PATIENT NAVIGATION PILOT PROJECT: RESULTS FROM THE COMMUNITY HEALTH ADVISORS IN ACTION PROGRAM (CHAAP)

Mona Fouad, MD, MPH; Theresa Wynn, PhD;
Michelle Martin, PhD; Edward Partridge, MD

To facilitate access to care and to ensure adherence to diagnostic follow-up of positive breast cancer screening or prescribed treatment for confirmed cancer, community volunteers were used as patient navigators (PNs) for a population of low-income, medically underserved women, primarily African Americans. Partnerships were established with local healthcare facilities, residents from the targeted areas were hired as county coordinators, and community volunteers were trained to serve as PNs. Patients who had a suspicious mammogram or confirmed diagnosis of breast cancer were recruited from 23 Alabama counties. For these patients, barriers to diagnostic follow-up or treatment were identified by PNs, who assisted in overcoming these barriers by referring patients to appropriate treatment facilities, guiding them through the healthcare system, and providing the necessary logistical, social, or emotional support. With this intervention, patients kept 93% of their appointments. Thus, for medically underserved patients with breast cancer or a suspicious mammogram, intervention by a network of community volunteers serving as PNs improves adherence to follow-up diagnostic procedures and treatment. PNs can help close the gap between development and delivery of cancer treatments to those who are medically underserved. (*Ethn Dis.* 2010;20:155–161)

Key Words: Patient Navigation, Community Volunteers, African Americans

From Division of Preventive Medicine, Department of Medicine, University of Alabama at Birmingham.

Address correspondence to Mona Fouad, MD; Division of Preventive Medicine; University of Alabama at Birmingham; 1717 11th Avenue South, MT 620; Birmingham, AL 35205; 205-934-4307; 205-934-7959 (fax); mfouad@uab.edu

INTRODUCTION

Breast cancer is the most common cancer in African American women. Although African American women have a lower breast cancer incidence rate compared to White women (118 vs. 134/100,000), their mortality is higher (34.3 vs. 25.3/100,000).[1] There are numerous possible explanations for this racial disparity, including stage at diagnosis, health care–seeking patterns, biological and genetic factors, and difficulties in adherence to complex therapeutic regimens. Furthermore, cancer survival outcomes are influenced by socioeconomic status, with those most economically disadvantaged surviving for shorter periods of time.[2]

Access to health services and adherence to diagnostic follow-up and prescribed treatment increase the chance of survival. Non-White women are less likely to adhere to recommendations for diagnostic follow-up.[3,4] In an evaluation of women with early-stage breast cancer, it was found that 31% of African Americans terminated their chemotherapy prematurely; the corresponding value for whites was 23%.[5] Early termination was associated both with African American race and poorer survival. Altogether, 60% of White women and 40% of African American women received complete treatment, and only 30% of all patients received complete treatment without any delay. These findings support the conclusion that adherence to prescribed treatment would reduce overall mortality and would be more cost-effective than enhancement of screening programs.[6]

This article reports on the outcomes of a community-based navigation approach to increase adherence to follow-up and treatment.

This article reports on the outcomes of a community-based navigation approach to increase adherence to follow-up and treatment. The project, Community Health Advisors in Action Program (CHAAP), utilized community volunteers trained as patient navigators (PNs) to assist low-income, medically underserved women, primarily African Americans, by facilitating access to care so they complete diagnostic follow-up to positive breast cancer screening or adhere to treatment of confirmed cancer. The hypothesis was that community volunteers trained as PNs for a population of underserved women could provide an appropriate level of assistance to ensure adherence to follow-up or treatment.

Specifically, the project recruited and trained PNs to: a) identify sources of health care in the community; b) link patients with a healthcare provider for diagnostic follow-up or treatment; c) guide patients through the healthcare system by reviewing their benefits, helping them complete paperwork and schedule appointments, and explaining the diagnostic or treatment processes; and d) assess patients' needs, identify barriers to follow-up or treatment, and find ways to overcome these barriers.

