

Empowering *Promotores de Salud* as Partners in Cancer Education and Research in Rural Southwest Kansas

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Less than 10% of all adult patients with cancer participate in cancer clinical trials (Baquet, Ellison, & Mishra, 2009; Comis, Miller, Aldigé, Krebs, & Stoval, 2003; Sateren et al., 2002). Participation in clinical cancer research studies is even lower for patients from vulnerable minority populations (Murthy, Krumholz, & Gross, 2004), and little is known about the participation rates of rural Latinos. Multi-level barriers hinder participation in clinical research among minority patients (Anwuri et al., 2013; Hubbard, Kidd, Donaghy, McDonald, & Kearney, 2007; Schmotzer, 2012). Among Latinos and other immigrant groups, limited English proficiency serves as a barrier to participation in clinical research, with about half of U.S. Latino families reporting Spanish as their primary language (Schnoll et al., 2005). Temporary pending migrant or undocumented status further impedes access to clinical research and services among immigrant Latinos in the United States (Loue, Faust, & Bunce, 2000). Fortunately, evidence suggests that when they are provided with opportunities to participate, minority patients participate in clinical research studies, including those focused on cancer, at the same rate as non-Latino Caucasians (Wendler et al., 2005).

Building community infrastructure to enhance participation in cancer research is critical, particularly in vulnerable ethnic minority and rural communities that typically face the additional burden of geographic isolation (Chiu, Mitchell, & Fitch, 2013; Schensul & Trickett, 2009). Interventions that use multi-level networking and capacity-building strategies have effectively engaged Latino communities in cancer research. Including multi-ethnic populations in all stages of the cancer research continuum is more likely to generate research programs that are more responsive to the groups largely affected by cancer disparities (Baquet, Commiskey, Daniel Mullins, & Mishra, 2006). In fact, a systematic

Purpose/Objectives: To describe community-based participatory processes used to develop *promotore* training on cancer research, and to assess the feasibility of training *promotores* from rural communities to disseminate cancer research information.

Design: Prospective, cohort design.

Setting: Rural communities in the state of Kansas.

Sample: 34 Spanish-speaking *promotores* attended an information session; 27 enrolled and 22 completed training.

Methods: With input from a community advisory board, the authors developed a leadership and cancer curriculum and trained Spanish-speaking *promotores* to disseminate information on cancer research. *Promotores* completed pretraining and post-training surveys in Spanish to assess demographic characteristics and changes in knowledge of cancer, cancer treatment and cancer research studies, and intent to participate in cancer research.

Main Research Variables: Cancer knowledge, awareness of cancer clinical trials, interest in participating in cancer clinical research studies.

Findings: Compared to pretraining, after training, *promotores* were more likely to correctly define cancer, identify biopsies, describe cancer stages, and report ever having heard of cancer research studies.

Conclusions: Completion rates of the training and willingness to participate in cancer research were high, supporting the feasibility of training *promotores* to deliver community-based education to promote cancer research participation.

Implications for Nursing: Nursing professionals and researchers can collaborate with *promotores* to disseminate cancer education and research among underserved rural Latino communities in Kansas and elsewhere. Members of these communities appear willing and interested in improving their knowledge of cancer and cancer clinical trials.

Key Words: *promotores de salud*; cancer research; Latinos; immigrants; lay health workers; community-based participatory research

ONF, 42(1), 15–22. doi: 10.1188/15.ONF.15-22

review of community-based participatory approaches to conducting randomized clinical trials found that most of these were effective in recruiting and retaining minority populations and resulted in significant health improvement (De las Nueces, Hacker, DiGirolamo, & Hicks, 2012).

A community-participatory model that has been employed effectively in minority communities and fits well within the Latino cultural context is the use of *promotores de salud*, or community lay health workers. Promotores programs have used social networks to successfully disseminate information on prevention (e.g., immunizations, physical activity) (Ayala, Vaz, Earp, Elder, & Cherrington, 2010), early detection (e.g., cancer screening) (Larkey et al., 2012; Wells et al., 2011), and self-management of chronic illnesses (e.g., diabetes self-care) (McCloskey, 2009). Recently, promotores have been used to increase participation in cancer research studies (Elliott, Belinson, Ottolenghi, Smyth, & Belinson, 2013; Guadagnolo et al., 2009; Livaudais et al., 2010), but the feasibility of extending these models to rural Latino communities requires further evaluation.

