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Promotores' perspectives on the virtual adaptation of a hereditary breast cancer education program

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Abstract

Breast cancer is the most common cancer in women in the United States (U.S.) and the leading cause of cancer related death among U.S. Hispanics/Latinas (H/Ls). H/Ls have lower rates of screening and longer time to follow up after an abnormal mammogram. We developed a comprehensive community health educator (*promotores*)-led education and risk identification program for Spanish-speaking H/Ls in California to increase mammography screening, genetic testing, and the understanding of the impact of family history on cancer risk. Due to COVID-19,

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Author Contributions

Fabian Perez and Laura Fejerman together with *promotores* and community partners Miriam Hernandez, Alejandra Martinez, Patricia Castaneda, Raquel Ponce, Maria Gonzalez, Cindia Martinez, and Ysabel Duron in the conception and writing of the manuscript. Angelica Perez, Juanita Elizabeth Quino, Eric Robles Garibay, Valentina A. Zavala, Xiaosong Huang, Susan L Neuhausen, Elad Ziv, and Luis Carvajal-Carmona provided input and edits contributing to the final version of the manuscript.

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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Compliance with Ethical Standards

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No non-human animal studies were carried out by the authors of this article.

we adapted the program to a virtual platform. The experience of transforming the program to a virtual platform provided unique opportunities for collaboration between researchers, community partners, and participants. *Promotores* are major partners in community based participatory research and in the provision of health care services, but their voices are often excluded from scientific reports. This commentary is an effort to provide a platform for *promotores* to share their experiences and for the readers to understand their approach in bridging the gap between health care services and communities.

Keywords

Promotores ; Health Promotion; Health Literacy; Family History; Hereditary Breast Cancer; Underrepresented Populations

Background

The community health educator or *promotores* model has been successful for increasing participation of underserved members of the H/L community in disease prevention services (Ayala, 2011; Cherrington et al., 2010). Numerous studies have shown that *promotores* can bridge the gap between the community and healthcare professionals (Ayala, 2011; Cherrington et al., 2010; Nuno et al., 2010). They are usually actively involved and aware of community-specific issues and barriers, have numerous connections to key gatekeepers, and hold their trust (Nuno et al., 2010). By partnering with *promotores*, numerous health professionals and researchers have been able to create successful interventions, such as the AMIGAS study which increased uptake of cervical cancer screenings in H/L women, and the Esperanza y Vida program which promoted breast and cervical cancer screening among H/Ls (Saad-Harhouche et al., 2010; Smith et al., 2013). A study published in 2021 centered on mental health in the H/L community in Southern California focused on the perspectives of the *promotores* perceived roles in the provision of mental health services (Gonzalez, 2021). The paper explained that *promotores* saw themselves as caretakers of the community and felt they needed to be included in delivery of services (Gonzalez, 2021). Specifically, the *promotores* felt they should be complementary to mental health professionals since their input and knowledge of the barriers and stigma would be necessary in creating sustainable impacts in their communities (Gonzalez, 2021). Most importantly, *promotores* address cultural stigma, identify misinformation, assist community members with their needs and concerns, and act as invaluable liaisons between communities in need, local clinics, and health systems (Ayala, 2011; Cherrington et al., 2010; Nuno et al., 2010; Smith et al., 2013).

Breast cancer is the most common cancer in women in the United States (U.S.) and the leading cause of cancer death among women who self-identify as Hispanic/Latina (H/L) (American Cancer Society, 2018; Power et al., 2018). Even though H/L women are less likely to develop breast cancer compared to non-Hispanic White (NHW) women, they tend to be diagnosed with more advanced disease stage (Power et al., 2018). Between 2011–2015, 57% of U.S. H/L breast cancer patients were diagnosed at an early stage (i.e., localized disease) compared to 65% of NHW patients (Power et al., 2018). Lower rates of and/or

irregular mammography screening, longer time to follow-up on abnormal mammogram, and lower rates of genetic testing contribute to this disparity (Power et al., 2018). Lack of awareness about the importance of mammography screening and the programs that are available for those without health insurance contributes to the lower participation of H/Ls (Ahmed et al., 2017; Hamilton et al., 2015). The reduced uptake of genetic counseling and testing may be explained by lack of awareness regarding genetic risk and family history, and by barriers associated with lack of health insurance to cover these services (Sohn, 2016; Sommers et al., 2017).

