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CARE: Collecting and Assessing Cancer Family History to Identify at Risk Individuals Educational Intervention for Community Health Workers

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CARE: Collecting and Assessing Cancer Family History to Identify at Risk Individuals

Educational Intervention for Community Health Workers

by

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ABSTRACT

Background: Collection of family health history (FHH) can identify individuals at increased risk and guide disease-specific recommendations for management, early detection, and prevention. Yet, collection of FHH is often low or infrequent despite national initiatives. In the Hispanic/Latino population, community outreach and education professionals (CORE-Ps) have effectively increased cancer prevention and control behaviors; but, limited research has been conducted to assess genetic and family health history knowledge among CORE-Ps. We sought to evaluate an educational program designed to improve cancer FHH and cancer genetics knowledge, self-efficacy and attitudes. **Methods:** The ARBOLES Program educates bilingual (Spanish-English) CORE-P to increase knowledge about the role of genetics in cancer. We conducted a 2-hour educational session about FHH as part of the ARBOLES program. We recruited 62 bilingual CORE-Ps. Session activities included building pedigrees, identifying red flags in a patient case scenario and a brief presentation of a patient case. **Results:** Majority of participants were college graduates (88.9%) and identified as patient navigators (39.3%). Mean age = 39 years (SD= 12.7). Although 96.8% had heard about FHH before, 50.8 % never collected FHH as part of their job, and only 24.6% reported ever referring a community member to a genetics specialist. Self-efficacy increased significantly ($t=-10.2$, $p= 0.032$) with large effect size (Cohen's $d= 1.61$). Wilcoxon signed rank test revealed statistically significant increase in cancer genetics knowledge, $z= -4.01$, $p<0.001$, with a large effect size ($r= 0.52$), and attitudes toward collection of FHH being useful as part of their jobs $z= -3.48$, $p<0.001$, with medium effect size ($r=0.45$). **Conclusion:** The educational intervention increased CORE-P's confidence about properly collecting FHH, assessing risk based on FHH, and referring community members to genetics specialists. Furthermore, participants reported they felt comfortable integrating the information they learned in their daily jobs and referring high risk individuals for cancer to genetics specialists. The current FHH session may be one approach to help address health disparities through appropriate risk assessment and referrals to genetic services within the Hispanic/Latino population. Future research can evaluate the longer-term behavioral impacts of the intervention on FHH data collection and referrals to genetic counseling.

CHAPTER ONE:

INTRODUCTION

Although multiple factors play a role in the development of cancer, 5-10% can be attributed to hereditary genetic factors (Garber & Offit, 2005). *BRCA1/2* mutations are the most common mutations associated with hereditary breast and ovarian cancer syndrome (HBOC) (Apostolou & Fostira, 2013). Identification of individuals who are genetically predisposed to hereditary cancer is extremely important for both the individual and his/her relatives as it allows for the opportunity to engage in/ or make decisions about cancer prevention or early detection options (Pruthi, Gostout, & Lindor, 2010). Although Hispanic/Latino women who live in the U.S carry *BRCA* mutations at higher rates than the general population (Weitzel et al., 2013), they are less likely to receive genetic services (Jagsi et al., 2015).

Collection of family health history (FHH) can identify individuals at increased risk, and guide disease-specific recommendations for genetic testing, management, early detection, and prevention (Valdez, Yoon, Qureshi, Green, & Khoury, 2010). Despite these benefits, collection of FHH is often low or infrequent (Smith et al., 2015). Barriers to collecting FHH are often related to lack of awareness and limited knowledge about the linkage between family history and disease (Rich et al., 2004). Several national initiatives have aimed to educate adults about the importance of FHH and how to collect it; however, the majority of these initiatives are limited to a homogenous non-Hispanic/Latino population. They are often targeted toward the general public and not populations at the greatest risk of hereditary cancer syndromes (K. Kaphingst, Lachance, Gepp, D'Anna, & Rios-Ellis, 2011). Additionally, existing literature indicates that in comparison with non-Hispanic whites, Hispanics are less likely to collect FHH and have lower awareness in regards to inherited risk due to barriers such as literacy, culture, and language (K. A. Kaphingst et al., 2012; Lynce et al., 2016).

In the Hispanic/Latino population, use of community outreach and education professionals (CORE-Ps) has been an effective approach to increasing cancer prevention and control behaviors, particularly among those with a Spanish language preference (Braun et al., 2015; Goodson, Chen, Muenzenberger, Xu, & Jung, 2013; O'Brien,

Halbert, Bixby, Pimentel, & Shea, 2010). CORE-Ps are often "front line providers" of cancer education, navigation, and support to Spanish preferring Hispanics and Preliminary research has demonstrated that CORE-Ps are interested in and enthusiastic into learn about FHH in general (Goodson et al., 2013).

When educating CORE-Ps about a new subject, it is important to be goal directed and include opportunities and experiences relevant to CORE-Ps to (Goodson et al., 2013). The adult learning theory, originated by Knowles, suggests that adults learn best by: building on previous experiences, solving problems instead of memorizing concepts, and directing their own learning (Knowles, 1978). The information-motivation- behavioral skills (IMB) model consists of the following three constructs related to the adoption of a new behavior: 1) information about the behavior, 2) motivation to perform the behavior and 3) skills necessary to perform the behavior. Both the IMB model, and adult learning theory have been utilized in the development of effective educational interventions in a variety of health care settings (Fisher, Fisher, Amico, & Harman, 2006; Taylor & Hamdy, 2013).

Guided by core competencies for the public health workforce set forth by the Centers for Disease Control and Prevention (CDC) and national coalitions (John et al., 2007), the Family Tree Program [Programa de ÁRBOLES Familiares: Assessing Risk of Breast Cancer through Outreach to Latinas with Education and Support] educates bilingual (Spanish-English) CORE-P to increase basic knowledge about the role of genetics in disease, identify the limits of their own genetic expertise, and help navigate at-risk individuals to health care professionals and genetic services. The ARBOLES training program includes a 2 day in-person training followed by a 4-month online training. Both training components include didactic and interactive activities and lectures conducted by genetic counselors, physicians, and researchers related to: genetics and genetic testing, HBOC in Latinas, communication, and ethical, legal, and social issues related to genetic testing. The in-person ARBOLES training is offered biannually in different states.

The goal of this study was to build upon the current ARBOLES training program by developing an educational session, informed by the adult learning theory and the IBM model, to evaluate and improve short term outcomes (i.e., knowledge, motivation, self-efficacy) and self-reported behaviors related to taking FHH and assessing risk for HBOC and making referrals to genetic services among bilingual CORE-Ps. We hypothesized that the intervention would increase all short-term outcomes and increase identification of high risk individuals and referral behaviors long-term in the Hispanic/Latino community.

