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Breast Screening Navigator Programs within Three Settings that Assist Underserved Women

Linda Burhansstipanov,

Grants Office, Native American Cancer Research Corporation, 3022 South Nova Road, Pine, CO 80470-7830, USA, LindaB@NatAmCancer.net, URL: <http://www.NatAmCancer.org>

Headquarters, Native American Cancer Research Corporation, 393 South Harlan Street, Suite 125, Lakewood, CO 80226-3571, USA

Mark B. Dignan,

Southeastern Program Evaluation, 1737 Richmond Road, Lexington, KY 40502, USA

Ann Schumacher Sr.,

Exempla/Saint Joseph Hospital, Family Practice Center, Midtown II, Suite 200, 2005 Franklin Street, Denver, CO 80205, USA

Linda U. Krebs,

Anschutz Medical Campus, College of Nursing, University of Colorado at Denver, Box C288-18 ED2N, Room 4209, 13120 East 19th Avenue, P.O. Box 6511, Aurora, CO 80045, USA

Grace Alfonsi, and

Denver Health Medical Plan Clinic, Denver Health Authority, Family Medicine, 301 West 6th Avenue, Denver, CO 80204, USA

CeCilia Ceci Apodaca

La Clinica Tepeyac, 3617 Kalamath Street, Denver, CO 80211, USA

Abstract

Medically underserved women in the Greater Denver Metropolitan Area had low rates of routine repeat mammograms in the latter 1990s. “Increasing Mammography Adherence among Medically Underserved Women” was designed to increase annual rescreening among medically underserved populations living in this area. Four community-based organizations collaborated to implement this 5-year study. A culturally modified navigator model including both face-to-face and telephone formats was used to facilitate mammography for African Americans, Latinas, Native Americans, and poor White women who had not been rescreened in more than 18 months. The navigator-implemented intervention was statistically significant at the 0.05 level for increasing rescreening.

Keywords

Navigators; Community-based participatory research; Breast cancer; Medically underserved; Screening; Early detection; Intervention; American Indians; Latinas; Poor White women; African-American women

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Correspondence to: Linda Burhansstipanov.

Institutional Review Boards and Health Insurance Portability and Accountability Act Approvals Institutional Review Boards (IRB) and Health Insurance Portability and Accountability Act (HIPAA) Education and Approvals were obtained by all Administrative Study Staff and Navigators from Exempla/Saint Joseph Hospital (IRB #200107) and Denver Health Authority [Colorado Multiple Institutional Review Board (includes Denver Health and Hospitals/ Denver Health Authority) COMIRB #02-809].

In 2000, although medically underserved populations (MUP) in the Greater Denver Metropolitan Area were participating in breast cancer screening by obtaining initial clinical breast exams (CBE) and mammograms, the majority was not being rescreened regularly and routine screening is paramount to early detection. Four organizations collaborated in 2003 to develop, implement, and evaluate the NCI-funded “Increasing Mammography Adherence among Medically Underserved Women” [NCI R25 CA 96540] Study [hereafter called the MUP study; Native American Cancer Research (NACR), Exempla/Saint Joseph Hospital (ESJH), and La Clínica Tepeyac (LCT)], a collaborative, community-based participatory research (CBPR) study focusing on MUP in greater Denver. This community-driven research project evolved from three distinct but intertwined areas and included a community coalition, a needs assessment from two different entities, and previous research conducted by one the study’s partners.

The American Cancer Society introduced a national initiative “Partnerships In Cancer Control Among Underserved Populations” (PICCUP), in 1997. Colorado took part in this initiative by establishing a statewide coalition. NACR, LCT, and ESJH participated in the formation of the coalition and remained active members of the Colorado Committee of PICCUP throughout its implementation. The MUP Coalition met every 2 months and discussed breast health, screening, accessing culturally acceptable services, and providing culturally appropriate follow-up care for women who receive abnormal results. Of primary focus were gaps in the continuum of care for those women in the Denver area. A coalition of PICCUP formed the Advisory Committee for this project.

During 1997, the Denver Metropolitan Affiliate Chapter of the Susan G. Komen for the Cure® supported a local needs assessment about breast cancer services and gaps. Also in 1997 and 1998, the University of Colorado Comprehensive Cancer Center supported the *Colorado Blueprint*, a statewide assessment and prioritization project to address access to clinical trials and quality cancer care for women and minorities. Based on both the local Komen needs assessment and the *Colorado Blueprint*, there was a need for the development of and access to culturally relevant navigator support programs. Both assessments recognized the dearth of culturally competent staff in-service training for professionals and navigators working with MUP in the greater Denver area.

