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# Community research collaboration to develop a promotores-based hereditary breast cancer education program for Spanish-speaking Latinas

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## Abstract

Breast cancer (BC) is the most common cancer in Latinas and the leading cause of cancer death. Latinas tend to be diagnosed at later stages, receive poorer quality care and have a higher risk of mortality than non-Latina White (NLW) women. Among women with a genetic predisposition to hereditary BC, genetic counseling can be beneficial. Latinas participate in genetic counseling at lower rates than NLW women. The goal of this study was to develop comprehensive, culturally appropriate materials for community health educators (promotores)-led hereditary BC education program for Spanish-speaking Latinas. We developed the curriculum through feedback from 7 focus groups, with a total of 68 participants (35 promotores and 33 community members). We used a mixed-methods approach that relied on quantitative analysis of survey questions and qualitative content analysis of the focus groups transcripts. Pre and post promotores' training survey responses suggested improvement in the promotores' cancer-related knowledge. Themes that emerged from the qualitative analyses were (i) barriers to health education and/or care; (ii) importance of educating the Latino community about BC and genetics and (iii) role of the promotores. Future research will further evaluate the impact of the

program in promotores' knowledge and community members' screening behaviors.

## Introduction

Breast cancer (BC) is the most common cancer in women [1]. However, there are differences in BC incidence among US populations [1–4]. In particular, Hispanics/Latinas (Latinas) have a lower incidence of BC when compared with non-Latina White (NLW) women [1, 5]. Despite having a lower risk of developing BC, Latinas are more likely to be diagnosed at later stages and have a higher mortality risk than NLW women with BC [6–9]. Some contributing factors to these disparities are the lower rates of mammography utilization, delayed follow-up of abnormal results or self-discovered breast abnormalities, and the fact that Latinas are less likely to receive guideline-concurrent BC treatment in a timely manner [10, 11]. Compared with other US populations, Latinos have the highest uninsured rate [12, 13]. Lack of insurance is a major obstacle to healthcare access including the use of preventive services, treatment and follow-up care. Additionally, many US Latinos struggle with systemic inequities that result in financial (e.g. high poverty), environmental (e.g. poor geographical access to providers), educational (e.g. health literacy) and language barriers, as well as provider bias [14].

Inherited genetic mutations, especially in the *BRCA1* and *BRCA2* genes, contribute to BC incidence; 5–10% of BC cases are explained by mutations in these genes [15, 16]. *BRCA* mutation carriers have a 60–80% lifetime risk of developing BC, while the general population has a significantly lower risk of 12% [17–19]. However, only 10% of carriers are aware they have the mutation [20]. Screening for *BRCA* mutations can potentially allow for women to prevent BC and/or engage in cancer screening to detect it early [21]. Consistent evidence documents that women at high risk of hereditary BC benefit from genetic counseling, which helps women and their families make informed decisions about genetic testing and early cancer detection or risk-reduction strategies [22, 23].

Despite the growing availability of genetic counseling and testing for hereditary BC, awareness and use of these services is comparatively low in this group [24–26]. For instance, in a large national health services study on *BRCA1/BRCA2* testing, only 18% of Latinas had undergone screening compared with 34% of White women [27]. Furthermore, a cross-sectional analysis of data from a clinical database of individuals in the United States tested for mutations in the *BRCA1/BRCA2* genes ( $N = 46276$ ) identified that ~4% of the women screened were Latina, while 87% were of European ancestry, even though Latinos represent ~17% of the US population [24]. This disparity of genetic testing practices can lead to disparities in cancer prevention, early detection and treatment.

The fear of a cancer diagnosis amplified by a sense of helplessness might discourage some Latinas from engaging in BC preventive behaviors [28]. A qualitative study conducted in Latinas from Salt Lake City identified a series of concerns as possible explanations for the low rate of genetic screening among Latinas [29]. Researchers found that even though lack of insurance and economic concerns were mentioned as the main barriers for risk assessment for hereditary breast and ovarian cancer and genetic screening, other factors that were considered important included limited English proficiency and cultural factors, such as embarrassment, modesty and secrecy. Limited English proficiency

was not only a barrier to screening, but it was also cited as a reason for perceived discrimination by health care providers.

Another study focused on Latinas at increased risk of having *BRCA1/BRCA2* mutations found that 57% were unaware of the availability of a *BRCA* mutation test, compared with 35% of White women [30]. However, the study found no difference between the two groups in terms of perceived benefits or desire to take the test [30]. Despite the barriers described, studies suggest that Latinas are willing to engage in counseling and screening [29–32]. Hence, our study focuses on hereditary BC education and risk screening (through family history identification) among Spanish-speaking Latinas given the known financial, environmental, educational and language barriers to genetic services [33].

The use of peer educators (*promotores*) is very effective in serving as a bridge between underserved Latino communities and the healthcare system [34–37]. Sharing a similar sociocultural identity (e.g. ethnicity, language, socioeconomic status and health care experiences) with other community members provides *promotores* a deep and unique understanding of the community's belief and value system [38]. Specifically, evidence supports the cost-effectiveness of *promotores*-led educational interventions to increase cancer screening in the Latino community [39–44]. Most studies found that educational interventions led by *promotores* had a significant increase in BC-related knowledge among participants [41]. However, evidence of the intervention effect on screening behavior is inconsistent among studies, with some showing a significant increase in screening after intervention and some showing no change [41, 45].

Although previous research has described *promotores* training and analyzed the effectiveness of group intervention for BC screening promotion among Latinas [46, 47], our study is unique in its focus on developing materials to train *promotores* about hereditary BC, including some key genetic concepts, as well as materials that the *promotores* can use to educate the community.

