had a relative advantage compared to prior screening methods and to other short screening tools. The perception that the FHS-7 was the least complex (i.e. short number of yes/no questions, no scoring, clear actionable referral guideline) was key for CBOs with limited resources and overburdened staff. CBOs suggested adapting the screening tool to clarify and simplify medical terms and adding questions about pancreatic and colon cancer risk to ensure that the screening tool was concordant with the most up-to-date guidelines. The adaptability of the screening tool was especially relevant given that guidelines for GCT referral are usually updated on an annual basis. Therefore, the ability to easily adapt a screening tool will be a key implementation strategy to enhance fit and sustainability over time (Shelton et al. 2020).

CBOs shared positive attitudes toward implementing HBOC screenings. However, similar to prior studies (Chou et al. 2021; Christianson et al. 2012; Delikurt et al. 2015; Greenberg et al. 2019; Hurtado-de-Mendoza et al. 2018; Mikat-Stevens et al. 2015), some participants expressed limited knowledge about HBOC and referral guidelines and low awareness of services to refer patients to GCT services, especially uninsured/underinsured patients. Academic-community partnerships can fill knowledge gaps by providing training for non-genetic professionals (MacDonald et al. 2010). Communities of practice, such as the City of Hope, that provide ongoing training and clinical support can be especially relevant to cover the training needs for CBOs (MacDonald et al. 2010; Yoes and Thomas 2020). Most genomics

training programs to date have demonstrated improvement in providers' knowledge, attitudes, and self-efficacy in screening and referring to genetic services (Paneque et al. 2016; Talwar et al. 2017). However, most programs have trained physicians and nurses (Talwar et al. 2017). Community health workers (CHWs) are uniquely positioned to reach underserved diverse populations and can serve as a bridge between the community and genetic services (Allen et al. 2016; Vadaparampil et al. 2021). Recent training programs specifically developed for CHWs serving the Latino community can fill this training gap (Almeida et al. 2021; Reyna et al. 2022; Vadaparampil et al. 2021). For instance, the Árboles Familiares (*Family Trees*) training program for CHWs covers topics identified by our study participants including HBOC risk factors, strategies to communicate about HBOC with cultural sensitivity, HBOC screening tools, GT financial assistance programs, and strategies to identify genetic services in their communities. Preliminary findings indicate that The Árboles Familiares training significantly increased HBOC knowledge, genetic literacy, and self-efficacy to identify and refer at-risk patients in bilingual CHWs (Vadaparampil et al. 2021). Similarly, "Tu Historia Cuenta" is a promotores-based virtual outreach and education program targeted to Spanish-speaking Latina women. The program includes education on HBOC, administration of a short validated HBOC screening tool, and referrals and navigation to appropriate services for women at-risk. The program successfully screened and identified at-risk women and had very high acceptability among Spanish-speaking Latinas (Tamayo et al. 2022). Developing strategies to implement these types of training programs is a key next step to reduce CBO staff knowledge gaps and increase referral competence. Additionally, providing CBOs access to patient-facing HBOC education materials in Spanish (Conley et al. 2021; Hurtado-de-Mendoza et al. 2020) can increase the CBOs capacity to provide outreach education to the community. Unfortunately, high quality patient-

facing genetics education resources in languages other than English are scarce (Beauchesne et al. 2023). Building a central curated repository of patient-facing education materials in diverse languages (Beauchesne et al. 2023) could help CBOs gain access to evidence-based resources.

CBO staff perceived the implementation of the screening tool to be compatible with their mission and values. The Latina cancer navigation site (site 1) and the academic-community cancer navigation site (site 2) stressed that the implementation of the screening and referral process was compatible with ongoing clinical practice that focused on other types of cancer screening navigation. Yet, one of the most prominent barriers was the limited available resources, including the shortage of staff and limited time. CBOs struggled to provide basic services such as access to mammograms, so adding HBOC screening and GCT navigation could be burdensome. Limited resources to refer for free/low-cost GCT could result in more time for navigation for understaffed CBOs. Implementing alternative genetic service delivery methods (e.g. group genetic counseling, training non-genetic providers, tele-health) could expand access to GCT for underserved communities (Cohen et al. 2019; Woodson et al. 2015). For example, some collaborative approach models train genetic counselors extenders, such as nurse navigators, to support genetic counselors conduct some tasks (e.g. risk assessments). These models include ongoing support and consultation from a board-certified genetic counselor (Cohen et al. 2019) and could be a cost-effective approach.