To address the lack of awareness and knowledge about hereditary breast cancer and genetics among H/Ls, and the difficulties associated with navigating the health care system to access related services, we developed the *promotores*' led 'Tu Historia Cuenta' program. This is a comprehensive program originally spearheaded by The Latino Cancer Institute (TLCI), a non-profit organization and national leader in H/L cancer issues, designed in Spanish by a team of H/L community and academic partners (The Latino Cancer Institute, n.d.). It aims to educate and identify women with strong family histories who would benefit from genetic counseling, and to help them access the services they need (Almeida et al., 2021).

Training of *promotores* for program implementation started in November 2019 and plans were made to start community outreach activities in March 2020. Soon after the first COVID-19 lockdown, we shifted to planning the adaptation of the program to a virtual platform. We have successfully pivoted and as of September 2022 have reached out to more than 1250 H/L women in Northern and Southern California, shared information about hereditary breast cancer, and identified those who would benefit from genetic counseling. This commentary aims to provide a platform for *promotores* in the program to share this experience as they moved from the traditional in-person training and community outreach activities to a virtual program. A secondary goal is to inspire genetic counselors to seek collaboration with *promotores* to increase genetic counseling and testing uptake in the H/L community.

Introducing The Community Partners

The 'Tu Historia Cuenta' team partnered with two community health organizations: Vision y Compromiso and Promoters for Better Health.

Vision y Compromiso is a non-profit organization that focuses on community advocacy, leadership development, capacity building, and acting as a health promotor training agency and professional network (Vision y Compromiso, n.d.). Vision y Compromiso operates in the majority of California, Nevada, and Mexico. Their network includes more than 4,000 health *promotores*.

Promoters for Better Health is a non-profit organization focused on bridging clinical care and communities that are disproportionately affected by healthcare barriers. Promoters for Better Health is based in Southern California and provides training and resources on nutrition, family caregiving, diabetes, leadership, and advocacy (Promoters for Better Health, n.d.).

A description of the *promotores*' training and community education activities

Original in-person training

Promotores' training: The process of developing the original curriculum to train *promotores* and the resultant materials have been previously described (Almeida et al., 2021). Briefly, the in-person training included a physical guide with illustrations that portrayed the story of Mariana—a fictitious H/L woman who was diagnosed with breast cancer while living in the U.S. The *promotores* attended an eight hour in-person education workshop which included lectures and group activities led by a bilingual researcher with expertise in breast cancer genetics. *Promotores* who attended the training workshop were asked to fill out a basic demographic survey (Almeida et al., 2021).

Community training led by promotores: We developed an hour-long hereditary breast cancer risk education curriculum and materials specific for Spanish-speaking H/L community members (Almeida et al., 2021). The materials were developed to assist *promotores* in the delivery of the content and included a Spanish-language PowerPoint presentation on background cancer information, a video of a personal story, the role genetics plays on cancer risk, and a brochure for community members to take home and share with their families and friends. All materials were adapted or developed by a team of native Spanish-speaking researchers and staff continuously engaging with *promotores* and community via a strong partnership with The Latino Cancer Institute (TLCI) (Almeida et al., 2021; Joseph et al., 2010; Rajpal et al., 2017).

The shift to virtual training

The implementation of 'Tu Historia Cuenta' was planned for early 2020. Due to the COVID-19 pandemic, all in-person outreach and education activities were cancelled. As a response to these unexpected circumstances, we modified the program to deliver it virtually. All aspects of the in-person training were included, with training sessions conducted via Zoom, a video conferencing platform. Surveys were adapted to be implemented via mobile phone. Community outreach, teaching, and follow-up were converted to the virtual modality.

When the trainings transitioned to a fully virtual format it became apparent that *promotores* required additional support on how to use virtual communication platforms. This training was provided by the *promotores*' organizations. After this initial basic introduction to the virtual platform, the research team moved onto the curriculum.

Some of the *promotores* had attended the in-person workshop prior to COVID-19, and for those individuals we offered a virtual refresher followed by multiple practice sessions. For new *promotores* we offered the entire workshop virtually followed by practice sessions. Practice sessions were mock community education sessions, where *promotores* scheduled, invited, and hosted their own Zoom meetings and went through a presentation with peers and the research team acting as community members (Reyna et al., 2022). The mock presentations allowed the *promotores* an opportunity to practice using Zoom and review the session content and the research team an opportunity to ensure the information was

accurately shared (Reyna et al., 2022). During the entire process of material development, transition from in-person to virtual, and implementation, we used a continuous community member engagement approach (American Cancer Society, 2018), involving the *promotores* in the adaptation of the curriculum and allowing them to provide their own personal interpretation of content as to facilitate transfer of information to the community.