CHAPTER TWO:

METHODS

Participant Recruitment

Participants were selected based on both eligibility criteria and geographic location. Participants living closer to training state were prioritized in order to facilitate tailoring of genetic resources guides to a specific location. Individuals were able to participate in the study if they were: bilingual English-Spanish: Promotoras, lay health workers, patient navigators, or health educator professionals connected with a clinic, hospital, or agency that provided health services to Latinos (e.g. vaccines, annual check-ups, cancer screenings). This study was declared exempt by the University of South Florida's Institute Review Board (IRB). Recruitment for this study followed the ARBOLES FAMILIARES Training Program recruitment strategies: Trainees were recruited through community-based cancer resource organizations, National Latino Cancer Network and Summit, national, local, regional, and community meetings by using flyers. Interested participants filled out an online application by going to the training website (www.arbolesfamiliares.org) listed in the flyer. An acceptance letter was sent to eligible participants along with an invitation informing them that participation in this educational intervention was voluntary and included completion of a pre and post questionnaire. Interested participants agreed to participate in the intervention by filling out the pre-questionnaire.

Instrumentation

Prior and immediately after the intervention participants were asked to complete a study questionnaire that asked participant demographics (age, level of education, and work setting) and evaluated the constructs described from the IMB model (Appendices A and B):

Health behavior information: FHH awareness was assessed by asking participants whether or not they heard the term family health history, collected FHH of their own, friends, or community members, and were familiar with various FHH tools. Cancer genetics knowledge was assessed with an 8-item agree, disagree, unsure adaptation of the National Human Genome Research Knowledge Scale (Vadaparampil, Quinn, et al., 2010). Knowledge of which FHH elements should be collected (type of cancer, number of affected family members, family size, etc.) was assessed using a question adapted from the Everyday Understandings of FHH of Cancer questionnaire (Lim & Hewison, 2014).

Health behavior motivation: Reasons to collect FHH and make referrals to genetics were assessed with 7 items, ranked on a 5-point Likert scale from strongly disagree to strongly agree, which assessed their agreement that collection of FHH is: useful as part of their jobs, able to identify individuals at high risk for cancer, able to encourage community members to seek medical services etc. The scale was adapted from previous evaluations of educational interventions made for CORE-Ps (Rivera et al., 2018; Rivera et al., 2016; Rush et al., 2015; Saad-Harfouche et al., 2011; Vadaparampil, Hutchins, & Quinn, 2013). Participants were also asked open-ended questions to describe what motivated them to learn about family health history. After the intervention, participants were asked on a 5-point Likert scale (not at all likely-extremely likely) how likely they were to: educate community members about family history, talk with community members about their family health history, and refer at-risk community members to appropriate genetic services.

Health behavior skills: Hereditary cancer risk identification skills were assessed using a case scenario in which participants had to identify the red flags that would indicate the person could be at high-risk for a hereditary breast and ovarian cancer, and which side of the family was more likely to carry a *BRCA* mutation. Self-efficacy for communication, collection and education about family health history, and making a genetics referral was assessed with a 9-item measure adapted from a previous self-efficacy scale used with community health educators and rated on a scale of 1 (not at all confident) to 5 (extremely confident) (Rivera et al., 2018).

Procedures

Guided by principles of Adult Learning Theory and IMB Model, we developed an in person educational session to increase CORE-P's: knowledge regarding collection of FHH and skills regarding building of pedigrees and identification of individuals at risk for HBOC (figure 1). The intervention lasted two hours and was conducted in-person by the first author at the ARBOLES training in New York (cohort 1) and Washington, DC (cohort 2).

The FHH intervention was added to the in-person ARBOLES training agenda. The intervention was given after three genetics lectures that included the following topics: HBOC overview; HBOC in Latinas; and Genetics 101. Objectives of these lectures along with the FHH intervention are described in Table 1.

Cohort 1 received the pre-evaluation survey prior to the educational intervention; Cohort 2 received the pre-evaluation survey prior to the in-person training attached to their acceptance letter.

The intervention included an interactive PowerPoint and interactive skill building activity (Appendix C). The Power Point presentation covered the following topics: *what is family history, why is family history important, red flags in a family and personal history that indicate an individual could be at high risk to develop HBOC, how to draw a pedigree, how to identify if a person is at high, intermediate, or low risk to develop a hereditary type of cancer*, and *resources available for individuals who are at high risk of HBOC.* During the presentation, participants were walked through a case scenario of a woman with a family history of breast cancer. Participants, along with the presenter, had to draw her family history, identify red flags in her family and personal history that could indicate she is at risk for a hereditary type of cancer, and identify local resources to help her find genetics professionals.

After the presentation, participants were divided into 6 groups for the activity (n=5-6 participants per group). Each group was given a case example with a patient chart which included the patient's personal and family history, ethnic background, and social history. As part of the activity, each group had to draw the patient's pedigree on a white board (provided as part of the activity), identify the family and personal history red flags for HBOC, evaluate the patient's risk for a hereditary type of cancer (low, moderate, high), and make a plan that included resources for the patient based on the patient's individual risk. Cases varied across each group with different risk levels based on family, personal and health behavior history. After completing the activity, each group had to pick a speaker to present their patient to the other participants. Each group had 5 minutes to orally present their case to the entire group. After each presentation, verbal feedback was provided to each of the groups by first author and ARBOLES faculty genetic counselors that were present at the training. Immediately after their presentations, participants completed the post-evaluation.

Table 1. ARBOLES Lectures and Learning Objectives

Tittle of lecture	Modality/duration	Objectives	Build-in activity
Breast Cancer	Online*	To summarize unique aspects of breast cancer in Latinas	
	Duration: 30 min	To describe the influence of genetics and inheritance on breast cancer	None
		To identify the features of hereditary breast cancer	
Hereditary Breast and Ovarian Cancer in Latinas: Overview	In-person	Understand the role of health disparities in Hereditary Breast and Ovarian Cancer in regard to Latinas	
	Duration: 20 min	Recognize the importance of referrals for hereditary breast cancer genetic counseling in Latinx patients	None
		Identify how CORE-Ps can contribute to improving the current situation.	
Genetics 101	In-Person	To define key genetics words and concepts	
	Duration: 30 min	To identify how genes are passed from parents to children	None
		To describe how genes work and their influence on risk	
Why is Personal and Family History important? / Basics of the pedigree	In-person	To describe family health history and why family history is important	
	Duration: 2 hours	To identify what features of an individual's personal and family history are suggestive of hereditary breast and ovarian cancer based on national guidelines	Pedigree building
		To identify and assess risk for hereditary breast and ovarian cancer	Case-scenario/ presentation
		To identify resources for individuals who are at increased risk for hereditary breast and ovarian cancer	

* *Participants are required to watch this module prior to attending the in-person training*

