De Madres a Hijas: A Culturally Tailored Intervention to Increase Knowledge on Hereditary Breast Cancer Risk among Latina Mothers & Their Daughters

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BACKGROUND

An important step toward understanding the role of BRCA and other cancer genes in Latinas is to increase the number of individuals who receive genetic testing and counseling (GTC). Latinas have the 2nd highest prevalence of BRCA gene mutations after women of Ashkenazi Jewish ancestry and the lowest level of awareness about GTC for inherited cancer risk than all other racial/ethnic groups, and are 4-5 times less likely to get tested compared to Whites.

Recognizing a lack of knowledge among Latina breast cancer survivors (BCS) and their daughters, Nueva Vida, developed an intergenerational intervention as an effective method to leverage cultural values and combat mistrust, laying the groundwork for learning and preventive action. The aim of De Madres a Hijas is to increase Latina mothers/daughters' knowledge about Hereditary Breast Cancer (HBC) risk, enhance their talking about familial HBC risk with relatives, and develop an "action plan" to make educated decisions on their own health.

At the conclusion of the health workshop, we want both mothers and daughters:

A) to **understand the basic concepts** of breast health and understand the anatomy of the breast.

B) to know **risk reduction strategies** and the **importance of family history** and how it relates to their own risk.

C) to leave the educational presentation with an **"action plan"** to make educated decisions about their own health.

METHODS

We used an explanatory pre-post mixed methods design to assess how the intervention contributes to an increase in Latina mothers/daughters' knowledge about HBC risk and promotes intent to participate in genetic counseling and testing.

We used descriptive statistics to characterize the study sample of Latina BCS and their daughters (n=48). Participants were administered a 13-item pre-post survey to assess knowledge (i.e., having a genetic mutation does not mean you will get cancer T/F). An expanded Consolidated Framework for Implementation Research (CFIR) comprised of 15 domains (e.g., Difficulty Understanding Genetics, Actions to Learn about Family History) guided the qualitative data analysis. Four Coders utilized template analysis to analyze the interviews.

Table 1.

De Madres a Hijas Demographics

Mothers		Daughters	
Country of Origin		**Country of Origin**	
Dominican Republic	1	Dominican Republic	1
El Salvador	9	El Salvador	5
Guatemala	2	Guatemala	2
Honduras	3	Honduras	2
Mexico	5	Mexico	3
Panama	1	Panama	1
Peru	3	Peru	1
		USA	9
English Proficiency		**English Proficiency**	
None	13	None	3
Some	8	Some	2
Moderate	1	Moderate	4
Well	1	Well	2
Very Well	1	Very Well	13
Insurance Status		**Insurance Status**	
Uninsured	15	Uninsured	20
Medicaid/Medicare	7	Medicaid/Medicare	3
Private Insurance	2	Private Insurance	1

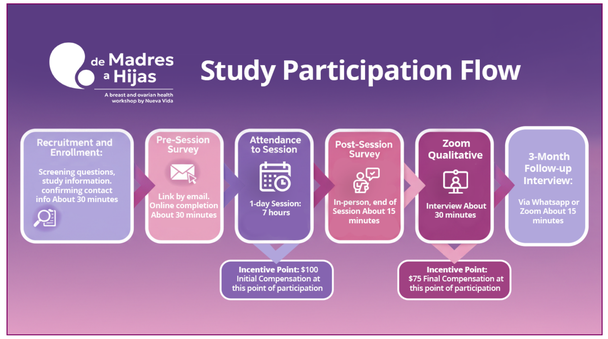


Figure 1. STUDY PARTICIPATION FLOW

RESULTS

This first-of-its-kind, community-based initiative leverages a one-day, workshop to educate BCS and their daughters about HBC, their risks, preventive behaviors and GTC. These workshops showed improved understanding of genetic cancer overall (7.9-10.5) with daughters showing a higher increase of knowledge (7.3-10.9). 83% reported behavior changes toward healthier daily activities and prevention-focused habits. As stated by a participant, ***"We were told to be aware if we feel pain… I did my self-exam and I didn't find anything, but I felt pain right next to my armpit and I felt more confident to make a follow up appointment and they found it (a lump)."*** Lastly, to extend the reach of the program, we have developed the Toolkit—a manual for other Latino-serving organizations hoping to facilitate these life-saving conversations in their communities.

QUOTES

"When my mom was diagnosed with cancer, it could have been detected earlier. Due to lack of information, she wasn't able to do that."

"We are very grateful for this workshop because we have definitely learned a lot and that is very important. Because when you know, you have tools and you know how to face any situation."

"Because I have understood that in the end no one knows your body better than you do yourself."

"I don't go to the doctor often, but since we had this session, I scheduled my physical. I hadn't gone to the doctor for about 2 years, maybe more, and now I have my appointment to learn how my body is doing and I'm going to ask my doctor to refer me to genetic testing…"

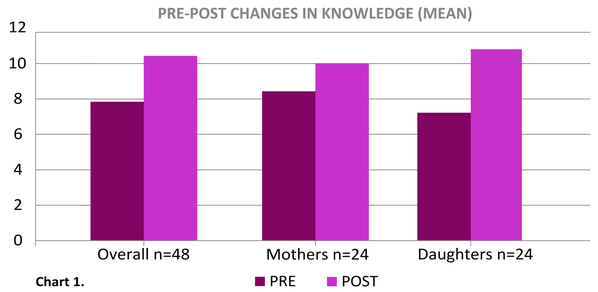


Chart 1.

DISCUSSIONS

Culturally tailored interventions are vital for ensuring that GTC services are accessible, effective, and equitable for all individuals, regardless of their ethnicity. Education plays a pivotal role in closing the gaps in GTC. Creating the opportunity for mothers and daughters to share this experience, provides not only knowledge building about GTC, but also a special bonding by listening and understanding each other's lived experience. Second generation Latinas show better literacy levels than immigrant Latinas who deal even with their own language reading and writing barriers. For the Latina community, it's crucial that we not only offer HBC education but do so in a way that resonates with their unique cultural perspectives.

CONCLUSIONS

The importance of ***De Madres a Hijas*** cannot be under stated. Women who are aware of their family history of cancer are more inclined to engage in risk reduction. But, due to both cultural norms and mistrust of a historically inequitable healthcare system, these life-saving conversations often don't happen within the Latina community. Research indicates that intergenerational, family-based health interventions are an effective method to leverage cultural values and combat mistrust, laying the groundwork for learning and preventive action. To date, there is limited research exploring whether this type of culturally tailored intervention could lead to increase in knowledge and prevention for Latinas at high-risk for breast and ovarian cancer.



Figure 2.

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