

Esperanza y Vida: Training Lay Health Advisors and Cancer Survivors to Promote Breast and Cervical Cancer Screening in Latinas

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Abstract The use of lay health advisors (LHAs) to promote community-based health education programs is well documented and is considered an effective way to reach underserved communities. Esperanza y Vida (Hope & Life) is an educational outreach program to increase breast and cervical cancer screening for diverse Latinas. It incorporates Latino LHAs (men and women) and cancer survivor role models, *sobrevivientes*, in the program delivery. An interactive training program, conducted by bilingual staff across three sites (Little Rock, Arkansas; Buffalo, New York and New York City) included 74 *sobrevivientes* and LHAs who were recruited and trained. All training attendees completed an initial application assessing socio-demographics, experience and availability as well as, true/false surveys at the beginning (pre-) and end of the training (post-) measuring knowledge levels of breast and cervical cancer health. Data analysis indicated a significant increase

of both breast and cervical cancer knowledge for attendees trained as LHAs (pre = 60%; post = 80%; $p = 0.000$), whereas *sobrevivientes* had a higher baseline knowledge of breast health (74%), and therefore did not show a significant increase following training (79%). However, *sobrevivientes* did display a significant increase in cervical cancer knowledge ($p = 0.003$). These findings demonstrate the impact of training and how LHAs may be recruited at different levels of knowledge and experience and be successfully trained in key program elements. Moreover, results indicate that *sobrevivientes* may be impacted differently, or require variations in training approaches. This information can be useful in developing and customizing curriculum for future lay health training programs.

Keywords Latinas · Cancer screening · Lay health advisor · Health disparities · Cancer survivors

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Introduction

Latina subgroups in the United States are more likely to have higher morbidity and mortality rates for breast and cervical cancer than non-Latina whites, and breast cancer is the most commonly diagnosed cancer among Latinas in the US [1]. Although the incidence rates of breast cancer are somewhat lower for Latinas than for Anglo women, Latinas have traditionally been more likely to have larger tumors and/or metastatic disease at the time of diagnoses [2, 3]. Moreover, although the mammography use rate for Latinas in the US is increasing [1, 4], Latina screening rates are still significantly lower than those for Anglo women [1]. Similarly, despite an overall decrease in the rate of new cases of invasive cervical cancer among women who are at least 30 years of age, rates for Latina women are about twice as high as those for non-Latina whites [5]. Unfortunately, many of these statistical rates refer to all women of Hispanic/Latino ethnicity, not discriminating by country of origin or birth, so it is unclear how these rates vary for the numerous Hispanic/Latino subgroups. Beliefs, knowledge and access barriers are frequently reported considerations that may impact screening behaviors, and the under-utilization of screening services are linked to higher incidence and mortality among Latino subgroups and other minority groups [6].

In 2008, the Centers for Disease Control and Prevention (CDC) stressed that eliminating these disparities requires culturally appropriate evidence-based programs and equal access to quality health care [7]. The CDC's national program REACH (Racial and Ethnic Approaches to Community Health) identified key principles and activities that can be used to address health disparities within minority communities living in the US that include "...recognizing and investing in local community expertise, working to motivate communities to mobilize and organize existing resources and designing health initiatives that acknowledge and are based in the unique historical and cultural context of racial and ethnic minority communities in the US" (p. 3) [7].

A recent review of the literature on community-based programs developed for Latino populations that incorporate Latino role models has shown them to be successful in reaching Latinos and increasing cancer screening behaviors, HIV testing, and healthy living [8–11]. In addition, both faith-based interventions and the use of peer counselors (e.g., *promotoras*) have been effective approaches to outreach in Latino communities [9, 12, 13]. Incorporating the use of peer counselors such as lay health advisors (LHAs) has been shown to be an effective strategy to increase access to health care and improve the health status of underserved populations [8, 14].