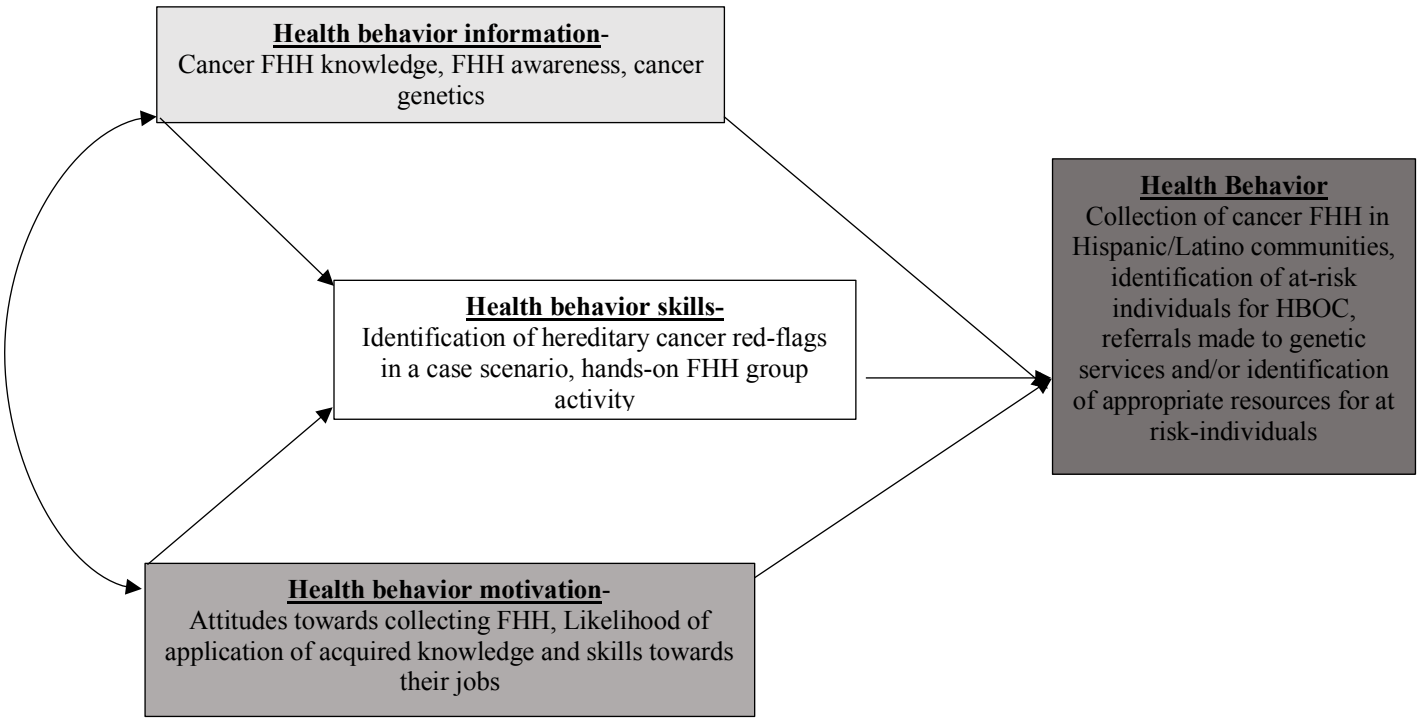

Figure 1. IMB Model Application to Educational Intervention.

Data Analysis

Participant's demographic and survey data were summarized using descriptive statistics for continuous variables, and frequencies for categorical variables. Given the non-normality of the data, Wilcoxon signed-rank tests were conducted to evaluate the short-term impact of the educational intervention on measures of knowledge, attitudes, and health behavior skills, t. For the self-efficacy scale, a paired-samples t-test was performed as data were normally distributed. For each of the three main outcomes, the Holme step-down procedure was used to adjust the critical p-value of 0.05 to account for the analysis of multiple items. Effect sizes were calculated by dividing the absolute (positive) standardized test statistic Z by the square root of the number of pairs for non-parametric measures. For self-efficacy, Cohen's d was determined by calculating the mean difference between the pre and post evaluations, and then dividing the result by the pooled standard deviation. Open-ended responses were analyzed by the first author who reviewed all responses and developed thematic categories. Once qualitative responses were coded, frequencies were calculated for each thematic category. Data analysis was conducted using SPSS version 25.

CHAPTER THREE:

RESULTS

There were no significant differences between cohort 1 and cohort 2. Results from both cohorts were combined and overall scores were calculated as follow.

Participant characteristics

Out of the 62 who were invited, 62 individuals agreed to participate in the FHH intervention, and 59 completed both pre and post evaluations. The majority of participants were college graduates (80.3%) and identified as community health educators (39.3%). Mean age = 39 years, SD= 12.7 years. About half never collected FHH as part of their job, and only 24.6% reported ever referring a community member to a genetics specialist (Table 2).

Pre and Post-intervention results

Health behavior information: Nearly all participants (96.8%) had heard the term FHH before and many had previously collected their own FHH (62.9%). Most participants were unfamiliar with FHH tools including the one developed by the Center for Disease Control and Prevention (CDC), My Family Health Portrait, and those developed by genetic testing laboratories (Table 3).

A Wilcoxon signed rank test revealed a statistically significant increase in cancer genetics knowledge, $z= -4.01$, $p<0.001$, with a large effect size ($r= 0.52$). The median score on the cancer genetics knowledge scale increased from 5.0 to 7.0. Participants had high baselines scores regarding knowledge about what to ask when collecting a FHH in a cancer scenario, no significant increased shown, demonstrating a ceiling effect ($z= -1.62$, $p=0.10$) (Table 4).

Health Behavior Motivation: After the intervention, participants showed a significant increase in regards to how much they agreed collection of FHH would be a useful as part of their jobs, $z= -3.48$, $p<0.001$, with medium effect size ($r=0.45$). Participants likelihood to collect FHH, educate community members about FHH, and make a referral to genetic services also increased after the intervention $z=-2.14$, $p=0.03$; however, effect size was small

(r=0.28) (Table 4). Common motivators for collecting and attending the FHH intervention among participants analyzed from open-ended responses are described in Table 5.

Health Behavior Skills: Ability to identify red flags for HBOC in a family history increased after the intervention ($z=-6.46$, $p<0.001$), medium effect size ($r=0.34$). A paired- sample t-test showed a significant increase in self-efficacy, $t=-10.2$, $p= 0.32$, with large effect size (Cohen's $d= 1.61$). The mean scores increased from pre ($\bar{x} = 27$, SD=8.7) to post ($\bar{x} = 39$, SD=9.5) (Table 4).