METHODS

The CHAAP Model

The CHAAP study, which was developed and implemented by program staff at the University of Alabama at Birmingham (UAB), was approved by the Institutional Review Board of UAB. Volunteers from the target communities were recruited and trained to serve as PNs. One community volunteer in each of the four counties was trained and hired as a coordinator to facilitate and monitor the work of the PNs.

Target Population

Initially, CHAAP was developed for low-income women, primarily African Americans, residing in four Alabama counties: two rural (Dallas and Sumter, with poverty rates of 34.9% and 36.6%, respectively) and two urban (Montgomery and Jefferson, with poverty rates of 17.4% and 15.7%, respectively).[7] The project subsequently expanded to 19 surrounding counties, thus serving 23 Alabama counties.

Inclusion Criteria

A goal of the project was to recruit PNs who were demographically similar to patients in the target communities, knowledgeable about community resources, willing to help community members, and were residents of one of the target counties, with access to reliable transportation. Patients were required to reside in or near one of the target counties, have a suspicious mammogram with recommendation for diagnostic follow-up or a diagnosis of breast cancer, aged $\geq$19 years, and consent to participate in the study.

Identification and Recruitment of PNs

Patient navigators were identified through two community-based outreach programs that used volunteers trained as community health advisors (CHAs): the Alabama REACH 2010 Coalition, funded by the Centers for Disease Control and Prevention to reduce the racial disparities in breast and cervical cancer screening,[8] and the Deep South Network for Cancer Control, funded by the National Cancer Institute (NCI) to build infrastructure for enhancing the participation of African Americans in breast and cervical cancer screening.[9] Other recruitment sources were community activists and grassroots organizations helping African American cancer patients. Volunteers were required to: a) accept at least a one-year commitment to the study; b) attend eight weekly training sessions of two hours each; c) attend monthly meetings to discuss their activities; and d) maintain contact with their assigned patients as needed.

The patient population was identified mostly through the Alabama Breast and Cervical Cancer Early Detection Program (ABCCEDP), which provides qualified women with full healthcare benefits at no cost or for a nominal co-payment.[10] Other sources for patient recruitment included primary care centers, county hospitals, Alabama Health Department clinics, and mammography facilities. Secondary methods involved word-of-mouth communication and flier distribution.

Curriculum Development

The CHAAP staff developed two manuals: one for training of program staff and county coordinators and one for training of PNs. Cicatelli Associates, Inc. (New York, NY) assisted with the development of the training curriculum. It provided training to CHAAP investigators on dealing with psychological, communication, and social issues that impact access to health care by low-income and minority patients.

Oncologists and other medical specialists were consulted in developing the disease-specific component of the curriculum. The content related to coping with cancer was developed with the help of psychologists. The skill-building section was developed based on our previous experience with training of CHAs.

Training

Program staff and county coordinators were trained in a two-day session. Training included an explanation of the consent process, the roles of staff and county coordinators, levels of patient navigation, approaches for assessing patient needs and overcoming barriers, policies and procedures including documentation of intervention assistance, and pre- and post-training questionnaires.

The training curriculum for PNs is outlined in Table 1. The initial training occurred in eight weekly sessions of two hours each, covering the subjects listed in Table 2. The core component focused on teaching PNs to assess needs and gather information, record the information in a notebook, make appropriate referrals for follow-up and treatment, communicate effectively with patients and service providers, motivate patients, assist in finding solutions to problems, provide peer counseling to address fear, encourage positive coping strategies, recognize the signs of depression, and offer information, reassurance, companionship, and sympathetic listening. PNs were also taught to understand the limitations of the navigation intervention and the boundaries between personal values and the work as a PN.

The disease-specific component provided basic information on breast cancer risks, screening, and treatment. Topics included steps of diagnosis, stages of breast cancer, treatment options, side effects, alternative treatments, and methods for coping with cancer. The training covered culture-specific characteristics of minority and low-income women, behavioral factors associated with breast cancer diagnostic follow-up and treatment options, and adherence to recommendations.