The aims of this study were to describe community-based participatory processes used to develop a promotores leadership and cancer research education training curriculum for use among rural, Spanish-speaking Latinos, and to assess the feasibility of training a core of rural, Spanish-speaking promotores to disseminate information on cancer and cancer research among rural Latinos. The intent was to build community capacity to test in a future study the effects of the promotores-delivered intervention on attitudes and willingness to participate in cancer research among rural Latino communities in Kansas.

Methods

Community Infrastructure

The researchers used three strategies to develop an infrastructure to support cancer health disparities studies among rural Latino communities: formation of a community advisory board (CAB), development of a cancer research training program for Spanish-speaking promotores from rural communities, and recruitment and training of a core of Spanish-speaking promotores to disseminate cancer research education throughout rural communities. The process began with the formation of a CAB whose members guided the development of the promotores training program, helped identify potential trainees, and mobilized the community at large to promote the training. The training was designed to empower promotores to be equal research partners with essential knowledge about cancer, cancer clinical research studies, advantages and disadvantages of participation in research, and

critical skills for disseminating information on cancer research studies through their social networks. The researchers recruited and trained promotores using a skills-building curriculum to enhance leadership and interpersonal skills to disseminate cancer and cancer research education at community health events. The University of Kansas Medical Center Human Subjects Committee approved this study.

Community Advisory Board

Initially, two key community leaders recruited other community leaders with the intent of obtaining broad representation of various community sectors, including hospital, school district, community college, local media channels, and community- and faith-based organizations. CAB member recruitment was expanded through use of community information sessions conducted by study investigators over an eight-month period. Fifty community members attended at least one CAB meeting, and nearly half of those members attended three or more meetings. The CAB met monthly for eight months, and meetings lasted about one to two hours each. CAB members provided input on the training and evaluation, and communicated regularly outside of scheduled CAB meetings by phone, text message, or email. CAB members were unpaid volunteers who stayed involved largely because this activity reinforced their leadership skills and mainly was organized around lunchtime to develop this community-based program.

The CAB guided development of the cancer research training program and promotores recruitment strategies, and engaged the community at large through use of local broadcast media. CAB members selected the content, colors, and design, and took photos that were incorporated into the cancer research education program. CAB members provided feedback on the training content and format, fostered collaborations with community agencies, and assisted with promotores recruitment.

Cancer Research Training Course for Promotores

With input from the CAB and other community leaders, the researchers drew on cancer research programs from the following institutions: the National Cancer Institute (NCI, 2014), the Native American Programs (2012) of the Mayo Clinic Comprehensive Cancer Center, Native American Cancer Research (2012), the Northwest Tribal Comprehensive Cancer Project (Guthrie, 2002), and the University of New Mexico (Otero, 2006) Cancer Research and Treatment Center. The researchers ultimately decided to use the NCI (2014) Cancer 101 curriculum without modifying the content because it was available in Spanish and covered

the competencies the researchers sought to impart in training. However, the researchers made significant adaptations to the delivery methods to accommodate low literacy and a variety of learning styles, and to incorporate principles of popular education (Wallerstein & Bernstein, 1988).

The cancer and cancer research studies training course was taught in Spanish by bilingual researchers and consisted of three group sessions that were three hours each (see Figure 1). Promotores were required to complete part A, Cancer 101, prior to participating in part B, which was covered in two meetings and focused on cancer research studies. Part A focused on five basic cancer education topics: definition and types of cancer, cancer disparities and barriers to care, cancer screening and early detection, cancer diagnosis and staging, and cancer risk factors and risk reduction. Part B covered key cancer research concepts, including randomization, eligibility, informed consent, in-depth information about types of cancer research studies, and examples of studies available in Kansas. During part B, participants identified barriers to participation in cancer research studies, risks and benefits, and questions to ask as patients, family members, and promotores. In addition, participants engaged in hands-on activities, such as finding information about cancer and cancer research on the NCI's comprehensive cancer information website (www.cancer.gov) and by calling the NCI's Cancer Information Service at 1-800-4-CANCER.