The primary goal of this study was to develop and refine materials for a *promotores*-based

education program on hereditary BC for Spanish-speaking Latinas. This program includes the development of specific materials to train promotores and materials for the promotores to educate the community. A second goal was to identify promotores' and community members' insights regarding the program and its content (focus on genetics). A third goal was to conduct a preliminary evaluation of the acceptability and performance of the materials on promotores' knowledge and confidence as well as the community's intention to learn more about their family history of cancer.

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## Materials and methods

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### Study overview

We conducted a mixed methods study using qualitative and quantitative analyses of multiple focus groups to inform the development of a hereditary BC education program for Spanish-speaking Latinas, including materials to educate promotores as well as materials that promotores can use to educate the community. Prior to development of program materials, we recruited and engaged a community advisory board (CAB) to obtain feedback on the rationale for the program and identify appropriate topics to include as content in the materials. As a starting point, we modeled the program on a hereditary BC awareness effort that was previously developed for the African-American community in the San Francisco Bay Area, which in turn drew on materials developed in English and Spanish for public hospital patients in San Francisco [48, 49]. We conducted several meetings with the CAB, a group composed of nine key community stakeholders, such as experienced promotores and community leaders, to obtain ideas and brainstorm about content and how to design materials.

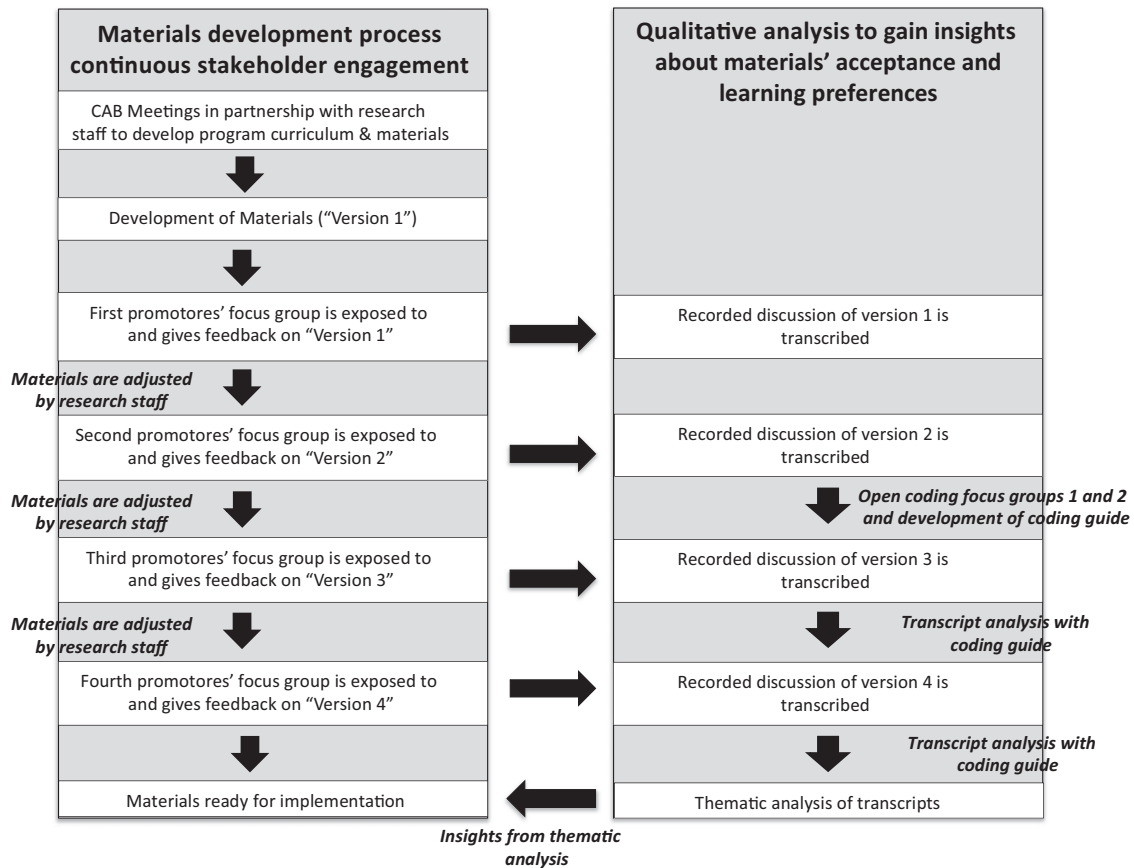
Secondly, we worked with promotores to ensure relevance and accessibility of the didactic materials and processes. Simultaneously, we engaged community members to obtain their perspective and perceptions as well as their understanding of the program [50]. Interactions with promotores and community members included informal discussions

and focus groups. The promotores' and community focus groups helped to (i) further inform the structure and didactic content of the education program and (ii) evaluate the perceived usefulness and effectiveness of the materials. More specifically, the focus groups with promotores were preceded by a session in which the research staff presented educational materials, followed by a discussion portion for participants to share their feedback. The focus groups with community members were preceded by a pilot education session led by promotores and followed by a discussion portion.

The development of the educational materials was the result of an iterative process: after each focus group discussion, our research team revised the materials to reflect and address the educational preferences mentioned during the discussion. As a result, at each meeting, participants were presented a different version of materials that had been revised according to the comments in the previous session (Fig. 1).