The Southern California team (Promoters for Better Health) was led by one supervisor and included 11 *promotores*, and the Northern California team (Vision y Compromiso) was led by one supervisor and consisted of 4 *promotores*. The 15 individuals did not start at the same time, the team grew throughout the entirety of the study, which affected the training pipeline. More experienced *promotores* acted as mentors and were an extra pair of hands in shaping and training new ones on how to teach the curriculum. The latter members of the team started by shadowing senior *promotores* during their classes, and once they were comfortable, they would lead their own class with the more experienced *promotores* in attendance as extra support. This system of mentorship was an important factor in the success of the program and the recruitment and training of new *promotores*.

The community education sessions included three short surveys to obtain information on: 1) basic demographic characteristics and prior exposure to genetic tests and to cancer screening, 2) family history of cancer (Joseph et al., 2010; Lee et al., 2013); and 3) the perceived utility of the information shared during the education session. A system of weekly communication between the research team and the *promotores'* organizations was in place to follow-up with those participants identified as high-risk or in need of basic cancer screening services (e.g., mammography).

The voices of *promotores*: A collaborative narrative of the *promotores'* experience during 'Tu Historia Cuenta' implementation

This section presents a narrative written by the *promotores* about their experience together. The *promotores* wrote their own narrative in Spanish, which was then translated by a native Spanish speaker from the research team into English. The different narratives were combined, edited, and reviewed in a meeting conducted in Spanish including the research team and the *promotores*. During this meeting, we all agreed upon a draft of the narrative to be included in the manuscript, which was then reviewed by the *promotores* and the research team before final submission. The *promotores* are listed as authors in this paper due to their active contribution to the writing of their perspective and overall review of the manuscript. Below, 'We' refers to the group of *promotores* who are actively educating the community as part of the 'Tu Historia Cuenta' program.

We believe that as *promotores* we must have the moral capacity and the love for service to help others and to want to see people improve and get ahead. *Promotores* must be aware of people's feelings without judging them. We need to understand that everyone has different perspectives because not all of us go through the same situations and circumstances even if we are all Latinos. There will always be barriers and adversities, but *promotores* are there to guide and help those who find in us a helping hand.

Dissemination of simple information that our communities can understand about the importance of cancer prevention to have the best quality of life for all families is crucial. Although there are many barriers, like language, discrimination, access to healthcare, and other social disparities, we, as *promotores* must inspire trust within our community, which takes credibility, transparency, empathy, honesty, commitment, and dedication. We act as the bridge between doctors, researchers, and members of our community.

We know about the disadvantages that Latinos face, and our responsibility to take care of ourselves and those around us. It was very interesting to learn about genetics and breast cancer for the implementation of “Tu Historia Cuenta” and having materials that allow us to share this information with the community in a way they can understand.

As we are implementing the program, we are learning that there is a lot of misinformation and taboos in our culture, which is a limitation to making well-informed decisions about our health. We have found that there is little awareness about our own bodies, chromosomes, cells, or women’s anatomy. We need to create awareness in the most vulnerable communities on the importance of self-care and to make sure people see a doctor when they have doubts and concerns about their health.

Below, we share some of the things we learned/experienced during the process of implementing the hereditary breast cancer education program in our community virtually during the COVID-19 pandemic.

Experience with the virtual platform and differences with pre-COVID-19 times

The COVID-19 pandemic forced us to change our approach in how we recruit and connect with women in our community. Prior to the pandemic, we recruited women in grocery stores, while we picked up our children, or after mass. Now, with the social distancing guidelines, we pivoted our focus to social media. Social media is a great tool for us because it is one of the main ways that our Latino community stays up to date with family, friends, and with what is going on in our neighborhoods. We promote our classes on social media and even host virtual “live” events to promote these classes and other programs we are working on. One of our fears during this program was running out of contacts in our personal and professional networks. Our will and dedication to continue educating individuals drove us to utilize other tactics and avenues to expand our reach. For example, we asked participants to share with their networks and re-invited women who had signed up but had not attended the class.

The use of the virtual platform has allowed us to continue to reach out to our community during troubling times, giving them important information about their health, and empowering them to make healthy decisions. Due to fear of COVID-19, many people in our communities were not comfortable with in-person group meetings, so the virtual platform gave us the opportunity to connect with one another and not risk our own health and the health of our families. We host the classes during times that most people are free and do not need to worry about the usual obstacles like transportation, childcare, and needing to

tend to their homes. Overall, the virtual platform allowed us to reach a greater geographical area, meeting women who we otherwise would have never met or connected with.

Many of our community members did not know how to use the virtual platform to access our education sessions. This forced us to take extra time to walk them through the Zoom settings and controls, how to join meetings, and tips for weak internet connections. It was incredibly fulfilling to not only learn how to use the virtual platforms but to also teach our community how to use technology in ways that they had not used before. It was stressful and quite challenging, but it was our goal to ensure that our participants understood how to use the virtual platforms not only for our classes but for other programs available to them as well.