LHAs have been described by many names, including community health workers, lay health advocates, *promotoras de salud*, outreach educators, and community health

advocates [15, 16]. A formal definition of a Community Health Worker (CHW) has been defined as "...a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served" (p. 228) [17]. LHAs are trained individuals who are trusted and respected and are a valuable resource to link under-served communities with the health care system [17]. The literature regarding LHAs for Hispanic and Latino populations is limited. Sharing similar social and cultural characteristics (e.g., ethnicity, language, socio-economic status, and health care experiences) equips LHAs with a distinct understanding of the community's belief and value system [18].

Incorporating LHAs is a popular and effective method for community-based interventions and health promotion in minority communities [10, 14, 19–21]. Specific to breast and cervical cancer, several programs and studies have incorporated Latino role models [22], churches [23], and LHAs (*promotoras or consejeras*) [22, 24], into successful interventions for reaching Latinas and positively increasing screening behaviors. Navarro's *Por La Vida* model in southern California demonstrated the need to work within and for local networks of Latinas [24, 25]. Similarly, Ramirez and colleagues demonstrated the replicability of *A Su Salud En Acción* project for reaching Latinos in multiple, diverse, urban communities across the US. [22]. Davis and Flannery reported in their study that Puerto Rican women indicated health information had to be from trustworthy sources (people), not just trustworthy information [26]. They suggest that friends from the church community are a good source of trusted health information. As it has been demonstrated that educational and outreach programs need to be culturally tailored to effectively encourage regular screening behavior [24, 27], research has also indicated that social support, a central component of the *promotoras'* intervention, is an important predictor of breast and/or cervical cancer screening [28, 29].

Based on these findings, and previous experiences with African American cancer survivor advocates and LHAs (i.e., The Witness Project) [30, 31], Erwin and colleagues developed an intervention to increase breast and cervical cancer screening for diverse Latinas in multiple communities. The program includes narrative by a breast or cervical cancer survivor that includes the experience of a cancer diagnosis, sociocultural issues of concern for Latino subgroups in the US, and seeks to counter fatalism and "death sentence" aspects of cancer. This narrative may also include presentations of spiritual concerns and prayer and acknowledges the importance of these elements in the cancer diagnosis and intervention process. *Esperanza y Vida (EyV)* includes groups of Latino women and men in the presentation as LHAs. Including men as LHAs and participants in the community programs shows respect for

the male role within the family regarding decision-making, increases their knowledge and understanding, and emphasizes the importance of keeping women healthy for the good of the entire family. The intervention is presented to men and women together, with an option to separate into gender-specific groups, if desired, led by a gender-appropriate LHA to discuss details of anatomy, disease risk, BSE, mammography, CBE and Pap tests.

A study of the effectiveness of the *EyV* program is being conducted in three different sites in the US: Arkansas (urban and rural), New York City (urban) and Buffalo, New York (urban and rural). It is a randomized controlled study comparing the effectiveness of a cancer education (intervention) program with a diabetes education (control) program to increase breast and cervical cancer screening. As part of a larger randomized-control study of the *EyV* intervention, we investigated the impact of training members of diverse Latino communities as LHAs and *sobrevivientes* (cancer survivor role models), as it is important that the training of LHAs and *sobrevivientes* be standardized and evaluated. This article presents the results of the training sessions for the LHAs and *sobrevivientes*, for the cancer programs that were conducted in Arkansas (AR), New York City (NYC) and Buffalo, NY (WNY) between the years 2006–2008.

Methods

Lay Health Advisors and *Sobrevivientes*

Volunteers were recruited by local *EyV* Project Coordinators, Community Advisory Board (CAB) members and through word of mouth and flyers posted at local Latino community sites. The majority of volunteers were specifically recruited by the local *EyV* Project Coordinator and the Patient Navigator to serve as volunteers because of their involvement in the Latino community and their willingness to serve the community, while other volunteers were recruited after they attended an *EyV* educational presentation. Volunteer LHAs and *sobrevivientes* were required to speak and read Spanish fluently and were asked to attend a two-day training session, where they were informed of the expectations of a LHA or *sobreviviente*, including time availability and travel requirements, and were offered a stipend for participating.