Table 2. Participant Characteristics

Characteristic	No.	(%)
Mean Age (SD)	39(12.7)	
Highest education finished		
High School graduate or GED	5	8.2
Some college	7	11.5
College graduate or beyond	49	80.3
Workplace		
Community Health Educator	24	39.3
Lay Health Worker	1	1.6
Promotor/promotora	3	4.9
Navigator	16	26.2
Other	17	27.9
Over the past year, how often have you collected FHH as part of your job?		
At least 2-3 times a week	5	8.2
1 time per week	6	9.8
2-3 times per month	3	4.9
1 time per month	4	6.6
2-11 times per year	3	4.9
1 time per year	4	6.6
Less than 1 time per year	5	8.2
Never	31	50.8
Over the past year, have you referred a community member to a genetics specialist?		
Yes	15	24.6
No	46	75.4

Table 3. Awareness of FHH(FHH) and Tools to Collect FHH

	Number and % aware	
Number and percent who …	N	(%)
Heard of the term FHH prior to this training	60	96.8
Collected own family health history	39	62.9
Were familiar with My family Health Portrait	11	18.0
Were familiar with Myriad Family History Tool	7	11.3
Were familiar Invitae Family History Tool	3	4.9

Table 4. Pre and Post-Intervention Results

		Pre-intervention			Post-Intervention			
Construct	**Measure (score range)**	**N**	**M**	**IR (25^{th}-75^{th})**	**M**	**IR (25^{th}-75^{th})**	**Significance (2-tailed)**	**Effect size *r***
Health Behavior Information	Cancer genetics knowledge (0-8)	59	5.0	4.0-8.0	7.0	4.0-8.0	Z=-4.01 P<0.001*	0.52
	FHH knowledge in a cancer scenario (0-5)	55	5.0	1.4-5.0	5.0	4.0-5.0	Z=-1.62 P=0.105	
Health Behavior Motivation	Attitudes towards collecting family history (7-35)	59	32	28-35	34	30-35	Z=-3.48 P<0.001*	0.45
	Likelihood of making referrals to genetics services and educating community members about their family history (3-15)	59	13	11-15	15	12-15	Z=-2.14 P=0.032*	0.28
Health Behavior Skills	Hereditary cancer risk identification in a case scenario (0-11)	59	8.0	8.0-9.0	9.0	8.0-11	Z=-3.01 P=0.003*	0.39
		N	**$\bar{x}$**	**SD**	**$\bar{x}$**	**SD**	**Significance (2-tailed)**	**Cohen's *d***
	Self-efficacy for communicating, collecting, educating about family health history, and providing resources and making a genetics referral (1-45)	56	27	8.7	39	5.9	P<0.001*	1 .61

Table 5. Motivations to Learn About Cancer FHH

Motivation category	N (%)	Quotes
Help minority populations/ reduce health disparities	**4(6.5%)**	*"Transmit the message to immigrants in my community either Spanish or English speakers"* *"The community I work for is underserved and has many barriers. The disparities are big and anything I can do to educate and prevent is important. Also, brining or having ways to support underserved community is important to decrease the stress levels these communities face and connect them at an emotional level increase their trust in us/me"*
Personal or family history of cancer	**11(18%)**	*"To learn about how our family history can impact the risk of developing cancer or any other disease, fascinates me. I had family member die of cancer and to learn if another family member is at risk before the disease can spread it will be helpful"* *"I have a genetic mutation. I was diagnosed with Lynch syndrome in 2017 after my 3rd cancer diagnoses. Prior to my 3rd breast cancer diagnosis, I had tested for BRCA 1/2 and BART test and both came back negative. I have a mutation in the PMS2 gene which puts me at higher risk for digestive and reproductive cancers"*
Cancer prevention and/ or early detection	**25(41%)**	*"Learning about family health history is important because it will help to explore someone's risk for developing hereditary illnesses. Once we know our risks to develop certain diseases, we can take appropriate steps to prevent or treat these conditions"* *"Being able to help community members identify risks that could be prevented and treated on time:*
Family members	**3(4.9%)**	*"My motivation is my family. How to keep them all healthy and aware of the different types of cancers that can affect them, including myself"* *"Being able to help my family with trying to find out where certain things come from in our family gene history"*
Educate others	**8(13%)**	*"My family and also my Latino community and I want to prepare myself so I can spread my knowledge out to the community and my family as well"*
Work they do with the community	**15(24.5%)**	*"Part of my job"* *"I am in charge of a mammogram program in the clinic I work, and I need knowledge about what I am working with"*
Learn more about the subject	**6(9.8%)**	"*To get a better understanding of the genetic factors that put people at risk of getting cancer"*

CHAPTER FOUR:

DISCUSSION

Educational initiatives that raise awareness of cancer-related FHH, tailored to populations at greatest risk of hereditary cancer syndromes , including minorities, are needed to reduce cancer health disparities (K. Kaphingst et al., 2011). Utilizing CORE-Ps to raise awareness of FHH and lack of knowledge of FHH in minority groups is a promising avenue to achieve this goal. The educational intervention described herein can be used as a potential model to educate CORE-Ps about the importance of FHH and the utilization of cancer FHH as an identification tool for at-risk individuals in the Hispanic/Latino community. Results suggest this theory-based educational intervention successfully improved genetics knowledge and self-efficacy to collect FHH, identify individuals at high risk, and provide appropriate resources for these individuals.

Improving self-efficacy is a particular key in regards to health education and health behavior change (Sheeran et al., 2016; Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986). According to Bandura's social learning theory, learning through personal experience is the most effective way of improving self-efficacy (Bandura & Walters, 1977). If individuals are successful at achieving a skill they felt was difficult, this will increase their satisfaction and confidence in putting that skill to use. In the context of the current study we expect increased self-efficacy will result in the increased completion of risk assessments and referrals. The hands-on activity, wherein CORE-Ps identified signs of a cancer-prone family health history and subsequently apply the information to evaluate the personal risk for hereditary cancer, may have been a key component for increasing self-efficacy. This hands-on activity gave CORE-Ps the opportunity apply knowledge and skills acquired during this educational activity and results align with what was expected according to both adult learning theory and social learning theory.

While utilization of solid practical skills is necessary to achieve improvement in self-efficacy, information and motivation, as explained by the information-motivation-behavioral-skill model, are also important (Fisher & Fisher, 2002). Increases in motivational attitudes were also identified though the effect size was moderate. Participants had strong positive attitudes towards implementation of collection of cancer FHH and the importance of HBOC risk identification skills to their jobs, prior to the intervention and limited room for improvement on the measure. For

example, the median attitudinal score increased from 32 out of 35 prior to the intervention and 34 post intervention. Furthermore, CORE-Ps' main motivation to participate in the educational session was to help identify individuals at high risk, with the goal to prevent or detect cancer at an early stage, along with educating their community members about FHH of cancer and their cancer risk.

The median score on knowledge of what to ask for FHH both before and after the intervention was 5 out of a possible 5, indicating there was no room for improvement among at least half of the participants and may have occurred because the high education level of the participants or it may indicate that this knowledge measure was too easy. The other measure of knowledge did leave room for improvement and changes were significant.