The case-management component included topics such as partnering with health and social agencies, basic communication skills, assessment of patient needs, procedures in making patient referrals, questions to ask during a visit with the healthcare provider, levels of intervention, and development of skills necessary to guide patients through the

Table 1. Training curriculum for patient navigators

Component	Subjects
Core	The roles and limitations of PNs in their community Self-empowerment Skill building
Disease-specific	Breast cancer risk Breast cancer screening Breast cancer treatment
Case-management	Navigating the healthcare system Identifying community and system resources Recording information Helping patients overcome barriers

treatment process. Further, PNs received training on values clarification, separation of values from behavior, and the difference between personal and professional values. Case studies and role plays were used to help PNs recognize their personal biases and analyze how these may impact their roles as helpers.

After completion of the training phase in each county, a graduation ceremony attended by county officials, health administrators, media representatives, cancer survivors, and family members recognized the PNs and acknowledged their new role in the community. All PNs received a certificate signed by a community leader and a $50 gift card.

Following the initial training, the PNs met monthly for maintenance training. In these meetings, team members discussed their progress and the implementation of techniques learned during the initial training and addressed newly developing issues in case management. The PNs were compensated $25 each month and received a $10 gift card for attendance of monthly meetings.

Implementation of the Program

The CHAAP staff established partnerships with six major healthcare networks and facilities in the four target counties. CHAAP investigators met with healthcare providers who were associated with county hospitals and state and local screening programs in the target areas to present the CHAAP program and request cooperation with it. Initially, patients were recruited mainly through referral from these healthcare organizations and facilities, where newly diagnosed cancer patients or patients with a suspicious mammogram were informed about CHAAP and provided with the telephone number of the county coordinator. After the program was established, patients were also recruited through word-of-mouth and community channels.

When a patient contacted the county coordinator, the coordinator explained the program and conducted a brief interview to determine the patient's eligibility. The coordinator identified a convenient time and place to obtain the patient's consent and to enroll her into the program. After written consent was obtained, the patient was matched with an appropriate PN. The assigned PN met with the patient to establish rapport, conduct a standardized needs assessment, and identify barriers to follow-up or treatment. The needs assessment included questions about:possible awareness issues; problems in dealing with the healthcare system; transportation problems; financial, social, and emotional issues; beliefs and attitudes that might hinder follow-up or treatment; and available resources.

The PNs assisted patients in overcoming these barriers by gathering information, making referrals to community and system resources, and providing logistical, emotional, and social support. The navigation intervention involved one or more of three levels.

Level 1, Referrers

Patient navigators referred women who had not followed their physician's recommendation for follow-up or treatment to an appropriate physician or treatment facility. The PNs were given a list of providers and facilities that were in partnership with the ABCCEDP.

Level 2, Navigators

Patient navigators guided women through the healthcare system by linking them with physicians or facilities,

Table 2. Training of patient navigators

Training Session	Subjects
Week 1	Project overview Training pretest
Week 2	Breast cancer review Introduction to navigation interventions The Belmont Report and patient confidentiality
Week 3	Intervention level I: referral Intervention level II: health-system navigation
Week 4	Values clarification Communication skill building
Week 5	Assessing patient needs Intervention level III: case management
Week 6	Addressing barriers to diagnostic follow-up and treatment Documenting the intervention process
Week 7	Coping with and adjustment to cancer Policies and procedures
Week 8	Resource cultivation Training posttest/training evaluation

Table 3. Selected demographic characteristics of patients

Race	
African American	91.6%
White	7.7%
Hispanic	.7%
Marital status	
Never married	29%
Married	24%
Divorced/separated	32%
Widowed	15%
Education	
College	7%
Vocational/some college	41%
High school	31%
Less than high school	21%
Total household income	
<$10,000	74%
$11,000–$20,000	19%
$21,000–$30,000	5%
>$31,000	2%
Employment	
Unemployed	77%
Full-time	16%
Part-time	6%
Self-employed	1%
Insurance	
None	21%
Medicare/Medicaid/SSI	27%
BlueCross/BlueShield	16%
Other	26%

reviewing their benefits, and helping them complete the necessary paperwork.