EyV employs a community-based approach, recruiting and training local Latino men and women as both LHAs and *sobrevivientes* to present educational programs. Volunteers included breast and cervical cancer survivors, trained as *sobrevivientes* to talk about their screening and cancer experience and demonstrate that cancer is not a “death sentence.” Lay residents of the community who had

an interest in helping others in their community to access health services, or those who believed in the mission of the program to promote breast and cervical cancer screening were trained as LHAs. All were over the age of 18. Trainings were conducted across all three sites and consisted of a total of 74 volunteers in Arkansas (36 volunteers), New York City (14 volunteers) and Buffalo, New York (24 volunteers). The trainings were conducted over an average of eight hours over a course of two days in community centers or meeting space at each study site. Each *EyV* Project Coordinator was knowledgeable about cancer education facts and conducted the training, compiled a training binder with all the necessary facts and resources for training and prepared the completion certificates for the LHAs and the *sobrevivientes*. The Project staff arranged the location of the training, and coordinated all the items for the day of the training.

Curriculum for Lay Health Advisor and *Sobrevivientes* Training

LHAs and *sobrevivientes* underwent formal training, using the same curriculum regardless of location. The training provided detailed information about breast and cervical cancer, screening guidelines and procedures, available services and how to teach breast self examination (BSE). During the training, Project staff assisted the *sobrevivientes* on the art of storytelling or narrative communication [32, 33] as an educational tool and used an experiential approach. The *sobrevivientes* were asked to share their story about diagnosis, treatment and triumph over cancer and received guidance from the Project staff on how to engage the audience and share their story in a brief, 5–7 min presentation. The *sobreviviente's* story is meant to build upon the underpinnings of the Latino culture and reflects the willingness of Latino women to use their personal stories of survivorship to promote screening, treatment and support for others. At the onset of the training session, each LHA and *sobreviviente* completed an initial application and a pre-test to assess their baseline knowledge about breast and cervical cancer prior to the formal training.

The curriculum of the *EyV* training was adapted from the Witness Project model that has trained women to be Witness Role Models and LHAs for almost 20 years [34, 35]. Training materials (available in both English and Spanish) were combined into a single binder and included materials on cancer, hand-outs of the training PowerPoint slides and relevant and up-to-date publications and brochures that are distributed at the *EyV* community educational program. All training materials were customized to match the specific study site (Arkansas–Mexicans, Buffalo–Puerto Ricans, NYC–Mixed Latino sub-groups)

regarding resources and challenges to access health resources and facilities. The training components included an overview of the *EyV* program, breast cancer facts, cultural breast cancer myths, screening procedures facts (clinical breast exam, mammography, breast self-examination and Pap exam), cervical cancer facts, female anatomy, Human Papilloma Virus (HPV), and the HPV vaccine. LHAs were trained on setting up a program and familiarizing themselves with the local screening and cancer resources. At the end of the training session, post-tests were completed by both LHAs and *sobrevivientes* in order to measure any change in baseline knowledge.

At the conclusion of the training session, all attendees were given a diploma of completion of the training and pictures were taken. A stipend of \$40 in the form of a gift card/cash were given to attendees in Arkansas, a cash incentive of \$64 was given to the Buffalo attendees and lunch was provided for the NYC attendees for their time spent at the training session.

Data Collection

Socio-demographic information was collected from the LHAs and the *sobrevivientes* prior to the training session. An initial application was administered and completed by the LHAs and *sobrevivientes* that assessed their demographics, experience and availability to participate in the training. The variables that were collected included, (a) age; (b) gender; (c) country of origin; (d) marital status; (e) employment status; (f) years of education; (g) years living

in the United States; (h) public speaking experience; (i) availability and interests; and (j) medical information from the cancer survivors.