CBO staff were very aware of their patient's needs and resources and how those could impact the implementation of HBOC screening. Consistent with previous studies (Gómez-Trillos et al. 2019; Hurtado-de-Mendoza et al. 2018; Orom et al. 2008), providers anticipated that Latinos may have incomplete information about cancer family history for various reasons including limited communication about cancer due to stigma or family separation, low access to

specialty care in some regions of Latin America, and challenges differentiating between certain types of cancers. Limited family history knowledge can result in additional time for CBOs to make several phone calls to find out the most accurate family history information, and may result in missed referrals when family history information is incomplete. In a study with a nationally representative sample, immigrants were one-third as likely to report cancer family history compared to non-immigrants, raising the concern that self-reported family history may inaccurately represent cancer risk (Orom et al. 2008). Similarly, another study found that Latina women who were born outside the US were significantly less likely to report breast cancer family history compared to Latinas born in the US, suggesting potential differences in the family cancer history awareness and flow of information between foreign born and US born Latinas (Tamayo et al. 2022). Current guidelines recommend referral for genetic counseling in some circumstances when there is limited information about family history (Daly et al. 2020). Increasing CBOs' awareness about the guidelines will be paramount.

Awareness of patient's needs and resources also raised other important equity concerns that need to be addressed. Because they serve an uninsured/under insured immigrant population with low income, CBO staff expressed concerns about access to GCT and follow-up health care. Barriers to accessing genetic testing have significantly decreased over the years due to reduced costs of testing and the availability of financial assistance programs through many of the testing laboratories (Hurtado-de-Mendoza et al. 2018). However, access to genetic counseling and follow-up health care for uninsured and underinsured individuals is still limited (Hurtado-de-Mendoza et al. 2018). CBOs noted how they leveraged partnerships with different organizations and institutions to gain access for uninsured/underinsured patients to different aspects of the GCT continuum. Other prior successful initiatives to enhance GCT access include partnerships

between CBOs and academic hospitals (Joseph et al. 2012; Komenaka et al. 2016; MacDonald et al. 2010), the Department of Health, CDC (Brannon Traxler et al. 2014; Joseph et al. 2012), and genetic testing companies (Martinez 2020). Therefore, fostering partnerships between CBOs and other stakeholders like academic hospitals, advocacy organizations, and the government can help leverage the resources of these organizations to overcome the aforementioned barriers. However, ensuring that these efforts are sustainable is critical. More importantly, promoting healthcare public policies that enhance equitable access to GCT and coverage of follow-up care and preventive services is paramount to achieve equity (Cragun et al. 2017; Modell et al. 2021).

This study has some limitations. The sample included CBOs from the Mid-Atlantic region. Thus, findings may not generalize to other regions. The focus groups were conducted with only four CBOs. We saw some differences in the levels of HBOC and GCT awareness between CBOs that focused only on cancer related navigation vs. those that provided a broader range of health services. Whether these differences impact implementation outcomes is unknown. Unfortunately, the data gathered from the four participating CBOs limits our capacity to discuss meaningful differences between the kinds of organizations given the sample size. Future studies should expand the number and type of CBOs engaged in research to further examine potential differences and properly tailor implementation strategies based on CBO characteristics (e.g., size, connection with academic centers/institutions, staff's awareness of HBOC/GCT, EMR systems). Additionally, the focus group transcripts did not specify the role of each speaker, which precludes us from discussing potentially different perspectives by roles. We did not provide information about the HBOC risk-screening tools' sensitivity and specificity to the CBO staff. Since the USPTF found all screening tools to be comparable, given the lack of evidence to recommend one over the other, and the fact that the sensitivity was $\geq 81\%$ across all

five, implementation preferences may be the deciding factor when choosing among validated HBOC risk screening tools. High sensitivity is important given the implications of finding individuals with a positive mutation, especially in CBOs serving populations with low access to cancer specialty settings. The focus groups conducted in this study focused on understanding which HBOC risk screening tool would be a better fit to implement into clinical practice and understanding barriers and facilitators to inform implementation strategies. Lastly, the study did not include validated quantitative assessments to measure implementation outcomes and barriers/facilitators. Future studies should use mixed methods to examine similarities and differences between qualitative and quantitative data.

Despite these limitations, the study has several strengths. There is emerging evidence that implementing HBOC screening tools at CBOs can enhance the reach of cancer genomic services among minoritized populations (Guan et al., 2021). Yet, few studies have examined implementation strategies outside cancer specialty settings and only a handful of studies have used Implementation Science to understand barriers and facilitators to guide implementation strategies (Guan et al., 2021; Roberts et al., 2017). The few studies that used Implementation Science frameworks to understand providers' perceived barriers and facilitators to implementing HBOC screening included mostly non-Hispanic White clinicians (PCPs, nurses, specialty clinicians) (Christianson et al. 2012; Greenberg et al. 2019; Hamilton et al. 2014). This study builds on prior efforts and advances the field forward in several ways. First, this study used an expanded CFIR as a guiding framework. This framework facilitated the assessment of barriers and facilitators in different domains to inform multi-level implementation strategies. Second, by integrating equity domains into CFIR, this study contributes to recent efforts to integrate health equity into Implementation Science frameworks (Chinman et al. 2017; Roberts et al. 2017;

Senier et al. 2019). Third, this study engaged ethnically/racially diverse staff at CBOs to select a HBOC risk screening tool that would best fit their setting. This type of collaborative process has not commonly been conducted in this emerging area of research (Guan et al. 2021). Engaging diverse stakeholders from CBOs through the research process can contribute to support equitable implementation of genomic medicine and ensure that the implementation of evidence-based guidelines benefit all populations equally (Chinman et al. 2017; Roberts et al. 2017; Senier et al. 2019; Shelton et al. 2020).