These findings are important in order to achieve the long-term goal of having CORE-Ps educate Hispanic/Latino community members about their personal risk for hereditary cancer. Multiple studies have highlighted the knowledge gaps in the Hispanic/Latino community in regards to what it implies to be at high risk for a hereditary cancer syndrome (Hann et al., 2017). A study by Vadaparampil et al. showed multiple misconceptions within the Hispanic/Latino community about cancer genetics such as believing that injuries cause cancer, believing that if one does not show symptoms there must be no reason to have genetic testing, among others (Vadaparampil, McIntyre, & Quinn, 2010). The current educational intervention could help CORE-Ps educate their communities about the importance of family health history and how to identify whether or not individuals could be at increased risk for cancer, along with clarifying misconceptions. Thus, leading community members to make informed decisions about their health and increasing their motivation to seek services such as genetic counseling.

Genetic counseling may help increase cancer prevention and/ or early detection by helping at-risk individuals further evaluate their hereditary cancer risk, which in turn may change their cancer screening and management recommendations. Previous studies have highlighted the contribution to significant improvement in health outcomes in minority groups by utilizing community health workers (Balcázar et al., 2010; Medina, Balcázar, Hollen, Nkhoma, & Mas, 2007). Educating COREP-s in cancer genetics can be a potential avenue to reduce health disparities and improve health outcomes as they can facilitate access to care through navigation of services, and community participation in health care services(Witmer, Seifer, Finocchio, Leslie, & O'Neil, 1995). Previous studies have highlighted the contribution to significant improvement in health outcomes in minority groups by utilizing community health workers.

There are limited studies in educating CORE-Ps about genetics and family health history (K. Kaphingst et al., 2011). A similar study done by Chen et al. showed significant promise in regards to referral to genetic services and collection of family health history behavior (Chen et al., 2018). This particular study, aimed at community health workers from Texas, was successful at improving their attitude, intention, self-efficacy, knowledge, and behavior towards FHH-based genomics. Although the study by Chen et al. and present study both had similar objectives in regards to utilization of CORE-Ps as connectors between genetic services and underserved populations, the present study was targeted to hereditary cancer and tailored to CORE-Ps who work within a particular community. Furthermore, the educational intervention of the present study included CORE-Ps from different states. This is a unique characteristic of this educational session as it allowed CORE-Ps from different states to meet and work together as a group during the different activities within the session. The integration of CORE-Ps from different places allowed them to identify genetic services in different areas of the country and to make connections between other CORE-Ps that had attended the educational session. The main benefit of establishing these connections is to build a more far-reaching (not just local) network of community healthcare workers who can exchange useful information on new genetic services and identify locations where gaps in service availability may exist.

Additionally, this educational intervention was tailored to CORE-Ps by employing theoretical frameworks to guide development of intervention and approach (adult learning theory and IMB model), which have been used in the development of effective educational interventions in a variety of health care settings (Kalichman, Picciano, & Roffman, 2008; Osborn & Egede, 2010), along with professional input from various health education and genetics experts throughout its formative stages. Targeting educational sessions to be reflective of the community served, incorporating research-based strategies and scientific knowledge, and providing opportunities for mobility and professional development are all factors that have contributed to previous successful community health workers programs and/ or interventions (Witmer et al., 1995).

Limitations and Conclusion

This study should be evaluated in light of certain limitations. Although the educational session had information about common-red flags in a family health history of cancer, the educational session mainly focused on HBOC.

Therefore, the current educational session might benefit from additional information in regards to red-flags for other types of hereditary cancers such as colorectal. Another important limitation is that individuals who agreed to participate in this educational session were already part of the ARBOLES training program and, as such, were already highly motivated and had exposure to some of the cancer-knowledge related topics that were discussed during the FHH intervention . Further research is needed to identify whether or not this intervention would be successful at improving short-term outcomes for CORE-Ps when it is delivers in a "stand alone" format". Finally, given high knowledge scores prior to the intervention, adaptations may be needed to make the one set of knowledge questions more difficult so there is room for improvement and/or pre-testing should be conducted on future study populations to determine if measures are targeted for the audience's level of education and knowledge.

Despite the above limitations, the educational intervention was successful in multiple ways. The educational intervention increased CORE-Ps confidence about properly collecting FHH, assessing risk based on FHH, and referring community members to genetics specialists. Furthermore, participants reported they felt comfortable integrating the information they learned in their daily jobs and in referring high-risk individuals to genetics specialists.

Future Directions

Future directions include the analysis of intermediate impact of the educational intervention on FHH collection, retained knowledge, and referral behaviors measured in this survey**.** This will be done using results of an online follow-up survey sent 9 months after the educational session to evaluate intermediate impact through self-reported data. Should the 9-month data find changes in referral behaviors increase then an argument could be made that this FHH educational session could be an effective approach to help address health disparities by increasing risk assessment referrals to genetic services within the Hispanic/Latino population.

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APPENDIX A:

PRE-INTERVENTION SURVEY

Baseline Survey

Programa de ARBOLES Familiares: Assessing Risk of Breast Cancer through Outreach to Latinas with Education and Support

Family Health History Activity Survey

This survey will help us identify strategies to improve your education about family health history and risk assessment in regards to Hereditary Breast and Ovarian Cancer in the Latino population.

1. For the questions in this survey, please either mark the appropriate box or space provided.

   Example:

   ☒ YE
   S

   ☐ NO

OR write your answer in the area(s) provided

2. Please select only one response for each question, unless the instructions indicate otherwise.

Family Health History Awareness

1. Prior to this training, have you ever heard of the term or expression 'family health history'?
   - ☐ Yes
   - ☐ No

2. Have you ever collected the family health history of

	Yes	No
Your own family	☐	☐
A friend	☐	☐
A community member	☐	☐

3. **Are you familiar** with any of the following tools?

	Yes	No
My Family Health Portrait (by the CDC)	☐	☐
Myriad Family History Tool	☐	☐
Invitae Family History Tool	☐	☐
"Does it run in the family?" (Genetic Alliance)	☐	☐
Other	☐	☐

If other, please specify:

4. **Have you used** any of the following tools?

	Yes	No
My Family Health Portrait (by the CDC)	☐	☐
Myriad Family History Tool	☐	☐
Invitae Family History Tool	☐	☐
Does it run in the family? (Genetic Alliance)	☐	☐
Other	☐	☐

If other, please specify:

Self-efficacy for communication about Family Health History

5. How confident do you feel about	Not at all confident				Extremely confident
Collecting your own family health history	1	2	3	4	5
Collecting a family member or a friend's family health history	1	2	3	4	5
Collecting a community member's family health history	1	2	3	4	5
Knowing what to ask when collecting a family health history of cancer	1	2	3	4	5
Identifying a person who is at high risk of cancer based on his/her family health history	1	2	3	4	5
Educating members from your community about the importance of family health history	1	2	3	4	5
Utilizing online family health history tools such as *My Family Health Portrait*	1	2	3	4	5
Providing resources or tools that members from your community can use to collect their own family health history	1	2	3	4	5
Making a referral to a genetics provider if there are concerns raised in the family health history	1	2	3	4	5

Attitudes towards collection of Family Health History

6. We have a few more questions about your thoughts about family health history. Please let us know how much you agree or disagree with each one.