### Theoretical framework

The conceptual framework used to design didactic materials for educating promotores and the community about hereditary BC and the program structure was based on the construct of 'relational culture' [51] and adult learning theory [52, 53]. In the context of our program, the 'relational culture' construct emphasized the relationship between community advocates, researchers, promotores and Latinos from the community as vital to the success of the knowledge transfer process. The aforementioned groups shared the same language and some cultural norms—which facilitated cultural and information exchange among them. In fact, research has shown that various groups tend to prioritize the known or familiar over the unknown or new and that these prioritization processes have implications for interactions with the healthcare system [51, 54]. Adult learning theory guided the flow of the program and activities planned for the promotores' training and community education, including considerations of prior knowledge, learning styles, stage of development, motivation, choice, resources available and relevance of materials [52]. Consistent with the



**Fig. 1.** Diagram illustrating the connection between the material development process and qualitative data analysis for promotores' educational materials. The same approach was used for the community.

construct of 'relational culture' and adult learning theory considerations, the program materials were adapted and developed using a continuous stakeholder engagement approach [55]. Critical to this engagement was partnering with The Latino Cancer Institute (TLCI), a national non-profit organization dedicated to eliminating the cancer burden in the Latino community through program development, cancer education, research collaboration and policy promotion, with strong leadership and diverse networks [56].

### Participants

Recruitment of participants was led by TLCI. Using its network, TLCI invited the members of the CAB,

identified and recruited promotores and community members to participate in the study and organized all of the meetings and logistics of the focus groups. A total of seven focus groups took place in the California cities of San Francisco, San Jose, Concord and Pittsburg between March 2018 and May 2019. To thank them for their time, community members, promotores and CAB members received \$25 per hour/per meeting. Participants provided verbal informed consent after learning about the goals of the research project and how their information would be used, shared and protected.

The study included two types of participants: promotores ( $n = 35$ ) and community members ( $n = 33$ ). Inclusion criteria for promotores were

(i) being at least 21 years old, (ii) Spanish-speaking or bilingual, (iii) self-identifying as Latino/a and (iv) viewing themselves as community health educators (no formal training as promotores was required). Moreover, we only recruited promotores who had *not* been previously trained on hereditary BC. Inclusion criteria for community members were (i) being at least 21 years old, (ii) Spanish-speaking or bilingual and (iii) self-identifying as Latino/a.

This study was approved by the University of California San Francisco Institutional Review Board.

## Program materials

### *Materials to educate promotores*

The curriculum to train promotores included a physical guide (see [Supplementary material](#)) with illustrations that portrayed the story of Mariana—a fictitious immigrant Latina who was diagnosed with hereditary BC while living in the United States—that was used during an 8-h in-person education workshop led by a bilingual researcher with expertise in BC genetics.

Mariana's story guided the reader through the process of seeking medical care after Mariana felt a lump in her breast, talking to the doctor, doing medical exams and understanding her options upon being informed that she carried a *BRCA1* mutation. In the physical guide, Mariana narrated her entire diagnosis process, while all the scientific and biological phenomena and terms were explained simultaneously. All basic medical and genetics terms were explained using plain language principles [57], given that the target population for this program were Latinas with low health literacy levels. Additionally, we included many graphics to facilitate comprehension. Mariana's story guide was used as the basis for the in-person workshop. During the promotores training workshop, we reviewed the different concepts included in the guide through discussion as well as through 'hands on' activities such as a candy DNA building project.

### *Materials to educate the community*

We also developed an hour-long hereditary BC risk education curriculum and materials specific for

community members. The materials were developed to aid promotores' delivery of the content: materials included a Spanish-language PowerPoint presentation addressing background cancer information, a video containing Mariana's story and a brochure for community members to take home. Mariana's story video was 8 min long, portrayed solely by Latino/a actors and only included key genetic concepts (e.g. gene, mutation) as to avoid confusion. Part of the didactic content in the video about hereditary BC was translated and adapted from material previously developed for the African American community [48]. The brochure was designed to highlight the main take home messages from the video that we wanted community members to remember and a list of resources where they could find additional information. Given promotores' expertise and familiarity with their community, we asked them, in the focus groups as well as during informal discussions, to provide feedback about the quality and cultural appropriateness of the content included in the community education materials.

All materials are in Spanish and were developed by native Spanish-speaking researchers in collaboration with our community partner at TLCI.

## Focus groups

### *Structure of promotores' focus groups*

We conducted a total of four sessions that informed the development of materials (i.e. Mariana's story guide, PowerPoint presentation and surveys) to train promotores about hereditary BC. The first two sessions included an informal presentation of materials by the research team followed by a focus group discussion aimed at capturing satisfaction with the didactic aspects of the program that tapped into dimensions of the Learner Verification and Revision framework [58] components including attractiveness (e.g. colors, figures, format, flow), comprehension (e.g. content, clarity) and cultural acceptability (e.g. content and language being culturally appropriate). The focus group portion of the meetings lasted between 60 and 90 min, was audio-recorded, conducted in Spanish and moderated by two bilingual members of the research team.

The dynamic of the focus group was unstructured as to elicit general insights from the promotores about the need of hereditary BC education in the Latino community and barriers or beliefs that might be prevalent and important to address as part of the program. The last two promotores' meetings consisted of a mock training workshop, followed by a focus group discussion of the materials. All promotores' focus groups included a demographic survey, and the sessions with the mock workshop included quantitative pre- and post- surveys.

Promotores answered the pre-workshop survey a week before viewing the educational guide. This survey was developed specifically to assess baseline familiarity with key concepts taught during the program. A hard copy of Mariana's story guide was sent by regular mail to the promotores, who were instructed to read it in preparation for the training workshop. During the workshop, promotores reviewed all the concepts included in the guide with the help of a Spanish-speaking researcher who led an interactive session using a PowerPoint presentation with an informal and open-dialogue approach, as well as hands-on activities.

After each promotores' meeting, we modified the program materials based on the obtained feedback and, therefore, materials discussed in the different groups were never exactly the same (Fig. 1).