Level 3, Case Managers

This level represented the most intensive intervention. PNs identified barriers to diagnostic follow-up and treatment, found solutions to these barriers, and provided women with peer social and emotional support.

RESULTS

Training of PNs

Four residents from the target areas were hired to serve as county coordinators. Of 62 community volunteers who applied to serve as PNs, 55 were eligible. After their consent was obtained, all of them were trained. Of the trained PNs, 23 navigated patients; 24 participated in other ways, such as organizing health fairs and awareness events; and 8 did not become active.

All PNs were African Americans, aged 20 to 70 years; with the exception of one male, all were women. Forty-one percent had a college or university education, 24% had a vocational or technical education, and 17% had a high-school education or GED. Seventy-eight percent had previous CHA training, 74% had previously helped someone deal with cancer, and 15% were breast cancer survivors.

Only 42% of the volunteers who were trained as PNs actually navigated patients. There was no association between the demographic data collected in the study and whether or not the trained volunteer navigated patients.

Enrolled as patients were 147 women with breast cancer or positive mammogram screening. Of these, 63% had a confirmed diagnosis of breast cancer. Selected demographic characteristics of the patients are found in Table 3.

Barriers to Cancer-care Access

The standardized needs assessment of patients revealed barriers to follow-up and treatment (Figure 1). Of patients with awareness-related barriers, 27% ($n=29$) needed more information about breast cancer, 26% ($n=28$) needed to know how to get help, and 19% ($n=20$) needed written information that was easily understood. Of those with emotional barriers, 17% ($n=17$) needed to feel good about the way they looked, 16% ($n=16$) needed reassurance about surviving breast cancer, and 13% ($n=13$) needed coping strategies to deal with the cancer.

Most prominent among the barriers related to the healthcare system was the need for help with filling out forms and understanding written information (26%, $n=23$). Next, 16% ($n=14$) needed guidance through screening and treatment, and 15% ($n=13$) needed help keeping up with appointments.

Of the patients with financial barriers, 47% ($n=37$) needed to know more about Medicare/Medicaid benefits. Of those with social barriers, 34% ($n=26$) needed help linking with a breast cancer support group, and 22% ($n=17$) needed to connect with a breast cancer survivor.

In addition to the barriers reported by patients on the standardized needs assessment form, barriers faced by patients during the navigation intervention were recorded by PNs on follow-up forms. Of all intervention activities of the PNs, 29% were devoted to addressing financial barriers and 28% to transportation barriers.

Barriers were overcome by an intervention tailored to the needs of each patient and implemented on one or more of three levels: referral, navigation, and case management. Intervention examples are provided below.

Level 1, Referral

Patient SU00-B was a 47-year-old divorced, unemployed, and uninsured

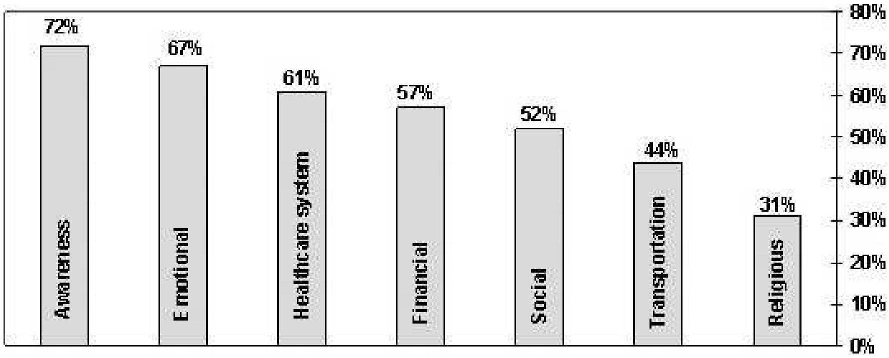

Fig 1. Barriers reported at needs assessment

African American woman with four children. The PN identified as barriers lack of insurance, limited knowledge about breast cancer, and financial difficulties. The PN referred the patient to ABCCEDP, and she received treatment at the local cancer center. Other agencies used were the Cancer Information Services, a program of the NCI, for educational materials on breast cancer and the Angel Squad, a cancer survivors support group, for gasoline cards.