The MUP study was also based on two prior studies conducted by NACR. The first was Native American Women’s Wellness through Awareness (NAWWA) [1]. NACR staff implemented this CBPR beginning in 1989 and began including a navigator component in 1994. The goal of NAWWA was to develop a culturally acceptable navigator model program (called “native sisters”) to increase the number of urban American Indian women who participate in early detection and breast cancer programs. The model used in Denver was significantly ($p=0.05$) increased screening in comparison to the “usual care” model used in Los Angeles [1–7].

A second project, Mammography Screening in Urban American Indians built on the successes seen in NAWWA and compared two navigator models (face-to-face and telephone support) to determine whether culturally relevant interventions increased adherence to mammography screening guidelines among urban American Indian women to identify if one navigation method was superior. Both the telephone and face-to-face native sister interventions increased native women’s adherence to annual breast screening; however, no statistically significant differences were found between the two native sister formats (face-to-face and telephone) [8, 9].

The MUP broadens the perspective of the previous studies by including other populations. This paper focuses on the results of this study looking at the relative effectiveness of a

culturally appropriate navigation intervention among urban Native American, Latina, and poor White populations and evolving navigation issues.

Methods

The previous studies led to the collaboration among three organizations dedicated to working with underserved populations in Denver: ESJH, NACR, and LCT. As partners in the MUP Coalition, the three organizations determined that, to enhance breast screening and, in particular, rescreening of MUP, a navigation model could be developed based on the lessons learned from NACR's studies, as well as the *Colorado Blueprint* and the Denver Affiliate of the Susan G. Komen for the Cure® needs assessment.

The “Increasing Mammography Adherence among Medically Underserved Women” (the MUP study) was designed to improve adherence with national quality standards by increasing the proportion of low-income, medically underserved women participating in rescreening.

The MUP study was based on the Social Cognitive Theory [10–12]. The selection of this theory for this study was motivated by the purpose of the study, the nature of the study population, and the type of behavior change desired.

The MUP was a CBPR and community-driven research study implemented by three partners, with each focusing on a particular population (NACR's focus was Native Americans, LCT's was Latinas, and ESJH's was poor White women, but also included African Americans and Asians). Each used the same procedures for study recruitment, retention, implementation of the intervention, and evaluation. The comparison group was medically underserved women as reported with the Colorado Mammography Advocacy Program (CMAP). Thus, the MUP data were compared to the existing CMAP database that provided demographic and screening information, but no identifiers.

The project team initially attempted to use medical records from three primary clinical settings; however, the records included significant racial misclassification errors and were not up-to-date. The project staff submitted an amendment to the ESJH Institutional Review Board during the fall 2004 to expand the recruitment strategies to include techniques other than medical records. Thus, the project staff used other minority organizations' membership or participation lists, recruited from other health care facilities throughout the Greater Denver Metropolitan Area, added advertisements within minority and medically underserved publications, and recruited during community events (e.g., PowWows, fund-raising events for local hospitals). All three community-based partners expanded its populations to include women of other races who were considered medically underserved, living in poverty, having had at least one previous mammogram, were over 39, and had not participated in screening within the previous 18 months. Those women who were Spanish-speaking were primarily from La Clínica's internal database and the navigator from that facility provided leadership for all Spanish-speaking and Latina females.

Navigator trainings started in 2001 and included a total of 80 h of training. Topics included onsite tours of clinical cancer settings frequently used by MUP; confidentiality; patient support care; breast cancer 100 (overview), 101 (screening and abnormal results), and 102 (obtaining appropriate follow-up care for abnormal results); and computer skills. Project staff implemented refresher sessions at least every 6 months. Both the project administrative staff and the navigators recommended topics for the refresher sessions. For example, the refresher topics in 2004–2005 included: review of education intervention process; data collection, management, and storage processes; obesity, energy balance, and cancer prevention and control; community resources to assist medically underserved women

throughout the continuum of cancer care; hormonal replacement therapy; new breast cancer treatments and clinical trials; hepatitis C; preliminary results and refinements for interventions and project close-out.

Cancer education materials included in the intervention were:

1. Breast screening brochure (personalized to the woman based on responses to her baseline survey). Each setting modified the template for the educational booklets and the local navigators personalized education booklets based on answers from survey.
2. Shower cards.
3. Pocket calendar.
4. Bead necklace depicting various sizes of tumors.
5. Breast models (to demonstrate breast self-examination).
6. Breast health flip chart (English and Spanish version from the NCI CIS Partnership Program or NACR's "Get on the Path to Breast Health"; <http://NatAmCancer.org>).