### *Structure of community focus groups*

The three sessions for community members consisted of an educational session led by promotores, followed by a focus group discussion conducted by the research staff. In the educational session, community members were exposed to a PowerPoint presentation that provided basic background knowledge on cancer and then watched Mariana's video. Promotores stopped the video at particular points to review concepts, as well as answer any questions. Finally, promotores summarized the content of the brochure to community members. Before the formal focus group discussion, community members answered a survey about their own BC family history, which was adapted from a survey previously developed to identify African American women who might benefit from genetic counseling [48] and a post-educational session feedback questionnaire.

## **Surveys**

### *Surveys for promotores*

Promotores were asked to complete three surveys: a sociodemographic survey, a baseline knowledge survey (pre) and a post-workshop knowledge survey (post). The sociodemographic survey assessed participants' age, country of birth, length of US residence, employment status, English proficiency, type of insurance and educational level.

The pre- and post- surveys were specifically developed for this program and included multiple-choice and true or false questions regarding genetics, heredity and BC risk. The questions were tailored to the materials developed in this project, and covered information identified in the literature and by the research team as important constructs related to genetics, hereditary cancer and BC risk [59]. We collected responses to the post-workshop survey for the last two promotores' focus groups (the first focus groups did not include the mock workshop). Consistent with elements from Learner Verification and Adult learning theory approaches, the post- survey also included questions about the workshop's clarity and appropriateness, promotores' level of comfort and confidence to lead an educational session, as well as how much knowledge and information they perceived to have gained from the workshop [60]. As we asked promotores to provide us with feedback about the survey items as well, we made iterative refinements to the surveys to enhance item clarity. In this manuscript, we report on those items from the pre and post workshop surveys that were consistent across the two mock-workshop sessions.

### *Surveys for community members*

Similar to our approach to survey assessment among promotores, we asked community members to complete a sociodemographic questionnaire. We also assessed community members' general cancer screening history (i.e. colorectal cancer screening, cervical cancer screening, mammography screening) and exposure to genetic testing (e.g. prenatal, cancer risk assessment). Community members also completed the BC-specific family history survey aimed at identifying women at high risk of hereditary BC [49] and the

post-education session feedback survey. As described above, the post-education survey for community members asked about the utility, quality and comprehensibility of the educational session components [60].

## Data analysis

### *Descriptive statistics*

Survey data were described and compared using R statistical software. We used chi-square and two-sided *t*-tests to measure demographic differences between the promotores and community participants. We used frequencies and percentages to assess the number of correct responses before and after the promotores' training workshop. Associations were indicated as significant at *P* values <0.05.

### *Qualitative analyses*

After each focus group session, a trained bilingual team member transcribed audio-recordings verbatim in Spanish. To ensure confidentiality, transcripts were de-identified.

Transcripts were analyzed using a Framework Analysis approach [61]. Two trained bilingual team members applied open codes to characterize comments in the focus groups transcripts. After reviewing and agreeing on identified codes, the coding guide was used to re-analyze the transcripts. Coders independently coded each transcript and then worked together to discuss any discrepancies or potential addition of new codes. Finally, codes were grouped within larger themes that were pre-defined by the research team (e.g. learning preferences or opinions related to the content included in the program) or that emerged during focus group discussions. The relevant portions of the transcripts that illustrated common codes were translated from Spanish to English for presentation purposes.

We incorporated all comments that were shared during focus groups to improve the acceptability and accessibility of materials. We qualitatively analyzed the focus group transcripts to identify concerns, learning preferences and feedback that could inform other programs for Spanish-speaking Latinos.

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## Results

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### Participant characteristics

The average age of the participants was similar between promotores and community focus groups, 41 and 45 years old, respectively (Table I). The two groups reported being in the United States for a similar amount of time: an average of 15 years for promotores and 17 years for community members. Even though most participants had relatively low levels of education and English proficiency, a larger proportion of promotores reported being fluent in English (31% versus 12%), were more likely to have private insurance (37% versus 9%) and have received at least some college level education (37% versus 18%) compared with community members.

Most participants were either from Mexico (71% of promotores and 67% of community members) or El Salvador (11% of promotores and 21% of community members) and reported being unemployed (56% of promotores and 75% of community members).

Level of English language proficiency and insurance status were both statistically significantly (*P*-value<0.05) different between community members and promotores (*P*-values 0.033 and 0.032, respectively).

### Screening and family history of cancer among community members

Seventy two percent of women from the community reported having had a pap-smear within the last three years. Of the 18 participants who were 40 years of age or older, one-third reported never having had a mammogram. Only six individuals were eligible for colonoscopy screening and all reported having had a previous colonoscopy exam.

One participant reported having personal history of BC before age 50, with no additional family history. Five individuals reported having a relative who has had ovarian cancer and four additional participants reported having had at least three members of the same side of the family with cancer of the breast, prostate or pancreas. When talking to