Level 2, Navigation

Patient JN04-A identified transportation, lack of insurance, difficulty understanding physician's findings, and lack of food as barriers to continued radiation treatment. The PN secured emergency transportation through Max VIP, a paratransit service; helped the patient apply for Medicaid; and made arrangements with the Urban Ministry, an inner-city mission serving the poor, to help the patient with food, utilities, and medication.

Level 2, Navigation

Patient JN01-B was an uninsured 70-year-old African American diagnosed with stage II breast cancer. The patient expressed concerns about finding transportation and paying for gas. The PN personally transported the patient to appointments until assistance was obtained from the Travelers Aid Society.

Level 3, Case Management

Patient JN05-A was a 58-year-old divorced and underinsured African American mother of three children. Barriers were financial difficulties, paying for gas and obtaining medical supplies to treat an infection. The PN arranged help from the American Cancer Society for medical supplies and from the Avon Cares Program for Medically Underserved Women for travel vouchers. The PN also accompanied the patient to appointments to provide emotional support during chemotherapy treatments.

Adherence

Based on the PN logs, of 1,384 scheduled appointments PNs successfully helped patients keep 1,286 appointments, resulting in an adherence rate of 93% (Table 4). Adherence outcomes by county are shown in Table 4 as well.

DISCUSSION

After developing the curriculum to train program staff and volunteer PNs, CHAAP personnel recruited and trained community volunteers who, acting as referrers, navigators, and case managers, helped breast cancer patients from 23 Alabama counties overcome barriers to diagnostic follow-up and prescribed treatment. Not all of those trained served as PNs; future studies could identify factors that predict success as a PN.

The program achieved an average adherence rate of 93%, with rates in three of the four counties >95%. Adherence rates to diagnostic follow-up after an abnormal mammogram are between 50%[3] and 81%.[4] One report indicates that 9% of women with abnormal mammograms do not perform any diagnostic follow-up.[11] Similarly, another publication shows that 8.6% of women with abnormal mammograms do not receive any follow-up care, and an additional 29.4% receive inadequate care (do not initiate follow-up in a timely manner or do not complete all recommended procedures).[12]

Since the mid-1990s, patient navigation has been used to improve diagnostic follow-up and treatment for cancer among medically underserved populations. Randomized trials have been conducted to test the effectiveness of patient navigation.[13,14] The adherence rates achieved by CHAAP were very high, which can be attributed to the unique design of the intervention. Typically, PN programs utilize as navigators clinic-based professional or lay personnel.[15,16] These individuals are employed to assist patients who have contacted the healthcare provider for diagnostic follow-up after a suspicious mammogram or a diagnosis of breast cancer. The navigators play a reactive role by dealing with problems as they arise. In contrast, CHAAP utilized community-based volunteers, who proactively recruited patients and helped them overcome barriers to seeking medical care.

Unlike typical navigators, the PNs of CHAAP were located in the community and followed the women through the entire cycle of care, navigating the patients from their homes and communities into the healthcare system and then back. By linking the community with the healthcare system, CHAAP addressed both the community

Table 4. Adherence outcomes by county

County	Number of patients	Appointments						
		Scheduled	Attended		Not attended		Unknown	
Dallas and surrounds	21	181	179	98.9%	1	0.6%	1	0.6%
Jefferson and surrounds	81	514	444	86.4%	24	4.7%	46	9.0%
Montgomery and surrounds	31	438	424	96.8%	10	2.3%	4	0.9%
Sumter and surrounds	14	251	239	95.2%	8	3.2%	4	1.6%
Total	147	1,384	1,286	92.9%	43	3.1%	55	4%

and the systemic barriers that prevented these patients from receiving adequate care.