Self-Administered Knowledge Questionnaire

As the overall training of volunteers was an iterative process over the course of 2 years to support the larger intervention study, there was some variation in methods over time. This resulted in two different versions of the pre-post test surveys being administered to the trainees. In the first year of the study, the pre-post test survey focused specifically on breast cancer items, whereas by the second year, the survey instrument was modified to include both breast cancer items and cervical cancer items. Due to funding limitations and agency requirements, we were only able to focus on topics related to breast cancer in year 1 of the study and expanded the training to include both breast and cervical cancer topics when we received a new source of funding in the following year. The pre- and post-knowledge surveys were completed as self-reports by each of the LHAs and the *sobrevivientes*. The initial survey contained a total of 13 multiple choice questions that pertained to breast cancer and screening while the second survey included six items related to breast cancer and screening, four questions on HPV and five questions that pertained to cervical cancer and screening (see Table 1). Volunteers were asked to indicate whether they agreed, disagreed or were not sure with each question. Scores were coded as correct or incorrect if they agreed or disagreed

Table 1 Knowledge questions for the pre/post test

Breast cancer knowledge
1. A mammogram is a low-dose x-ray of the breast
2. A bruise or hit to your breast can cause cancer
3. If you check your breasts every month, you don't need to get a mammogram once a year
4. Exposing breast cancer to the air during surgery can cause cancer to spread
5. Mammograms can find breast lumps that are too small for doctors to feel
6. More Hispanic/Latina women get breast cancer than White women
Cervical cancer knowledge
1. A Papanicolaou (Pap exam) is a test that can detect changes in the cervix that could turn into cervical cancer if not treated
2. The HPV is a virus that increases the risk for breast cancer
3. If a women has had a hysterectomy for reasons other than cancer, she does not need to continue getting PAP exams
4. The HPV vaccine prevents infection from all types of the HPV infection
5. Once a women stops having children, she does not need to continue getting PAP exams
6. Most people who have genital HPV infection do not know they are infected
7. More Hispanic/Latina women get cervical cancer than White women
8. If a women is in a monogamous relationship, she does not need to continue getting PAP exams
9. More Hispanic/Latina women are diagnosed with the Human Papilloma Virus (HPV) infection than White women

with valid or invalid statements, and respondents that indicated a response of “not sure” were coded as incorrect.

Data Analysis

Scores from the pre- and post-knowledge tests were computed as the average percent correct of the responses to each question and were compared across all participants. Comparisons of pre-post test scores were made using paired-samples *t*-tests. Baseline characteristics were compared between the LHAs and *sobrevivientes* and all three

study sites (AR, NYC and WNY). All analyses were conducted using SPSS 16.0 software; Chi-Square was used for categorical values and one-way ANOVA was used for all continuous values.

Results

Table 2 displays a summary of the baseline characteristics between the LHAs vs. *sobrevivientes*. Of the 74 trainees that participated in the training, 28 attendees (38%) were

Table 2 Demographic variables by volunteer type

	Lay health advisor		<i>Sobrevivientes</i>		Total		<i>p</i> -Value
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Age							
18–39	26	40.6	0	0.0	26	36.2	0.077
40–59	34	53.1	7	87.5	41	56.9	
60 Or older	4	6.2	1	12.5	5	6.9	
Gender							
Female	48	73.8	8	100.0	56	76.7	0.099
Male	17	26.2	0	0.0	17	23.3	
Type of cancer survivor							
Breast			7	87.5			
Breast and cervical			1	12.5			
Country of origin							
Puerto Rico	22	34.9	3	42.9	25	35.7	0.081
Mexico	34	54.0	1	14.3	35	50.0	
US	3	4.8	1	14.3	4	5.7	
Other	4	6.3	2	28.6	6	8.6	
Marital status							
Married	44	71.0	4	80.0	48	71.6	0.970
Divorced	2	3.2	0	0.0	2	3.0	
Widowed	1	1.6	0	0.0	1	1.5	
Single	12	19.4	1	20.0	13	19.4	
Never married	3	4.8	0	0.0	3	4.5	
Employment							
Yes	39	62.9	4	50.0	43	62.3	0.480
No	23	37.1	4	50.0	26	37.7	
Years of education							
5 Or less	2	3.3	0	0.0	2	2.9	0.480
6–10	14	23.0	1	12.5	15	21.7	
11–15	28	45.9	6	75.0	34	49.3	
16–20	17	27.9	1	12.5	18	26.1	
Years living in US							
1–4	4	12.5	0	0.0	4	11.1	0.757
5–9	9	28.1	1	25.0	10	27.8	
10–14	5	15.6	1	25.0	6	16.7	
15–19	5	15.6	0	0.0	5	13.9	
20 Or more	9	28.1	2	50.0	11	30.6	
Mean # of programs (SD)	60	1.78 (2.9)	5	5.00 (7.6)	65	2.03 (3.5)	0.046