**Table I.** Sample characteristics (*N* = 68)

Characteristics	Community members	Promotores	<i>P</i> -Value
<i>N</i>	33	35	
Age, mean (SD)	45.0 (11.4)	41.0 (11.5)	0.156
Years in United States, mean (SD)	17.2 (7.3)	14.6 (8.5)	0.203
English language proficiency (%)			<b>0.033</b>
Basic	4 (12.1)	1 (2.9)	
Fair	12 (36.4)	5 (14.3)	
Good	13 (39.4)	18 (51.4)	
Advanced	4 (12.1)	11 (31.4)	
Insurance status (%)			<b>0.032</b>
No insurance	10 (30.3)	7 (20.0)	
Private	3 (9.1)	13 (37.1)	
Public	20 (60.6)	14 (40.0)	
No response	0 (0.0)	1 (2.9)	
Education level (%)			0.136
Elementary	4 (12.1)	0 (0.0)	
Middle school	2 (6.1)	1 (2.9)	
High school	17 (51.5)	16 (45.7)	
Trade school	4 (12.1)	5 (14.3)	
University (4-year college)	6 (18.2)	13 (37.1)	
Country of origin (%)			0.506
Brazil	1 (3.0)	0 (0.0)	
Colombia	0 (0.0)	2 (5.7)	
Cuba	0 (0.0)	1 (2.9)	
El Salvador	7 (21.2)	4 (11.4)	
Guatemala	2 (6.1)	1 (2.9)	
Mexico	22 (66.7)	25 (71.4)	
Peru	1 (3.0)	1 (2.9)	
United States	0 (0.0)	1 (2.9)	
Employment status, employed (%)	8 (25.0)	15 (44.1)	0.171
Screening history (%)			
Pap-smear in the last 3 years	23 (72%)	NA	
Mammogram if age 40+ (ever)	12 (66%)	NA	
Colonoscopy if age 50+ (ever)	6 (100%)	NA	
Family cancer history (%)			
Personal history of breast cancer before age 50	1 (3%)	NA	
Family history of ovarian cancer	5 (15%)	NA	
Male breast cancer	0 (0%)	NA	
At least 3 members on the same side of the family with breast, prostate or pancreatic cancer	7 (21%) <sup>a</sup>		

<sup>a</sup>Three individuals in this category also responded that they had a family history of ovarian cancer.

participants about the screening and family history survey questions, it became clear that there was a strong need for basic BC education given that participants did not know that family genetics had any influence on BC risk, or even that family traits could be inherited and have any potential relationship with disease risk. Hence, participants were not

equipped with the basic knowledge to properly assess whether an individual would benefit from genetic counseling and/or testing. Researchers' impression of the limited hereditary BC knowledge, and subsequent need for education, was confirmed by the pre-workshop knowledge survey results as illustrated on [Table II](#).

**Table II.** Pre- and post-workshop knowledge survey results for promotores (N = 15)

Question	Pre-test: number (%) of incorrect or 'Don't know' answers	Post-test: number (%) of incorrect or 'Don't know' answers
1. Tumors are always malignant (True/False/Don't know)	2 (13)	0 (0)
2. A gene is . . .	7 (47)	1 (7)
i. like an instruction page that tells the body how to work		
ii. It is too small and therefore not important in cancer risk		
iii. Don't know		
3. Babies inherit half of their genetic material from their mother and half from their father (true/false/don't know)	2 (13)	0 (0)
4. If my brother's wife and my aunt's husband have cancer, my risk of developing breast cancer is higher than that of other women? (yes, no, don't know)	0 (0)	0 (0)
5. Any woman can have breast cancer, even if no other person in her family has had it (true, false, don't know)	1 (7)	0 (0)
6. What are some ways to decrease the risk of breast cancer?	3 (20)	0 (0)
i. Nursing for long periods		
ii. Regular physical activity		
iii. Healthy eating		
iv. All the options mentioned above help reduce the risk of breast cancer		
v. Don't know		
7. A genetic test can be performed with a blood or saliva sample (yes, no, don't know)	4 (27)	1 (7)
8. Cancer is . . .	1 (7)	0 (0)
i. Uncontrolled cell division		
ii. Controlled cell division		
iii. Don't know		

(i) Los tumores son siempre malignos (Verdadero, Falso, No se/No estoy segura/o), (ii) Un gen. . . Correct Option 'Es como una página de instrucciones que dice al cuerpo como trabajar', (iii) Los bebés heredan la mitad de su material genético de su mamá y la otra mitad de su papa (Verdadero, Falso, No se/No estoy segura/o), (iv) Si la esposa de mi hermano y el marido de mi tía tienen cáncer, ¿quiere decir que mi riesgo de desarrollar cáncer de mama es mas alto que el de cualquier otra mujer? (Si, No, No se/No estoy segura/o), (v) Cualquier mujer puede tener cáncer de mama, incluso si ninguna otra persona de su familia lo ha tenido (Verdadero, Falso, No se/No estoy segura/o), (vi) ¿Cuáles son algunas formas de disminuir el riesgo de cáncer de mama? Correct option 'Todas las opciones antes mencionadas ayudan a reducir el riesgo de cáncer de mama', (vii) Una prueba genética se realiza con una muestra de sangre o saliva (Si, No, No se/No estoy segura/o) and (viii) El cáncer se caracteriza por la. . . correct option 'División celular descontrolada'.

### Feedback regarding the promotores and community educational sessions

Promotores in the sessions that included the mock workshop reported that the materials improved their knowledge about hereditary BC, and most of them felt confident to share the information with the community. Slightly over 80% of promotores responded feeling comfortable to share the informational video and answer questions from the community (Fig. 2a).

Community participants provided feedback about their experience in and perceptions of the educational session occurring immediately before

the focus group discussion. Approximately 67% percent of participants reported having previously heard about genetics and BC risk. All participants reported that the workshop and the video were useful in learning about hereditary BC. Ninety-four percent of individuals reported planning to seek more information about their family history of cancer. Although the materials and sessions were developed for the Latino population, 70% of community participants reported finding at least one piece of the information confusing (Fig. 2b).