Collection of family health history…	Strongly disagree 1	Disagree 2	Neither agree or disagree 3	Agree 4	Strongly agree 5
will be useful as part of my job	1	2	3	4	5
can identify individuals who may be at an increased risk of developing cancer	1	2	3	4	5
will encourage members of my community to seek medical advice if found to be at high risk	1	2	3	4	5
is important to members of my community	1	2	3	4	5
will help me personally to take better care of my health	1	2	3	4	5
will help my family members to be more informed about their risk for cancer	1	2	3	4	5
Will help community members who I work with	1	2	3	4	5

7. What motivates you to learn about family health history?

Cancer History and Beliefs

8. Have you, or anyone close to you had cancer?
   - ☐ Yes
   - ☐ No

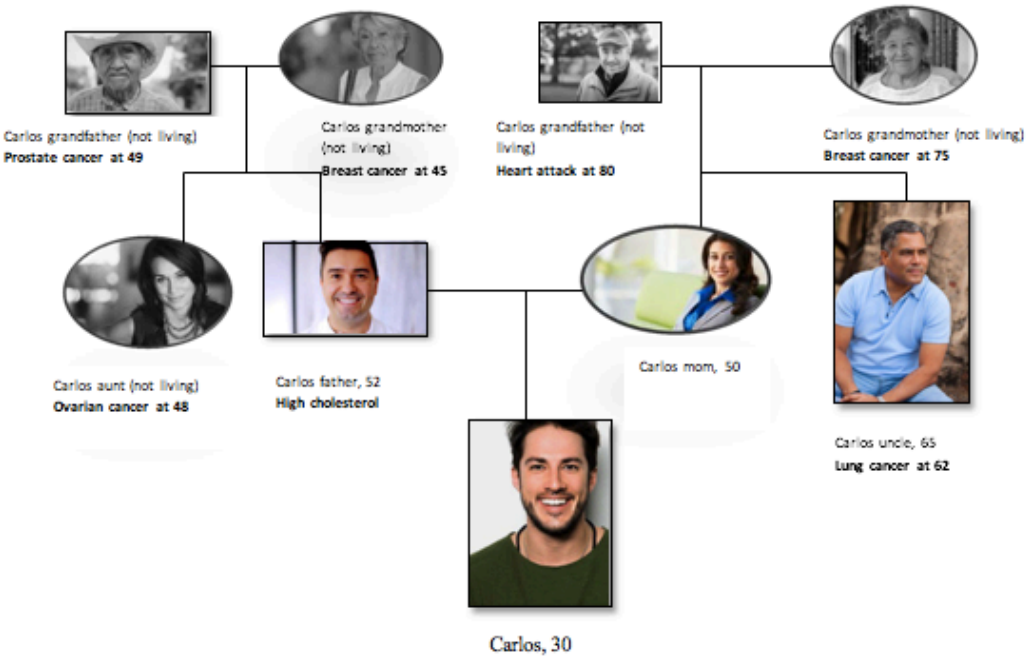
9. For the following statements regarding cancer, please choose the response that shows whether you agree, disagree or are unsure.

Statement	Agree	Disagree	Unsure
Cancer that is inherited **cannot** be prevented	☐	☐	☐
Breast cancer screening methods can detect cancer early in women at risk for inherited cancer	☐	☐	☐
Knowledge of a person's family history of cancer may give options for cancer prevention	☐	☐	☐
Knowing if a person's cancer is due to an inherited gene mutation will **not** usually change medical management	☐	☐	☐
Majority of cancers are hereditary	☐	☐	☐
Being at an increased risk for cancer means you will develop cancer	☐	☐	☐
Women can inherit a gene from their father that puts them at high risk for breast cancer	☐	☐	☐
Men and women can inherit a *BRCA* mutation	☐	☐	☐

10. Juliana, a community member, comes to talk to you about her cousin Adriana who recently was diagnosed with breast cancer. She mentions she is worried not only about her cousin but also about her own risk of developing cancer. Knowing this information, which questions would you like to ask Juliana about her family health history?

1.
2.
3.
4.
5.

11. This is Carlos Family Tree:



Which of the following you think are red flags that indicate Carlos could be at high risk for a **hereditary** cancer (please select all that apply):

- ☐ Carlos paternal grandmother having breast cancer
- ☐ Carlos paternal grandmother, aunt, and grandfather being diagnosed with cancer before age 50
- ☐ Carlos aunt having ovarian cancer
- ☐ Carlos uncle having lung cancer
- ☐ Carlos grandfather having prostate cancer
- ☐ Carlos drinking 1 beer per week
- ☐ Carlos being overweight a year ago
- ☐ Carlos maternal grandmother having breast cancer at 75
- ☐ Carlos father having high cholesterol
- ☐ Carlos maternal grandfather having a heart attack

12. Who in Carlo's family is more likely to carry a BRCA mutation?
    - ☐ Carlo's father
    - ☐ Carlo's mother

13. Which of the following information do you think are required to collect for a family history of cancer?

	Yes	No	Don't know
Type of cancer (e.g. breast, colon, etc.)	☐	☐	☐
The number of affected family members	☐	☐	☐
Age of onset of cancer in affected family members	☐	☐	☐
Family size	☐	☐	☐
Information of whether the affected family members lived together	☐	☐	☐
If any member of the family had surgery before age 1	☐	☐	☐

Background Information

14. What is your current age?

15. How many years of school have you completed?
    - 8 or less years
    - Some high school
    - High school graduate, or GED
    - Some college
    - College graduate or beyond

16. Which of the following best describes your workplace?
    - Community Health Educator
    - Lay Health Worker
    - Promotor/ Promotora
    - Navigator
    - Other (Please specify):_____

17. In what ways (if any) do you educate community members about hereditary breast and ovarian cancer (check all that apply):
    - As part of one to one patient education (one patient at a time)
    - As part of community education
    - Not Sure: Click here to enter text.
    - We do not yet educate community members about hereditary breast and ovarian cancer

18. Over the past year, how often have you collected a family health history as part of your job?
    - At least 2-3 times a week
    - 1 time a week
    - 2-3 times a month
    - 1 time a month
    - 2-11 times a year
    - 1 time a year
    - Less than 1 time a year
    - Never

19. Over the past year, have you referred a community member to a genetics specialist?
    - Yes
    - No

20. From a scale of 1 through 5 how likely do you think you would be incorporating the following actions to your daily job after the training:

	Not at all likely				Extremely likely
Talk with community members about their family health history	1	2	3	4	5
Educate community members about family health history	1	2	3	4	5
Refer community members who you think are at high risk based on their family history to the appropriate genetic services	1	2	3	4	5

21. From a scale of 1 through 5 how important are the following actions to you as a community health worker:

	Not important at all				Extremely important
Talk with community members about their family health history	1	2	3	4	5
Educate community members about family health history	1	2	3	4	5
Refer community members who you think are at high risk based on their family history to the appropriate genetic services	1	2	3	4	5

APPENDIX B:

POST-INTERVENTION SURVEY

Baseline Survey-Post-Test

Programa de ARBOLES Familiares: Assessing Risk of Breast Cancer through Outreach to Latinas with Education and Support

Family Health History Activity Survey

This survey will help us identify strategies to improve your education about family health history and risk assessment in regards to Hereditary Breast and Ovarian Cancer in the Latino population.