Recruitment and Training of Promotores

Eligibility criteria for the promotores training program were aged 18 years or older, self-identified as Latino, fluent in Spanish, and able to attend in-person training sessions. Participants were recruited by word of mouth by CAB members and flyers. Recruitment of promotores occurred over a period of two months. One information session of three hours was organized, and 34 participants attended. Three research staff members attended the information session for recruitment and surveyed eligibility of participants.

Training sessions were conducted in Spanish by bilingual research staff with expertise in delivery of promotores de salud training programs. Each three-hour training session or class was offered twice on different days of the week and different times of the day (morning and late afternoon) to accommodate all participants. An average of 10 participants attended each session. Incentives in the form of \$20 gift cards were provided after attending each session.

Following Paulo Freire's theory of empowerment education (Wallerstein & Bernstein, 1988), in which individuals are encouraged to actively participate and take responsibility for their own education, the researchers' curriculum and evaluation methods sought to build

Cancer 101 "Aprendámos sobre el cáncer" (Session 1)

Definition of cancer and types of cancer:

- Define cancer and the process through which normal cells become cancerous.
- Describe two types of cancer and where they occur.

Cancer disparities and barriers to care:

- Give two facts about cancer disparities among Latinos.

Cancer screening and early detection:

- Give two examples of cancer screening methods.

Cancer diagnosis and staging:

- Describe what is meant by the term *biopsy*.
- Give two reasons why learning about staging is important.

Cancer risk factors and risk reduction:

- Name two risk factors and two risk-reduction behaviors.

Activities/tools: Worksheets, group discussions, short videos, cancer education bingo, and evaluation (head, heart, and feet)

Cancer research studies training: Empowering the community to ask questions about cancer research studies (Session 2)

What do we know about cancer?

What do we not know about cancer?

Define cancer research studies.

Understanding participation in cancer research studies:

- Define informed consent and the right to stop.
- Describe what is meant by eligibility criteria.
- Describe how participants are assigned to groups in randomized research studies.

Case study: The Havasupai case:

- State why cancer research studies are important for them, their families, and their communities.

Activities/tools: Short videos, worksheets, brochures from the National Cancer Institute, randomization activity with envelopes, myths and realities about informed consent, and evaluation (why cancer research studies matter to me)

Cancer research studies training: Participating in cancer research studies (Session 3)

Types of cancer research studies:

- Give two examples of types of cancer research studies.

Identifying barriers:

- Name two barriers to participating in cancer research studies.

Balancing risks and benefits:

- Mention two risks and two benefits of participating in a cancer research study.

Questions to ask about cancer research studies:

- Give three examples of questions to ask about cancer research studies.
- Search for education tools for cancer research studies.
- Describe a research study available in their community.

National Cancer Institute:

- Give website and phone number.

Activities/tools: Review an example of an informed consent and its parts, short videos, questions about cancer and cancer research studies, and personal evaluation of training sessions

Figure 1. Description of Cancer 101 and Cancer Research Studies Training for Promotores de Salud

a trusting environment for open dialogue, allowing for interactive activities that expanded the learning experience for participants and facilitators. Each training session began with a dynamic “warm-up group activity” to engage the group in conversation about the session topic. Sessions continued with a description of the topic to be covered and an interactive discussion, and ended with a practical activity to help participants develop skills to apply the new concepts. All sessions incorporated interactive learning strategies (e.g., case studies, worksheets, role playing). Minimum reading was required, and sessions used a variety of interactive video and graphic materials. At the end of each session, participants shared a summary of the objectives and goals reached individually and as a group.

Evaluation of Promotores Training Program

After obtaining written informed consent to participate in the training and evaluation, bilingual-bicultural research staff conducted baseline assessments through individual interviews prior to the first training session. A two-month post-training assessment was completed by telephone.