**Table III.** *Predetermined or emerging themes, codes and definitions*

Theme	Codes	Definition
(a) Codes related to more specific feedback on program materials		
<b>Learning preferences</b>	Interested in information/guidance <sup>4</sup>	Would like more guidance, time with the material tools or support on how to teach the topic and/or answer possible questions from audience and/or mentioned need for/importance of learning tools (presentation guide, workshop, training) so they know how to teach others and/or reported needing a version of the guide with simpler, more accessible information and language for the general population.
	Liked materials <sup>2</sup>	Liked the way the material was divided into different sections (e.g. enjoyed how information was split into a more technical language versus easy-to-understand language) and/or liked Mariana's story.
	Liked the graphics	Enjoyed the graphics, visual aspect of the guide, made it dynamic to learn/read material and/or visual aspect facilitated understanding, made learning more concrete and/or described the guide as 'attractive' and appealing to read.
	More inclusive content	Would like the information to be more inclusive (e.g. showed interest in having Latinas compared with other ethnic groups)
	More information <sup>6</sup>	Would like the information to be expanded and/or have more terms defined and/or mentioned need for/importance of including links with more information, explanation.
	<b>Opinions related to the content included in the program</b>	Culturally appropriate
Easy to disseminate		Information from the guide was easy to disseminate and/or teach.
Easy to understand or follow/educational <sup>1</sup>		Very accessible, practical and clear/accessible language and terminology for general community and/or appreciated that terms were defined throughout the story, guide was simple, easy to understand and/or concepts were well explained. The guide was easy to follow; and/or Mariana's story made it easier to follow the process step by step. Promotoras learned something after reading the material and/or believed the guide was informative.
Important <sup>3</sup>		Believed the information on the guide to be important/relevant.
Interesting <sup>5</sup>		Reported the guide, material, Mariana's story, topic, etc. to be interesting, engaging.
Local resources		Referred to the importance of/need for including local breast cancer-related resources.
Relatable <sup>7</sup>		Promotores could relate to the breast cancer topic and/or Mariana's story in a personal way; and/or Mariana was a relatable character.
Confusing, complex genetics information		Were confused with a genetics-related concept, term, information in the guide and/or found it to be complex, complicated and hard to understand. Referred to the complexity of learning genetics-related content.
Unnecessary information		Believed there was at least one unnecessary piece of information/topic; and/or believe it is unnecessary to go too in depth on a specific topic.
<b>Role of the promotores</b>	Confident	Felt comfortable, confident to share the material/disseminate information.
(b) Codes related to general views on health education in the Latino community		
<b>Barriers to cancer screening and</b>	Barriers <sup>1</sup>	Reported at least one barrier to seeking care/screening (e.g. mistrust/distrust of health care providers, misconceptions, fatalism, lack of health insurance or knowledge of US healthcare system, language barriers, etc.).

**Table III.** (continued)

Theme	Codes	Definition
<b>prevention, including genetic screening</b>	Educate men <sup>7</sup>	Need for/importance of educating men in the community because their support or lack of support may influence women's decisions to engage in preventative behaviors.
	Positive view on hereditary conditions <sup>6</sup>	Reported need for/importance of a positive look on heredity conditions (e.g. not all hereditary information passed on is negative).
<b>Importance of the content included in the program</b>	Early detection/prevention <sup>3</sup>	Mentioned or supported breast cancer prevention and/or early detection in general and/or early prevention & breast cancer information dissemination at a young age.
	Importance of learning and understanding genetic concepts/counseling <sup>2</sup>	Importance of/need for knowing and understanding genetic concepts/counseling.
<b>Role of the promotores</b>	Community importance <sup>4</sup>	Saw themselves as the connection between community and healthcare professionals and/or highlighted importance of/need for helping community members.
	Importance of dissemination <sup>5</sup>	Believed in the importance of disseminating health information/facts within the community and/or excited, willing to disseminate information.
	Leading by example	Belief that leading by example ('doing what they preach') is important.
	Share experience	Importance of sharing personal experiences.
<b>Learning preferences</b>	Unsure about role	Unsure about what they could and could not do as promotores (e.g. unsure if they could do more than only educate and recommend).
	Importance of questions	Emphasized the importance of questions asked after a presentation (e.g. good tool to assess effectiveness, clarity and misconceptions).
	Interactive lesson	Need for/importance of having an interactive lesson (e.g. using candy 'prototype' to learn about DNA).
	Online tools	Need for/importance of online tools to help review material and guide, train promotoras.
	Spanish language	Having the material in Spanish makes them feel more comfortable with the topic and/or appreciated the material being in Spanish.

The most frequent codes within categories are identified with superscripts (1 designates the most frequent code).

### Pre- and post-workshop knowledge survey results for promotores

A total of 15 promotores responded to the pre- and post-workshop survey questions. The average proportion of incorrect or 'do not know' responses in the pre-survey was 17% (min: 0% and max: 47%), while most questions were answered correctly in the post-survey—average proportion of incorrect or 'do not know' responses was 2% (min: 0% and max: 7%) (Table II).

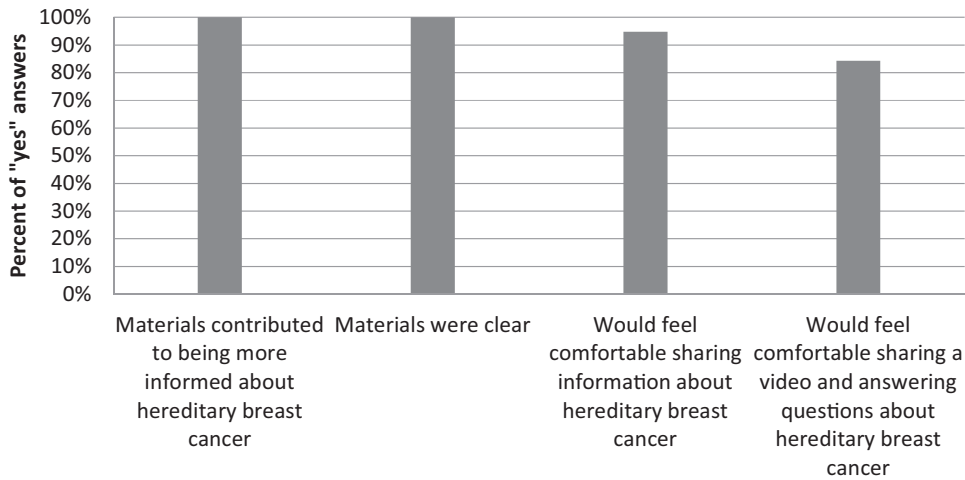
### Qualitative findings

In addition to collection of feedback from promotores and community members regarding the materials, participants also shared more general thoughts and