1. For the questions in this survey, please either mark the appropriate box or space provided.

   Example:

   ☒ YE
   S

   ☐ NO

OR write your answer in the area(s) provided

2. Please select only one response for each question, unless the instructions indicate otherwise.

Self-efficacy for communication about Family Health History

1. How confident do you feel about	Not at all confident				Extremely confident
Collecting your own family health history	1	2	3	4	5
Collecting a family member or a friend's family health history	1	2	3	4	5
Collecting a community member's family health history	1	2	3	4	5
Knowing what to ask when collecting a family health history of cancer	1	2	3	4	5
Identifying a person who is at high risk of cancer based on his/her family health history	1	2	3	4	5
Educating members from your community about the importance of family health history	1	2	3	4	5
Utilizing online family health history tools such as *My Family Health Portrait*	1	2	3	4	5
Providing resources or tools that members from your community can use to collect their own family health history	1	2	3	4	5
Making a referral to a genetics provider if there are concerns raised in the family health history	1	2	3	4	5

Attitudes towards collection of Family Health History

5. We have a few more questions about your thoughts about family health history. Please let us know how much you agree or disagree with each one.

Collection of family health history…	Strongly disagree 1	Disagree 2	Neither agree or disagree 3	Agree 4	Strongly agree 5
will be useful as part of my job	1	2	3	4	5
can identify individuals who may be at an increased risk of developing cancer	1	2	3	4	5
will encourage members of my community to seek medical advice if found to be at high risk	1	2	3	4	5
is important to members of my community	1	2	3	4	5
will help me personally to take better care of my	1	2	3	4	5
will help my family members to be more informed about their risk	1	2	3	4	5
Will help community members who I work with	1	2	3	4	5

6. What motivates you to learn about family health history?

Cancer History and Beliefs

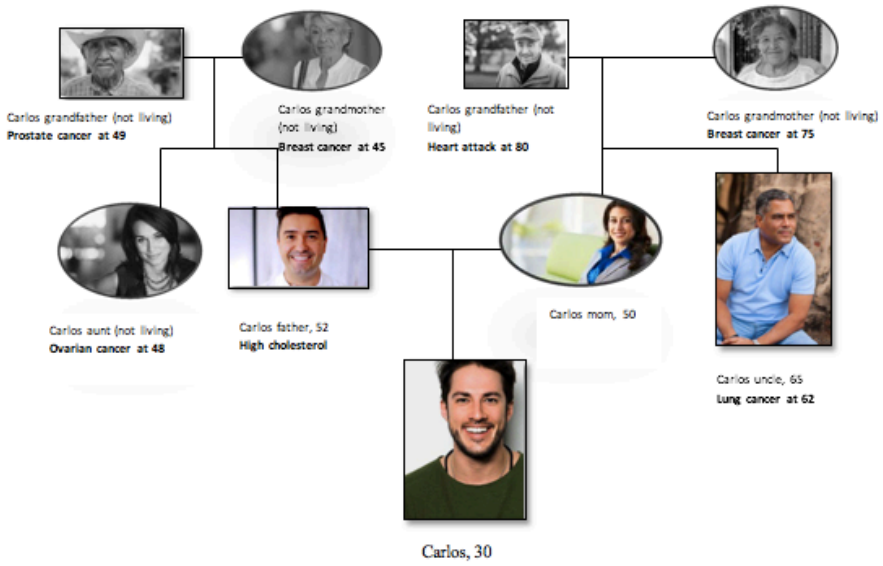
7. For the following statements regarding cancer, please choose the response that shows whether you agree, disagree or are unsure.

Statement	Agree	Disagree	Unsure
Cancer that is inherited **cannot** be prevented	☐	☐	☐
Breast cancer screening methods can detect cancer early in women at risk for inherited cancer	☐	☐	☐
Knowledge of a person's family history of cancer may give options for cancer prevention	☐	☐	☐
Knowing if a person's cancer is due to an inherited gene mutation will **not** usually change medical management	☐	☐	☐
Majority of cancers are hereditary	☐	☐	☐
Being at an increased risk for cancer means you will develop cancer	☐	☐	☐
Women can inherit a gene from their father that puts them at high risk for breast cancer	☐	☐	☐
Men and women can inherit a *BRCA* mutation	☐	☐	☐

8. Juliana, a community member, comes to talk to you about her cousin Adriana who recently was diagnosed with breast cancer. She mentions she is worried not only about her cousin but also about her own risk of developing cancer. Knowing this information, which questions would you like to ask Juliana about her family health history?

1.
2.
3.
4.
5.

9. This is Carlos Family Tree:



Which of the following you think are red flags that indicate Carlos could be at high risk for a **hereditary** cancer (please select all that apply):

- ☐ Carlos paternal grandmother having breast cancer
- ☐ Carlos paternal grandmother, aunt, and grandfather being diagnosed with cancer before age 50
- ☐ Carlos aunt having ovarian cancer
- ☐ Carlos uncle having lung cancer
- ☐ Carlos grandfather having prostate cancer
- ☐ Carlos drinking 1 beer per week
- ☐ Carlos being overweight a year ago
- ☐ Carlos maternal grandmother having breast cancer at 75
- ☐ Carlos father having high cholesterol
- ☐ Carlos maternal grandfather having a heart attack

10. Who in Carlo's family is more likely to carry a BRCA mutation?
    - ☐ Carlo's father
    - ☐ Carlo's mother

11. Which of the following information do you think are required to collect for a family history of cancer?

	Yes	No	Don't know
Type of cancer (e.g. breast, colon, etc.)	☐	☐	☐
The number of affected family members	☐	☐	☐
Age of onset of cancer in affected family members	☐	☐	☐
Family size	☐	☐	☐
Information of whether the affected family members lived together	☐	☐	☐
If any member of the family had surgery before age 1	☐	☐	☐

Follow-Up Information

Now that you have completed the educational session:

12. From a scale of 1 through 5 how likely do you think you would be incorporating the following actions to your daily job after the training:

	Not at all likely				Extremely likely
Talk with community members about their family health history	1	2	3	4	5
Educate community members about family health history	1	2	3	4	5
Refer community members who you think are at high risk based on their family history to the appropriate genetic services	1	2	3	4	5

13. From a scale of 1 through 5 how important are the following actions to you as a community health worker:

	Not important at all				Extremely important
Talk with community members about their family health history	1	2	3	4	5
Educate community members about family health history	1	2	3	4	5
Refer community members who you think are at high risk based on their family history to the appropriate genetic services	1	2	3	4	5

APPENDIX C:

SKILL-BUILDING ACTIVITY WORKSHEET

Activity Instructions

For this activity you will be working in groups (5-6 people). The goal of this activity is that you and your group will be able to:

1. Identify red flags related to a hereditary cancer
2. Assess risk for a hereditary cancer in an individual
3. Illustrate a family health history in a pedigree form
4. Identify appropriate resources for your patient
5. Build a strategy plan for your patient

What you will be doing

You will be working with your group through a patient scenario. The activity will be divided into 6 sections. These sections will help illustrate the patient family health history, identify red flags, assess the patient's risk, find resources for him (her), and build a strategy plan. At the end of the activity each group will have 5 minutes to present their case scenario to the other ARBOLES trainees. You will have a genetic counseling student assigned to your group if you have any questions.

Part 1: Getting to Know Your Patient

Hi! My name is Carlos, I am 32 years old and I would like to talk to you because I am concerned about my family health history. My mother got diagnosed with breast cancer at 45, she is now 52. Fortunately, her sister (my aunt) is healthy, but her daughter (my cousin) was diagnosed with breast cancer a year ago, she is now 45. Both my grandparents (from my mother side) passed away when I was 4 years old from a heart attack.

My father who was a smoker suffered from lung cancer, he was diagnosed at 64 and passed away when he was 68. He has two brothers, Uncle David and Jose, who are both healthy. Neither of them have any children. My grandparents on my father's side are both alive and healthy; although, my grandma has diabetes. My great grandmother from my father's side also had diabetes.

Social history: Carlos lives in New York City. He does not have a lot of time to cook, and eats at McDonalds most of the time. He loves to eat ice cream and drinks coke regularly. He doesn't smoke, but his girlfriend does and she lives with him. Carlos mother and father are from Cuba. Carlos does not have health insurance.

Activity 1

Who is who?

You now have your patient's family history. A good step to get you organized is to identify which members of the family are first, second, or third degree relatives, and what condition they have. Please see the example below and complete the rest of the table:

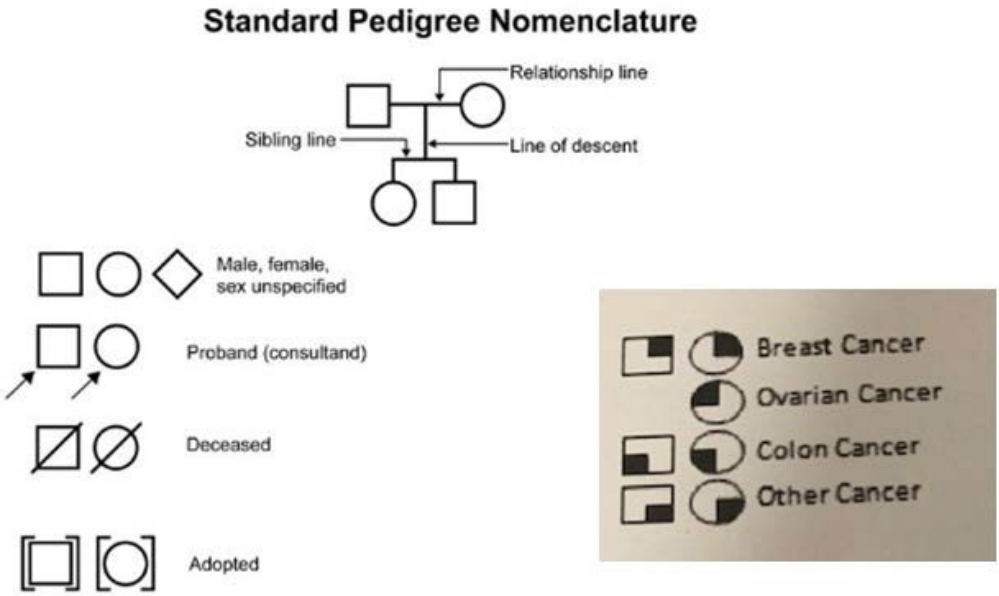
Family member	**Degree relative**	**Condition**
Carlo's mother	First degree	Breast cancer diagnosed at 45

Activity 2

Let's draw our Patient's pedigree

On your table you will find a white board and some markers. Work together with your team and draw your patient's pedigree on it. You will be presenting your patient's case at the end of the activity; therefore, draw the pedigree big enough so that others can see it.

Please use the guideline below and the PowerPoint presentation in your binders to help you draw your pedigree:



Activity 3

Now that you have your pedigree, I would like you to work together with your groups and highlight the things that could indicate your patient is at high risk for developing a hereditary cancer. Please use the pink highlighter to highlight the most significant red flags, and the yellow one to highlight the things from your patient's family history that are not red flags for a hereditary cancer.

Activity 4

Let's find resources!

Use the IPad on your table to find resources for your patient. Please make sure to take into consideration where the patient lives and her/his insurance status. Use one of the sides of your board to write the name of the organizations and resources you found. During your presentation, you will be asked to explain why you chose those resources and how they will benefit your patient.

Activity 5

Let's make a plan

Work with your group to develop an action plan for your patient. Make sure you discuss the following questions with your group:

5. Based on the activities you just did, do you think your patient is at increased risk for a hereditary cancer?
6. What type of cancer does your patient have or is at risk for (hereditary, familial, or sporadic)?
7. What would you tell your patient?
8. Would you make a referral for your patient?
    - ☐ If so, where?
9. What other things would you tell your patient to do? (please consider the social history of your patient)

Please write the most important points of your plan in the third side of your board.

Activity 6

You are ready to present!

Your group will have 5 minutes to present your case.

You may assign somebody as the presenter of your group, or each member may present a specific portion of the case.

Please make sure you include the following in your presentation:

- □ Present your patient- who is she/he?
  E.g. Adriana is a 39 year old patient who came in for consultation because of a strong family of breast cancer
- □ Present your pedigree
  Walk your classmates through your patient's family history
- □ Identify red flags
  Please tell your classmates what makes you think your patient might be at increased risk and why
- □ Resources
  Please tell your classmates what resources you found and why they would be beneficial for him/her
- □ What's the plan
  Walk your classmates through your plan (please make sure you include all answers to the questions you discussed with your group while developing it)