Through open-ended questions, the researchers explored promotores’ knowledge and cultural beliefs about the causes of cancer and its treatment and perceived barriers to access to cancer information among Latinos. Structured survey items were used to collect data on participants’ demographic characteristics, cancer knowledge, and interest in participating in cancer research. The baseline survey assessed demographic and socioeconomic characteristics including age, gender, race or ethnicity, country of origin, education level, type of health insurance, access to health care, acculturation, English proficiency, marital status, employment status, household size, and weekly and annual income. To assess cancer knowledge at baseline and post-training, participants were asked to respond “true” or “false” as to whether they agreed with statements about cancer topics (definition of cancer, types of cancer, cancer early detection, cancer staging, and cancer risk factors). Participants also completed a series of “yes” or “no” questions about whether they had heard of cancer research studies and their interest in participating in a cancer clinical research study and donating biospecimens (e.g., blood, saliva, tissues) for cancer research.

Data Analysis

Descriptive demographic data were analyzed using PASW Statistics, version 18 (formerly SPSS Statistics), to report frequencies and proportions. Participants’ pre-post changes in knowledge of cancer and interest in participating in cancer research were assessed using McNemar’s test for paired nominal data.

Findings

Of 27 promotores enrolled in the training program, 22 (82%) completed at least two of three training sessions and the pre- and post-training assessments. Reasons for not completing the training included travel distance and job scheduling conflicts. Among the 22 promotores who completed the training and assessments, 77% (n = 17) completed all three sessions, and 23% (n = 5) completed two sessions. The majority of participants were female and married (see Table 1). Most participants were of Mexican origin (89%); almost half (41%) were from the state of Chihuahua in northern Mexico. Almost a quarter of promotores had less than a high school education, and the majority were employed full time (70%). Half reported limited English proficiency (i.e., speak English “not well” or “not at all”).

At baseline, promotores’ cultural beliefs about cancer included getting hit, getting scared, punishment from God, sexual intercourse, witch spell, and environmental sources (cell phone use, bacteria, fertilizers, maguery flowers, water, pollution, and cold food). Participants often reported using alternative medicines to treat cancer, including rattlesnake capsules, guanabano (soursop) fruit, syrup from leaves, herbs,

Table 1. Sample Characteristics (N = 27)

| Characteristic | n |
|--------------------------------|----|
| Age (years) | |
| 18–39 | 12 |
| 40–64 | 15 |
| Female | 21 |
| Married | 21 |
| Country of origin | |
| Mexico | 24 |
| United States | 2 |
| Honduras | 1 |
| Education | |
| Less than high school graduate | 6 |
| High school graduate | 8 |
| Some college | 9 |
| College graduate | 4 |
| English proficiency | |
| Very well or well | 14 |
| Not well or not at all | 13 |
| Full-time employment | 16 |
| Weekly income (\$) | |
| Less than 500 | 12 |
| 501–800 | 11 |
| Greater than 800 | 4 |
| No health insurance | 7 |
| Language spoken at home | |
| More Spanish than English | 13 |
| Only Spanish | 11 |
| English and Spanish equally | 2 |
| More English than Spanish | 1 |

Table 2. Knowledge of Cancer and Interest in Cancer Research Studies Among *Promotores de Salud* (n = 22)

| Item | Preassessment | Postassessment | p |
|---|----------------|----------------|---------|
| | n ^a | n ^a | |
| Cancer Knowledge | | | |
| Cancer is a disease caused by the uncontrolled growth of abnormal cells. | 3 | 15 | < 0.001 |
| Biopsies are a cell or tissue examination to determine the presence or extent of cancer. | 12 | 19 | < 0.05 |
| Which of the following are risk factors for cancer? | | | |
| Smoking and exposure to chemicals and radiation | 8 | 7 | 1 |
| Unhealthy lifestyles and sun exposure | 4 | 4 | – |
| Genetics | 2 | 5 | 0.25 |
| Which of the following are early detection cancer screenings? | | | |
| Pap smear and mammogram | 10 | 15 | 0.06 |
| Which of the following describe what cancer stages are? | | | |
| There are four stages. They delineate the progress of the cancer. | 2 | 10 | < 0.01 |
| Awareness of and Interest in Participating in Cancer Clinical Research Studies | | | |
| Have you ever heard of any cancer clinical research studies? | 9 | 19 | < 0.01 |
| Have you ever participated in a cancer clinical research study? | – | – | – |
| Would you be interested in participating in a cancer clinical research study? | 21 | 19 | 0.5 |
| If you decide to participate in a cancer clinical research study, would you consider giving a sample of the following? | | | |
| Saliva | 22 | 21 | 1 |
| Tissue | 17 | 17 | – |
| Blood | 22 | 21 | 1 |