Another difficulty has been gauging how involved our participants are when they attend our meetings compared to in-person because most women keep their cameras off. In past programs when we hosted education sessions in person, we could see who was paying attention and it was easier to keep participants engaged. In the virtual sessions, it is difficult to know if participants are truly paying attention and simply have their camera off, or if they are busy doing other things and are distracted. As a result, sometimes we feel a lack of personal connection which is incredibly important in the work we do. We noticed that many participants do not ask as many questions as they did in past in-person programs. We believe that because participants are in their own homes with their children and families around, they lack the privacy and the feeling of a safe space to ask personal questions about their health or other concerns.

If you would have asked some of us at the beginning of this pandemic how the program would differ if we held it completely virtually, we would have said that less people would attend meetings and that this would not go well. Now that we have been working on this for over a year, we truly believe that despite the challenges we described, such as the difficulty to connect with participants, we were able to reach out to more people in our community because of the removal of barriers like transportation and because it is more convenient for people to join if all they have to do is click a link.

Lessons learned about us and our community

Learning about breast cancer genetics and having to teach our community such a complex topic using a virtual platform during a pandemic presented us with challenges as well as an incredible opportunity to learn about ourselves and our communities.

We learned about the importance of being patient and actively listening to the needs of those around us. We noticed a lack of awareness about health-related issues generally, and the need of our community to access information in Spanish to help them make informed decisions about their health and that of their families. Often, our community members do not take advantage of resources available because information about these programs is not adequately catered to them. However, 'Tu Historia Cuenta' was created with the H/L community in mind, which gave us and the participants the confidence needed to ask

questions and resolve our doubts. Individuals particularly appreciate that we share resources that they can access in the area where they live.

Unfortunately, there is a lot of misinformation that aims to disarm our community with fear and uncertainty instead of trying to educate and empower them. We noticed that many of the women who participated in the “Tu Historia Cuenta” program do not have a good understanding of their own anatomy, for example confusing the cervix with the uterus and ovaries. We often had to spend time to explain about the different organs, showing the need for more health education in our communities.

As *promotores de salud*, we must learn new things to be able to take back and share with our community and those around us. Breast cancer risk is an especially important topic because we noticed that the statistics do not lie. Many women who joined our classes and even some of us were going through chemotherapy, had mastectomies, or had close friends or family members who had gone through what we were teaching about. Therefore, it is important to teach about genetics and prevention because cancer can affect anyone. When we connect with a woman during the class, we are not only educating that person, but through them, we are also educating their family and friends. Through this program, we all have an amazing opportunity to learn more about genetics and to go back to our community to teach them about the impact family history has on cancer. It gives us extra motivation to learn other things and ask more questions to increase our own knowledge. This program exemplifies to us the importance of our role and how the community gives us their trust. It is a wonderful feeling to see our work being appreciated. Knowing that we have the research team and our supervisors as backup if we have questions makes us feel supported and confident in teaching a difficult topic like genetics.

We are interested in learning more to continue to teach these classes and other topics as well. As a result of our experience with “Tu Historia Cuenta”, we feel capable in our ability to assist with other research projects in the future. We are happy to help educate our community and take part in helping inform them to make healthy decisions for themselves and their families. As *promotores de salud*, it is our responsibility to constantly learn, grow, and adapt to whatever is thrown our way to serve and empower those around us.

Concluding thoughts: the importance of a bidirectional partnership

Promotores have a major role in bridging the gaps between communities, healthcare professionals and providers, and researchers but are frequently overlooked during the planning stages of research projects and the presentation of findings. Bidirectional partnerships with *promotores*’ groups and their community-based organizations may enhance clinical and research programs, including genetic studies. Inclusion of *promotores* in all stages of planning and execution of research may improve the ability of research studies to recruit, retain and intervene with H/L study participants. As members of the community, they can contribute important insights to successfully implement outreach and education programs. By working with *promotores* during planning stages as well as throughout implementation, researchers and genetic counselors can ensure that their studies and programs are built to effectively address the needs of the population. Additionally,

genetic counselors should be partnering with *promotores* to better connect with community members and assist with the provision of services. Promotores' are interested and motivated to be included in scientific presentations and activities and be seen as part of the provider network. This commentary is the result of investigators and *promotores* working together to share the *promotores*' experiences and the important role they play in improving the health of H/Ls.

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Notes and shared content generated by *promotores* in the process of writing this manuscript are available from the authors upon request.

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