Conclusion

CBOs are uniquely positioned to connect underserved diverse populations to genetic services due to the long-lasting trust, shared culture and language, and commitment to the community (Almeida et al. 2021; Reyna et al. 2022; Vadaparampil et al. 2021). While implementing a short HBOC screening tool can appear seamless, this study illustrated the implementation challenges that under-resourced CBOs face. Findings from the study point to the need to develop multi-level implementation strategies including adapting the screening tool to improve the fit with the target population and the changing guidelines, providing training to CBO staff, investing in CBOs to enhance their resources, fostering partnerships between CBOs and different stakeholders, and promoting health policy changes to enhance equitable access to GCT and follow-up care for diverse uninsured/underinsured populations. Findings from this study can inform the development of a HBOC screening needs assessment and an implementation strategies toolkit that could be tailored for different types of CBOs.

Authors' contributions

Author Alejandra Hurtado-de-Mendoza confirms that she had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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The research presented in the paper was conducted to fulfill a degree requirement for the first author (AB) who was completing her Master's in Genetic Counseling. She conducted this research for her Master Thesis.

Conflict of Interest

Alexandra Bowen, Sara Gómez-Trillos, Geoffrey Curran, Kristi D. Graves, Vanessa B. Sheppard, Marc D. Schwartz, Beth N. Peshkin, Claudia Campos, Nathaly Garces, Chiranjeev Dash, Luisa Aburto, Nancy Valencia-Rojas, Gina Hernández, Antonio Villa, Paula Cupertino, Pilar Carrera, and Alejandra Hurtado-de-Mendoza declare that they have no conflict of interest.

Human Subjects and Informed Consent

Approval to conduct this human subjects research was obtained by Georgetown University Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

Availability of data and materials

The authors welcome inquiries from investigators interested in possible collaboration and use of de-identified data from this study. The data has not been placed into a public repository.

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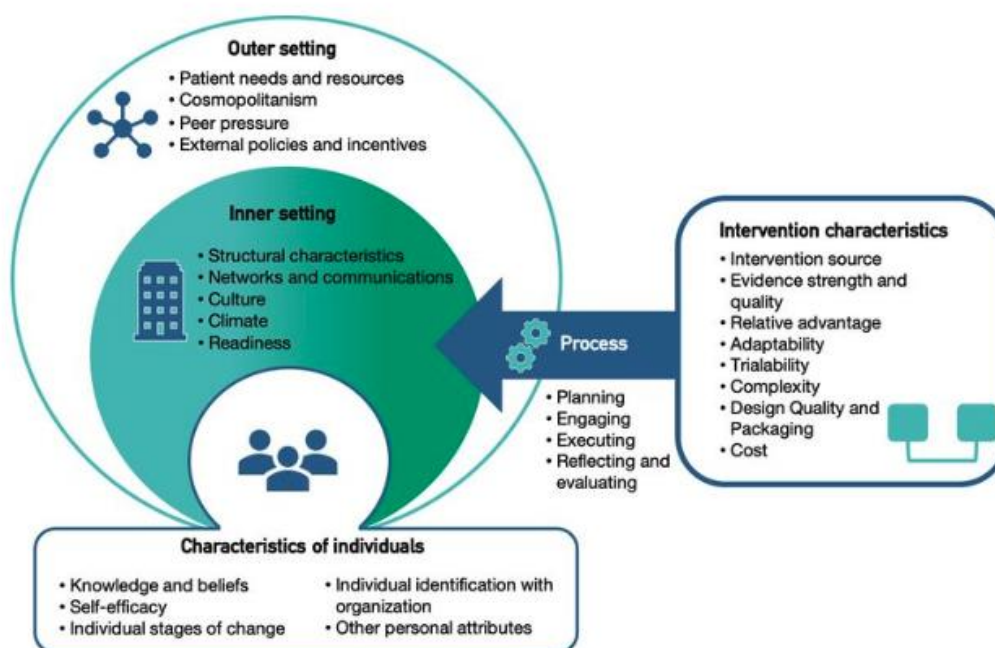
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Figure 1. Consolidated Framework for Implementation Research



Consolidated Framework for Implementation Research (CFIR) - for more info see:
<https://cfirguide.org/>