^an refers to the number of respondents who answered “yes.”

cacti, and salty water from rivers. Lack of knowledge and resources (50%), lack of insurance (23%), and language (14%) were identified as the overall barriers to cancer information faced by the Latino community. Promotores recommended access to low-cost cancer screening (36%), development of community-based education programs (27%), use of community health workers (23%), and access to affordable insurance (14%) as promising approaches to overcoming these barriers among Latinos.

When comparing pretraining and post-training assessments, promotores demonstrated an increase in cancer knowledge in several areas. They were more likely to correctly define cancer (14% versus 68%, $p < 0.001$), biopsies (55% versus 86%, $p < 0.05$), and cancer staging (9% versus 46%, $p < 0.01$). Also, they were more likely to be able to identify cancer early detection examinations (46% versus 68%, $p = 0.06$). Finally, they were more likely to report having heard of cancer research studies (41% versus 86%, $p < 0.01$), and slightly less likely to report interest in participating in cancer research, although this difference was not statistically significant (96% versus 86%, $p = 0.5$) (see Table 2). Pre- and post-training, most participants (96%–100%) agreed that they would consider donating their blood and saliva for cancer clinical research studies, and 77% agreed that they would donate a sample of their tissue.

Discussion

In the current study, the researchers developed and implemented a community-based and culturally relevant training program for promotores de salud to promote awareness and interest related to cancer research among Latinos in rural Kansas communities. With the engagement of an active CAB, the researchers were able to recruit and train 22 promotores who have committed to the delivery of community-based presentations to promote awareness of cancer research studies among other rural, Spanish-speaking Latinos in Kansas. Promotores reported increased knowledge of cancer and awareness of cancer research studies after the training. Interest in participating in cancer research studies did not change significantly after training and was exceptionally high (more than 95%) at pre- and post-training assessments.

The high interest in cancer research studies among rural Latinos is striking. This finding contradicts the myth that minorities are less willing to participate in clinical research. Promotores were willing to consider donating biologic specimens. Given the high completion rates for the training and the pre-post increases in knowledge, the findings support the feasibility of training promotores to deliver cancer education and promote cancer research.

Although not statistically significant, promotores' interest in participating in cancer research studies

and clinical trials decreased in a few participants after completion of training. Training sessions included a comprehensive list of questions and concerns that should be addressed when deciding on participating in cancer research studies and clinical trials. This emphasis on the pros and cons of the decision could have made them more cautious about participating in cancer research studies and clinical trials. Latinos tend to have less access to information on cancer research because of cultural and language barriers. For example, a large survey of about 900 Latinos found that more than half did not know what a clinical trial was (Wallington et al., 2012). Initially, Latinos' lack of knowledge may make them somewhat naïve and unquestioning, but once they are made aware of the risks and benefits of participating in research, they may be better equipped to make an informed decision.

Several lessons were learned through the current study. Maintaining the participation of promotores in the program required regular and consistent engagement between project staff, community leaders, and promotores. Traveling large distances from small towns in southwest Kansas and work schedule conflicts limited the participation of promotores in the training sessions. Despite this, the program had significant success and moved many promotores from having a limited cancer knowledge base to being a resource for cancer information for others in the community. Overall, the researchers found relationship building and maintenance to be of primary importance to the rapid development and launching of the training program. Cancer education activities were welcomed and promoted in the local media because they were seen as an initiative of community members.

The researchers found a number of misconceptions in the Latino communities related to folk beliefs about the causes and treatment of cancer, highlighting the importance of increasing access to cancer information in these populations. Participants were engaged and receptive to this information, indicating the untapped potential in reaching these underserved areas via promotores.