The navigators created a newsletter on health issues (with limited inclusion of cancer information), a collaborative effort by all three study sites and disseminated through each sites' ongoing awareness and outreach activities. This newsletter was added to the project based on findings from the "Increasing Mammography for Urban American Indian Women" study that ended in 2003. The control group in that study felt neglected because there had been no contact with them while the education intervention was implemented. As a result, the urban Indian control group was hesitant to take part in the post intervention survey. To avoid such a reaction from the populations within the MUP study, the staff created and disseminated four newsletters that highlighted multiple health issues, including healthy recipes from each of the respective communities.

The navigators recruited patients from their respective settings and during culturally specific community events (such as a May Latina health event or the fall NACR PowWow). After collecting baseline survey information, the navigator scheduled either a face-to-face or telephone education session. Several of the participants requested the education intervention at the same time as the initial survey. The intervention included culturally appropriate education and one-on-one assistance with scheduling a mammogram and CBE. Any factors that appeared likely to interfere with the woman taking part in the breast health screening were discussed and strategies were implemented to overcome those barriers (e.g., some participants needed bus passes, others needed child care services while they took part in the screening). The navigator called or contacted the woman (some had no phone services) to determine if or when the breast health screening was completed. Each navigator tracked their own patients (dates of survey, intervention, scheduled breast health screening, and follow-up calls).

NACR navigators drafted an intervention summary checklist to document that each navigator provided all aspects of the intervention. The intervention included both face-to-face and telephone navigation formats based on results of the urban American Indian intervention that documented both approaches to be successful. The participants selected which format they preferred and the navigator complied by either meeting the woman at a mutually convenient location or by conducting the intervention by phone.

The navigator's intervention provided support for women who received abnormal results from mammograms. They helped schedule appointments for follow-up, obtained Health Insurance Portability and Accountability Act (HIPAA) approvals to accompany the women

to their respective appointments, met with the patient and/or family/loved one to select questions for the provider; accompanied the women to appointments including the visits with each of the cancer care providers; recorded the session with the provider (with permission); helped translate medical terminology into easy-to-understand language; assisted the patients in accessing quality treatment; assisted the patient and families in obtaining traditional Indian healing and spiritual healing ceremonies; and provided assistance for participation in local culturally specific breast cancer support circles.

Results

A total of 326 medically underserved women were recruited and offered enrollment. Of the 326, 316 enrolled. The ten not enrolled moved prior to the intervention. Three dropped out after enrollment, reducing the total to 313. Of the 313, 12.2% were Caucasian, 8.6% were African American (served by Caucasian navigator), 45.4% were Latina, and 33.9% were Native American. The women ranged in age (at enrollment) from 40 to 85 years (mean, 52.9±9.3). The mean ages of Caucasian, African American, Latina, and Native American women were 52.8, 55.4, 50.4, and 55.6, respectively, and there was no statistically significant difference by race/ethnic group ($p<0.05$).

One half of the study population changed their address every 18 months. Some stayed within the Denver Metropolitan Area, but more than half relocated to Mexico or their home Indian Reservation. In addition, during the study, the programs that allowed unauthorized Latinas to obtain health care services were no longer allowed to provide services to people who did not possess an immigration card (legal policy change in 2005). As a result, only 113 women received the intervention and follow-up survey. Follow-up information on mammogram status was attempted through medical record review. However, the medical records' accuracy were still insufficient as the records were more than 6 months behind on having information uploaded, the study staff was unable to use medical records (<10% of the medical records reviewed for the follow-up were accurate). Therefore, the follow-up surveys included self-reported information. Of the 113, 62 (55%) had a rescreening mammogram based on self-reported information ($p<0.000$; Table 1).

Statistically significant associations were found between having received the intervention and reporting a rescreening mammogram for all racial/ethnic groups ($p<0.05$). These results suggest that the navigator intervention was effective in increasing adherence to recommendations for rescreening mammograms across the four racial/ethnic groups included.

The study team also investigated the influence of provider recommendation on mammograms in light of the intervention. Overall, more than half (61%) of the participants reported that their health care provider had recommended that they have a mammogram. Interestingly, of the women NOT receiving such a recommendation, all who received the intervention DID have a mammogram. Thus, it appears that the intervention may help to support women in obtaining mammograms even in the absence of a provider recommendation.

About 12% of repeat mammograms were abnormal, and all but two had recommendations for follow-up and included assistance by the navigator. Follow-up recommendations included repeat mammogram (43%), ultrasound (7%), biopsy (27%), lumpectomy (10%), and other (13%).

Discussion

More than half (61%) of the women in the intervention group reported that their provider recommended a mammogram and, of those, over half (52%) had a repeat mammogram. Thus, the provider recommendation is important, which is consistent with other literature. However, these provider referrals were primarily from the ESJH study site. Both the Native Americans and Latinas had issues with rarely having the same provider from one year to the next. This lack of consistency resulted in the Native American and Latina women being less influenced by a provider referral for mammography screening.