administered the pre-post test that included questions related to breast cancer and 46 (62%) attendees were administered the pre-post test surveys that included both breast and cervical cancer questions. Sixty-six attendees (89%) were trained as LHAs and 8 *sobrevivientes* (11%) were trained as *sobrevivientes* (seven breast cancer survivors, one breast and cervical cancer survivors). As shown in Table 2, the majority of the trainees were female (77%); ages ranged from 18 to 67 years, with an average age of 43 years; 72% were married; and 62% indicated they were currently working. Half of the trainees were born in Mexico; 36% in Puerto Rico; 11% were born in the US or other Latin American countries; average years in school was 12.6 years and they had been living in the US for an average of 14.8 years. There was a significant difference between LHAs and *sobrevivientes* on the average number of programs attended ($p = 0.046$). Due to the small number of *sobrevivientes*, survivors were more frequently asked to attend programs since a significant component of the program was to share their story about their cancer experience. No statistically significant differences between

the LHAs and *sobrevivientes* groups by ethnicity were found on any of the variables, although there was a higher percentage of females serving as LHAs than males (female = 48 vs. male = 17), and *sobrevivientes* were older than the LHAs (*sobrevivientes* = 54 years vs. LHAs = 41 years) however these variables were found not to be statistically significant.

Table 3 presents LHAs and *sobrevivientes*' mean pre-post-training scores for breast and cervical cancer items. Overall change in knowledge scores (both breast and cervical cancer items) indicate that LHAs scored significantly higher on the post test ($t[32] = 5.42, p \leq 0.001$), as well as *sobrevivientes* ($t[3] = 4.75, p = 0.018$). For breast cancer items, LHAs significantly increased their knowledge from pre-post test ($t[55] = 8.16, p \leq 0.001$). For cervical cancer knowledge items, both the LHAs ($t[32] = 4.69, p \leq 0.001$) and the *sobrevivientes* ($t[3] = 8.66, p = 0.003$) displayed an increased score in the post test.

Table 4 displays the pre-post test scores for the LHAs and *sobrevivientes* at the three study sites (WNY, AR & NYC). There were no statistically significant differences across sites for overall pre- post-training scores. However, there was a significant difference for pre-test scores on breast cancer specific items $F(2, 67) = 4.3, p = 0.017$ across all three sites, with trainees at NYC demonstrating a higher pre-test score for breast items compared to AR and WNY.

There were no statistically significant differences in the pre- and post-training cancer knowledge across the primary Latina sub groups for this training (Puerto Ricans vs. Mexicans).

Table 3 Change in pre-post test scores by volunteer type

	<i>N</i>	Mean	SD	<i>p</i> -Value
Lay health advisor				
Overall cancer knowledge				
Pre test	33	60.2	19.96	0.000
Post test	33	79.6	11.42	
Change in score	33	19.4	20.57	
Breast cancer knowledge				
Pre test	56	54.0	16.36	0.000
Post test	56	78.4	22.74	
Change in score	56	24.5	22.44	
Cervical cancer knowledge				
Pre test	33	58.6	24.42	0.000
Post test	33	79.8	16.77	
Change in score	33	21.2	25.96	
<i>Sobrevivientes</i>				
Overall cancer knowledge				
Pre test	4	75.0	8.39	0.018
Post test	4	89.9	6.59	
Change in score	4	14.9	6.26	
Breast cancer knowledge				
Pre test	8	74.1	17.61	0.377
Post test	8	79.2	9.04	
Change in score	8	5.1	15.37	
Cervical cancer knowledge				
Pre test	4	69.4	10.64	0.003
Post test	4	97.2	5.56	
Change in score	4	27.8	6.42	

Discussion

The use of LHAs provides for a culturally appropriate and linguistically concordant health education program to be implemented, and addresses barriers to cancer screening in medically underserved communities. More information is needed to assess training methods and the ability to ensure the fidelity of program materials by a cadre of volunteers. This report of our findings on the training of LHAs and *sobrevivientes* as well as the characteristics of all of our volunteers is an effort to address this need.