Limitations

Several limitations of the study are noted, first of which is the lack of a control group; however, the researchers have no reason to suspect secular changes in cancer knowledge and interest in cancer research over the two-month period of the training, particularly in the remote rural areas where the training was delivered. The ability to generalize this project's results to other U.S. Latino promotores may be limited. The researchers' sample may not be representative of all promotores because those who are interested in receiving training on cancer and cancer research are most likely, by nature, more interested and willing to participate, particularly in rural

areas where access to this information is more limited. In addition, Latinos are a heterogeneous population and the majority of the participants were of Mexican origin, Spanish-speaking, and recent immigrants. Also, the researchers did not have a validated measure of acculturation, nor did they ask about years spent living in the United States; instead, they relied on self-reported language spoken at home as a surrogate measure of language acculturation. Another limitation refers to the self-selection bias of reporting interest and attitudes of promotores who already were interested in completing a training curriculum about cancer research. Because of the self-selection bias, promotores involved in the study possibly could have reported an overall more positive attitude about and interest in participating in clinical trials. Nevertheless, the findings provide a significant contribution to future cancer disparities community-based research efforts, particularly those targeting rural communities.

The trained promotores continue to be engaged in outreach activities to promote awareness of cancer early detection and participation in cancer clinical research. Working with the CAB and promotores, investigators developed a social media campaign to disseminate information on cancer research studies among the Latino community in southwest Kansas. Along with the media campaign, promotores will perform individual one-on-one education sessions on cancer research studies with 10 community members each and will track their activities. Training outcomes of these educational sessions will be assessed using short questionnaires. Promotores' experiences in disseminating information about cancer research studies will further empower them to be involved in planning and implementing future cancer health disparities research studies.

Implications for Nursing

Historically, nurses have functioned as important gatekeepers linking patients to clinical trials in academic settings. However, more than 85% of cancer care is provided in community oncology practices, highlighting the importance of providing community nurses, as well as those in academic settings, with training on clinical research (Klinger, Figueras, Beney, Armer, & Levy, 2014).

Recruiting ethnic minorities into research requires a personal approach with direct contact to overcome barriers to participation, such as lack of awareness of research, challenging life circumstances, low literacy, and limited English proficiency. Clinical trials nurses serve as a critical bridge to underserved communities for clinical researchers because nurses tend to be better versed in patient education, advocacy, and local community needs (Rubin, 2014). Several studies have shown that

Knowledge Translation

Spanish-speaking community members can be engaged in efforts to increase their representation in cancer research.

Community-based cancer education is associated with improvements in knowledge of cancer and cancer research among Spanish-speaking *promotores*.

Train-the-trainer approaches show promise for addressing racial and ethnic disparities in rates of participation in cancer research.

including nurses on clinical trial study teams results in improved recruitment and retention, particularly among ethnic minority patients (Barthow et al., 2014; Holmes, Major, Lyonga, Alleyne, & Clayton, 2012; Rubin, 2014).

This study found that empowered community health workers are eager to collaborate and share their knowledge of cancer and cancer clinical trials with the community at large. Therefore, trained *promotores* can serve as an important adjunct to nurses in expanding opportunities for equitable participation in cancer research in community settings where the majority of cancer care is provided. Nursing professionals can further extend their effectiveness and reach in engaging diverse communities in research by working in collaboration with community health workers to disseminate clinical research information and opportunities among underserved rural Latino communities. Coordinated efforts of nurses and community health workers to promote enrollment in cancer clinical trials offer great promise for addressing inequities in research participation and ensuring more equitable distribution of the benefits of clinical research. Supporting nurses and community health workers in these roles is critical.

Conclusion

Training completion rates and willingness to participate in cancer research were high among *promotores*, and knowledge of cancer and cancer research was improved. These findings support the feasibility of training *promotores* to deliver community-based education to promote cancer research participation. Such training may cause some participants to be more cautious as they become better informed about participating in cancer clinical trials.

The authors gratefully acknowledge community members; community partners; community mobilizers Arturo Ponce, Dora Ponce, and Irma Robbins; and promotores de salud in southwest Kansas. Special thanks to Carolina Stefany Parede Molina, BS, who supported the final revision of the article and dissemination of its findings to promotores de salud.

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