The project team from the three community settings organized a community event to share the preliminary study findings. The event included a health fair coordinated by Denver Health and Hospitals, dancing by American Indian youth hip hop, and healthy Latina food (provided through separate donation by ESJH). Preliminary findings were shared through a short Power Point® explanation and a handout in both English and Spanish.

Medical records from each of the clinical settings were identified that met the research criteria of medically underserved, uninsured or underinsured, and lack of participation in breast health screening within the previous 18 months. However, all three sites had issues primarily with (1) racial and ethnic misclassification or missing information and (2) delayed updating of medical information. After repeatedly trying to correct the information in the records, eventually almost all records were reviewed that indicated any relevance to the patient being underserved (e.g., no insurance) and the woman being at least 40 years of age. Thus, records review is typically considered a “gold standard” but it was insufficient for the MUP study.

At the time of grant submission, there were four breast health screening programs that worked with the three MUP and four clinical facilities that provided treatment to women in the Greater Denver Metropolitan Area. By the time this study was awarded, there were only two screening programs that targeted the MUP communities and only one facility (ESJH) that provided free breast cancer treatment to the uninsured and underinsured. The screening programs experienced a series of problems with the mammography equipment, resulting in several screening days cancelations, primarily for the American Indian population, but also affecting the Latinas. For those women diagnosed with breast cancer, the navigators worked with ESJH, but also continued to work with other clinical facilities to avoid overburdening ESJH. This required many hours of negotiation on a one-on-one basis.

HIPAA training was required for all navigators. Because the NACR and LCT navigators primarily worked with four health care facilities, they completed up to four HIPAA trainings. This was challenging, but was necessary because each health care facility required their own education and would not accept HIPAA training from another Denver facility. In addition, the medically underserved patients sometimes were referred to clinical settings that were rarely used by other study participants. For those clinical settings, the patients authorized the navigators’ access to their private information via individualized HIPAA privacy approval protocols specific to each facility. Overall, none of the patients refused navigators access to any private information and almost all of the patients were enthusiastic that the navigators would help explain the information or explanations of their providers.

Several protocols that previously allowed Latinas to obtain medical assistance regardless of legal documentation were revised during the study. LCT specializes in providing care to Latinas regardless of insurance or documentation. These changes provided several challenges for those working with undocumented patients. Some were referred back to Mexico to obtain their care. The navigators either continued to track their access to care

directly through long-distance phone calls or through contact with family members in the US.

During the 5-year study, LCT had four executive and/or acting directors. This change in leadership required a great deal of re-education about the project. Additionally, the navigators at La Clínica also changed a few months following the introduction of a new director, requiring a great deal of peer education and repetition of training modules. All navigators were dedicated and efficient. The repetition of the trainings helped the administrative staff begin to videotape *most* of the trainings so that the new personnel could view the videos and then the MUP staff would update and help improve the skills required for the intervention. There was no staff turnover in the other settings.

Conclusions

It seems that access to breast health screening would be easy to obtain due to the Centers for Disease Control and Prevention's Breast and Cervical Cancer Early Education Programs which are supported in all 50 states and in 14 of the 565 federally recognized tribal nations. In addition, the Susan G. Komen for the Cure® provides screening for women who fall through the cracks. Yet, throughout this project, the study team, particularly those working with Native Americans and Latinas, experienced many problems in being able to schedule screening and adhere to the preplanned schedule. In 1 year, NACR had three out of four screenings canceled, two of these due to the equipment repair needs. However, NACR was not able to get on the schedule to "make up" those dates once the mammography equipment was repaired or replaced. All three organizations referred women for screenings to the other partners' screening dates and this helped address the challenges of inconsistent access. However, this required that NACR navigators be present for the LCT and ESJH screenings and LCT navigators were present for the NACR and ESJH screenings. ESJH did not have this issue.

As has been documented in other breast health programs [13, 14], consistent and supportive health administration within the organization is essential. The numerous changes in executive director and navigators from LCT required additional time and effort to keep the project moving forward. Luckily, each executive director was supportive and the program would not have been successful without their help. There were a total of four navigators from LCT and each was effective and enthusiastic about her role. The navigators from ESJH and NACR also were supportive and shared the peer education the new navigators required to help keep the project on track.

We feel that this study has important implications for working with underserved groups. Trained navigators seem to have a positive impact in communities that suffer from a lack of consistency in their health care system.

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Table 1

Rescreening mammogram based on self-reported information

		<u>Had mammogram</u>		<u>Total</u>
		<u>Yes</u>	<u>No</u>	
Had intervention	No	3	197	200
	Yes	62	51	113
Total		65	248	313