This was not an educational study per se, and the findings of the training program were examined and analyzed retrospectively. This training data review was sparked by the intervention programmatic variations by study site (reported elsewhere) [36], that demonstrated several significant variations across the sites. We were also impressed by the comparable high screening outcomes at all sites, although baseline rates varied significantly for most types of screening exams (i.e., pap test vs. mammography) [37].

Table 4 Pre-post test by program site

	AR			NYC			WNY			Total			p-Value
	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	
Pre test: all cancer ques.	13	64.1	13.20	4	63.3	22.77	25	48.0	31.86	42	54.4	27.31	0.181
Post test: all cancer ques.	13	85.1	9.45	4	78.3	22.03	20	78.3	9.64	37	80.7	11.40	0.232
Pre test: breast	31	53.9	21.75	14	66.3	23.00	25	41.8	30.35	70	52.1	26.57	0.017
Post test: breast	30	78.6	17.15	14	79.9	12.77	20	77.5	15.56	64	78.5	15.58	0.906
Pre test: cervical	13	61.5	15.46	4	55.6	20.29	25	47.6	35.21	42	52.6	29.45	0.383
Post test: cervical	13	86.3	15.81	4	80.6	26.25	20	78.9	15.67	37	81.7	16.81	0.471

We consider it important to review the training data across all sites in order to better understand these program results.

As found in formative research with Latina focus group participants [38, 39], and in the population of women reached by the intervention [36, 37, 40], knowledge about cancer, anatomy and health risks is relatively low for Mexican, Puerto Rican and Dominican groups of recent Latino immigrants in the US. It is not a common topic of conversation in the home countries, and there are few educational opportunities to learn these facts in the US, especially for individuals with lower literacy skills. Therefore, given the opportunity, LHAs increased cancer knowledge from 60% to 80% correct. However, due to personal experience, *sobrevivientes* show a higher baseline knowledge score of 75% compared to the LHAs (60%).

Results from the pre- and post-program surveys indicated that after participating in the training session, LHAs reported increased knowledge about breast and cervical cancer. Pre-test breast knowledge scores differed significantly between the LHAs and the *sobrevivientes*. Baseline scores on the pre-test were significantly higher for the *sobrevivientes* compared to the LHAs and there was no change in impact of breast knowledge. *Sobrevivientes* increased their cervical knowledge scores in the post test. *Sobrevivientes* play a very different role than the LHAs. The *sobrevivientes* not only brought with them their personal experience with cancer, but also were very passionate about getting the message of “early detection can save lives” across to the Latino population who, in many cases, tends to have had negative experiences with cancer. Their main focus was conveying their personal narrative to the audience.

The results of this study are primarily limited to the Latino sub groups (Mexican and Puerto Rican) living in the specified study sites and cannot be generalized across Latino sub groups living elsewhere. These LHAs were subgroups that were in our geographic region of the study.

The lessons gained from the training have implications for effective LHA training programs to increase preventative and screening services. It is very important for program sustainability that *sobrevivientes* play an important role by maintaining the program over time. Communicating

personalized risk levels are valuable for teaching information about risk factors and cancer survivors can become influential and credible messengers for cancer control messages [33, 41]. Community based programs that utilize LHAs increase the likelihood of program sustainability within the communities they serve [42].

The major limitation of this study is the methodological variations that reduced the sample sizes for some pre- and post-test comparisons. Missing data was a limitation of the study since many of the attendees did not complete the entire application that was collected at the beginning of the training as well as the pre-post tests. Another limitation was that the training was conducted solely as a pen and paper assessment, however, future trainings will be carried out using an electronic Audience Response System (ARS). By incorporating the use of an Audience Response System (ARS) in the larger intervention study, we have improved and streamlined data management significantly, resulting in increased rates of survey questionnaire completion as compared to traditional pen and paper methods. Furthermore, this training program may offer a potential model for other programs that are interested in incorporating LHAs and cancer survivors into community health programs.

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