In this intervention, county coordinators were generally community-based volunteers. In the only instance in which the county coordinator was not a community-based volunteer but a member of the program staff (Jefferson County), the adherence rate was lower (86%) relative to the other counties (95% to 99%). Although other factors may have contributed to this lower adherence, the results suggest that a county coordinator from the community who shares the same demographic and cultural background with PNs and patients may be more successful in implementing the program than an outside staff member.

The CHAAP program was devised on the premise that, in each community, informal leaders are recognized as a reliable source of advice, help, and referrals. The program recruited these volunteers to participate in training designed to increase their knowledge about breast cancer, enhance their leadership skills, and build linkages with local service providers and community leaders. The PNs were comfortable within their neighborhood and cultural environment and were familiar with the traditional and nontraditional resources in their communities. They shared a background of being a volunteer who can motivate people and is eager to offer peer support. "As a patient navigator," wrote one volunteer, "I have learned that every day you should reach out and touch someone. Cancer patients love the human touch—holding hands, a warm hug, an encouraging smile, or just a friendly pat on the back."

The training program enabled PNs to work across multiple healthcare systems, both rural and urban, and not only in a single hospital, as practiced in most of the existing patient navigation interventions. Further, the coordination with the ABCCEDP, as well as the fact that CHAAP was built upon existing community infrastructure developed through our previous work, contributed to its success. Within two years, the program expanded from the original four counties to 19 neighboring counties, and this rapid growth is evidence of its effectiveness. Because of the community-based design of CHAAP, patient satisfaction with the program was very high and can be summed up in the following quote: "I know that God smiles at people like you who help people like me. CHAAP is a wonderful program with extremely excellent people! With my deepest appreciation for all you and others of CHAAP do, thank you!"

Patient navigation in an urban environment may be more difficult than in rural areas due to problems obtaining appointments in busy urban clinics, a more complex healthcare system and infrastructure, and a higher percentage of patients who reside in neighboring counties but commute to the urban county for medical care. The impact of setting should be investigated to develop more effective interventions. The cooperation and support of local healthcare providers and the use of their facilities and screening programs are essential.

The present study has limitations inherent to its design. For example, the protocol did not include abstraction of medical records or review of patient charts. The appointment data were gathered exclusively from PN logs and were not verified by medical records. Randomization was not appropriate due to familiarity between patients and PNs, who lived in the same community. Because the study design did not include a comparison or control group, the extent to which members of this population may have kept their appointments without an intervention is unknown. However, in view of the barriers present in this population, it is apparent that patients would have had difficulty adhering to their appointments without the assistance of CHAAP.

Although PN programs typically seek to reduce the time between diagnosis and completion of treatment,[15,16] CHAAP was primarily concerned with adherence to treatment and did not measure the time within which treatment was completed. Further research is needed to evaluate the cost-effectiveness of community PN interventions and to investigate factors determining the success of such programs.

Experience with the CHAAP program demonstrates that a sustainable infrastructure of community volunteers and resources can be established for medically underserved breast cancer patients facing barriers to health care. It confirms that community peer-navigation interventions improve adherence to diagnostic follow-up and treatment.

Patient navigators, operating under programs such as CHAAP, can help close the gap between development and delivery of cancer treatments to those who are medically underserved.

Patient navigators, operating under programs such as CHAAP, can help close the gap between development and delivery of cancer treatments to those who are medically underserved. Physicians should take advantage of such programs to assure optimum diagnosis and treatment for all of their patients.

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AUTHOR CONTRIBUTIONS

Concept and design of study: Fouad, Wynn, Martin, Partridge
Acquisition of data: Wynn, Martin
Data analysis and interpretation: Fouad, Martin, Partridge
Manuscript draft: Fouad, Martin, Partridge
Obtaining funding: Fouad, Martin
Administrative, technical, or material assistance: Wynn
Supervision: Fouad, Wynn, Partridge