opinions related to educating Latinas on health topics, as well as barriers to health care and health education in this population. Below, we present results from the qualitative analyses in two major categories: (i) findings related to the program materials and (ii) findings related to health education in the Latino community. We grouped codes within general themes that were either predetermined by the research team or emerged during code analysis. Themes, codes and definitions are shown in Table III.

#### (i) Specific feedback on the program materials

A detailed description of themes and codes within this category is shown in Table III(a). We present a



**Fig. 2.** Perceptions and feedback from community and promotores on educational sessions. (a) Promotores' perceptions and feedback ( $N=15$ ). (b) Community perceptions and feedback ( $N=33$ ).

summary of some of the themes with exemplifying quotes from focus group participants.

### Learning preferences (predetermined theme)

Promotores appreciated that the workshops were led by someone with content expertise: 'many times, there are doubts, misinformation that one hears, so for me, it was very important to have someone prepared and who responded to all the questions I had about BC'. One of the promotores shared that 'the visual is very good. It's fine because there are people who sometimes tell us 'oh, I don't like reading and there are many letters.' So the images are simple, and help explain'. The code capturing statements expressing approval for the visual aspect of the guide became more common as we received feedback and improved the graphics. In general, promotores and community members expressed high satisfaction with the materials having graphics and figures to facilitate learning. However, some of the promotores also expressed that they would have liked to have access to additional materials and information and that it would be important to have more guidance and practice before they go out to educate their community about hereditary BC.

### Opinions related to the content included in the program (predetermined theme)

Community members agreed that the materials were easy to understand and mentioned learning something from them. The 'easy to understand or follow/educational' code was more frequently applied to the last focus groups compared with the earlier ones, suggesting that the feedback provided by participants was instrumental in improving the clarity of the materials. Community members also reported enjoying the brochure and other didactic materials (e.g. video); one participant said that 'the brochure was very good, the information was very complete and the class was very productive'. Promotores also found the materials clear and useful. For instance, one promotora said 'for me the guide was very practical, very basic, very clear. I really like the drawings, they are very attractive, especially the genetics part'. Overall, promotores liked the materials, found them to be engaging and Mariana's story to be relatable. In fact, one participant shared 'It was like when I arrived... anyone who comes from a foreign country, alone, and who doesn't have insurance, doesn't know where to go or how to support herself, doesn't have anyone, and doesn't really know what's going to happen'.

Participants in the community and promotores' focus groups mentioned that they found the information about genetics interesting and relevant for cancer prevention. For instance, a participant stated 'it's good that they teach about genetics because that's how we know if we have a mutation and help our children prevent it [the cancer]. So, if we have a mutation, we can help our children prevent it too'. For most of the promotores focus groups, there were mentions of the genetics-content as complicated/difficult to understand. As a result of these comments, we incorporated a longer discussion about the genetics concepts during the in-person workshop. For the community focus groups, there was a decrease in mentions of the complexity of materials from the first to the last focus group which we attributed to the decreased complexity in subsequent versions of the materials. One community member shared 'For me, the explanation about genetic mutations was very important, it was very clear, and I understood those concepts very well'.

#### *(ii) Health education in the Latino/a community*

A detailed description of themes and codes within this category is shown in [Table III\(b\)](#). We present a summary of some of the themes with exemplifying quotes from focus group participants.

#### **Barriers to cancer screening and prevention, including genetic screening (emerging theme)**

Both promotores and community members reported concerns about barriers to access health care and health education among Latinos. One community member said, 'someone mentioned you should go to the doctor, but what if you don't have a doctor?' Another participant mentioned that 'there is a lot of medical terms we do not know'. Concordantly, throughout the promotores' focus groups, participants mentioned facing at least one barrier to healthcare; those barriers were either structural or cultural. In terms of structural barriers, participants mentioned lack of insurance and knowledge of the American healthcare system, as well as language

barriers. Regarding cultural barriers, the most common were misconceptions (e.g. beliefs about mammography causing cancer or being unbearably painful), fatalistic views, mistrust of health care providers and cultural values, such as prioritizing their family's health over their own. One promotora said 'as women and mothers, many times we first pay attention to the children, the husband or the rest of the family, leaving ourselves to the side or thinking we don't matter or that it will just go away. But if we are not well, how will our family be fine?' One of the promotores highlighted the importance of sharing accurate information and hints to the issue of mistrust: 'for me, this information is very valuable, and I want to take it to my community. I think it is really important to share correct information, because many times when someone gives the wrong information, you scare the person and the person doesn't know if the things you are saying are true or not'.

Finally, given that the promotores are motivated to disseminate health information, as well as appreciate the value of educating the community on health topics, many of them emphasized the importance of disseminating the content learned during the workshop. One promotora said 'well, we don't have to wait to get cancer so that we are well informed. They say ignorance is what kills us, right? And I think 'wow I love all this,' and it is very interesting to give all this information to the community'. Another promotora mentioned finding the information especially easy to share; she said, 'because I learned it with easy, simple words, it is with that same simplicity that I can share this information with another person'.

#### **Importance of the content included in the program (emerging theme)**

During the different focus groups another theme that was frequently brought up was the importance of educating the Latino community about hereditary BC and genetics. A community participant shared that 'it is also very important for me to come to this meeting because of my mother's cancer history. So, I did want to know how I could avoid it, and it is important to know one's genetics and ways to avoid or prevent it'. Additionally, some promotores emphasized the

importance of knowing and understanding genetic concepts, as well as seeking genetic counseling when appropriate.

Another recurrent topic was the importance of knowledge and awareness to prevent cancer. In the words of one of the community members: ‘and as Hispanics we sometimes ignore or forget it [the cancer] and is very important because the earlier we identify it, the higher our probabilities for a recuperation, effective treatment’. Promotores also highlighted the importance of BC prevention and early detection.

### **Role of the promotores (emerging theme)**

During the promotores’ focus groups, the role of the promotores in the community was mentioned multiple times. They presented themselves as the connection between knowledge and the community. One participant shared ‘but now with everything I learned I know that I have that power to help these women and other families and stop this. The incidence of cancer in the Latino community can be further prevented and eradicated’.

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## **Discussion**

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Promotores-based BC awareness, screening and navigation programs for the US Latino community have been shown to be effective [35, 46, 47, 62]. In the age of precision-medicine, populations facing economic, educational, language and cultural barriers to access basic health care are at risk of being left behind. Few hereditary breast and ovarian cancer education materials and trainings have been developed for Spanish-speaking Latinos [49, 59, 63, 64] and for promotores who provide services to Latinos [65]. The goals of this study were to develop a hereditary BC education program for the Spanish-speaking Latinas, identify promotores’ and community members’ insights regarding the materials and conduct a preliminary evaluation of the program.

In order to develop materials that could be effectively used by promotores and understood by community members, we followed a continuous stakeholder engagement approach [55]. This

iterative feedback process aimed to address common barriers to healthcare and health education that have already been shown to disproportionately affect Latino communities [29, 66–68].

Community participants and promotores were similar in terms of average age and time since immigration to the United States. However, promotores reported having obtained a college education and being fluent English speakers more frequently than community members. Higher educational attainment among promotores has also been observed in other studies when compared with the average community participant [38, 39, 41, 69].

During the first focus group with promotores, we realized that our initial educational guide was not as clear as intended. With every focus group conducted, we learned how word choice, specific illustrations and format could influence a positive experience and increase participants’ willingness to learn about hereditary BC. After every focus group our team gathered the information and comments provided by participants and examined how their suggestions could be incorporated to improve the materials. The interactions with the stakeholders were fundamental in adjusting not only the content of the written and graphic materials, but also the dynamics of the in-person workshop for promotores and community members. Specifically, as we interacted and engaged promotores and community members, we developed additional hands-on or group activities to reinforce concepts (e.g. role play, building of candy DNA and sperm/egg mutation transmission probability game).

Pre- and post-surveys conducted before and after the promotores mock workshops provided additional information on how well promotores understood the program content. Participants’ low pre-workshop, baseline knowledge survey scores regarding basic genetics and genetic testing were consistent with previous research [68, 70]. The improvement in the results of the post-session survey suggested that stakeholder-driven changes of materials had a positive impact on their understanding. Additionally, we observed changes in the frequency of some codes (e.g. decrease in ‘confusing information’ mentions). Such decrease suggested that as

materials and teaching tools were refined, there was an improvement in their clarity.

As part of the community meetings, we collected information regarding cancer family history. Even though only one woman reported personal history of BC, 27% reported a family history of cancer that would have required a follow-up conversation to clarify the information. If confirmed, such individuals would have been considered candidates for genetic counseling. We believe that the high proportion of reported family history of cancer among community participants was due to self-selection based on the advertised content of the education program. It was expected that those willing to spend time learning about hereditary BC already had a prior perception of the topic's personal relevance.

In addition to this self-selection bias due to personal interest and family history, we believe there were other sources of recruitment bias. First, focus groups and workshops were usually conducted during business hours, thus our participants were more likely to be currently unemployed or working part-time. For promotores workshops, we recruited through a community-based organization, hence promotores in the program were all connected to the organization. There was also variability in terms of prior experience of promotores. Even though we only recruited promotores with no prior experience educating the community about BC and genetics, some promotores had been involved in programs on cardiovascular disease or diabetes prevention, while others were still learning. Community members were recruited from promotores' social circles and from parents at a public school, and therefore the sample of community members was not a random sample.

We would like to highlight that despite the observed decrease in confusion among participants as we iteratively modified materials based on their feedback, 70% of community members continued to find at least one topic or piece of information unclear—which we plan to address in future revisions. Such finding underscores the challenge of effectively disseminating genetics information and teaching complex topics to lay individuals, especially to those from communities that tend to receive less formal education due to structural barriers and inequities.

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## Conclusion

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In conclusion, our study strongly suggests that educational materials on complex concepts, such as genetics and cancer, can be effectively created as a collaborative effort between researchers and a strong and dedicated CBO to engage the community. Findings indicated that there is great need and desire for education on genetics of BC in this population. However, education is only the first step towards reducing racial and ethnic disparities in genetic screening rates for hereditary BC. The Spanish-speaking Latino community must also receive support navigating the complex healthcare system so they are able to access screening with full understanding and decision-making ability. Therefore, future research should focus on ways to induce agency through awareness and knowledge of hereditary BC, with an emphasis on basic genetic concepts, as well as to facilitate access to appropriate resources and follow-up measures.

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## Supplementary data

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[Supplementary data](#) are available at *HEAL* online.

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## Conflict of interest statement

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None declared.

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