A Nurse-Delivered Intervention to Reduce Barriers to Breast and Cervical Cancer Screening in Chicago Inner City Clinics

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Synopsis

An 18-month intervention was implemented to increase breast and cervical cancer screening among poor African-American women in Chicago. Breast and cervical cancer screening programs were set up in two public clinics, one community-based and the other hospital-based. Nurse clinicians and public health workers were used in these programs to recruit women in the clinics and in targeted community institutions to receive free breast and cervical cancer screening. The following barriers were specifically addressed by the intervention: accessibility of screening, knowledge about breast and cervical cancers, access to followup screening examinations, and access to treatment. A computerized followup system was specifically designed to track patients.

During the 18 months of the intervention, 10,829 visits were made by 7,654 low-income women. A total of 84 cases of breast cancer and 9 cases of cervical cancer were detected.

Awareness of the program, as measured by a survey after the completion of the intervention, increased in both clinics compared with baseline results. Knowledge about breast and cervical cancers also increased, as measured by scores on tests given before and after a class on breast and cervical cancers. Followup rates were 86 percent for women attending the programs. More than 90 percent of the women referred for evaluation of breast abnormalities kept an appointment.

In summary, the intervention was successful in reducing barriers to breast and cervical cancer detection and in attracting a high-risk group of women.

LT IS WELL KNOWN that minority women are more likely to present with advanced stage breast and cervical cancers and are less likely to survive from these diseases than are white women (1,2). There is a subset of minority women, those attending public health facilities, who have breast and cervical cancer survival rates that are even lower than national norms (3,4). Contributing to these decreased survival rates are numerous barriers that prevent low-income minority women from obtaining appropriate screening and treatment for breast and cervical cancers.

Although there is substantial discussion about the need for increased breast and cervical cancer screening among poor African American women, there have been few interventions designed to identify and overcome certain barriers to screening.

Cost is one potential barrier that prevents women from receiving appropriate cancer screening. For example, screening mammography examinations are expensive (5,6) and thus out of the reach of many poor women. Lack of awareness of or access to screening examinations is another barrier. In publicly funded health settings, cancer screening services are not always available, or women may not be aware of where to get such services (7).

There are also barriers to followup and treatment that prevent women from obtaining screening and

returning for needed followup examinations at recommended intervals. When a woman presents with an abnormality, linkage with diagnostic and treatment facilities may not be available or, if available, may not be timely (7,8). Finally, it may be difficult to contact women attending public clinics for followup because of many factors associated with poverty and urban living.

In 1983, in response to low screening rates for breast cancer and high proportions of late stage breast cancer at Cook County Hospital in Chicago. a breast cancer detection program was initiated at that institution (7). Subsequently, in 1986, a consortium, including Cook County Hospital (CCH), the Chicago Department of Health (CDOH), and the University of Illinois School of Public Health was awarded a National Cancer Institute contract to expand and evaluate this program at Cook County Hospital and to initiate a similar program within a community-based public health center. A community outreach component was also developed to raise community awareness, provide education, and recruit women into the community-based screening program (9).

The program, which included screening for cervical cancer as well as breast cancer, was designed to overcome a number of barriers identified by the investigators as contributing to the late detection and treatment for breast and cervical cancers among low-income African American women attending Chicago public clinics (δ). We will describe the clinic-based interventions and the barriers to screening that these interventions addressed.

Methods

The Breast and Cervical Cancer Screening Program was set up at two sites—a CDOH neighborhood health center and a CCH primary care clinic. At CCH, these services expanded the existing breast screening program, located in the largest primary care clinic in the hospital complex. At the community based CDOH center, on the southside of Chicago, this expansion represented a new program. At both sites these were freestanding programs that were housed within existing medical clinics serving low-income women. Screening services for breast and cervical cancer began in June 1989.

The intervention involved client recruitment and education, physical examination, including Papanicolaou (Pap) smear and mammography where indicated. It also involved the tracking of women using a computerized data base developed specifically for the purpose of this intervention. A significant infrastructure existed to support the intervention. CCH and CDOH already provided free mammographic services for women. All necessary diagnostic and treatment services were likewise provided at CCH. Radiology technicians from the CDOH were trained by the Department of Radiology at CCH which also provided second readings of abnormal mammograms from the CDOH.

To implement the intervention, culturally sensitive nurses were recruited and trained onsite for 12 weeks. The curriculum included cancer control theory and breast and cervical cancer screening examination techniques; public health strategies to reach the community with a health promotion intervention; and lastly, information on social support and adult education stategies emphasizing women's health issues.

The nurses all had prior experience in a public health care setting and had familiarity with populations of women similar to those whom the intervention was designed to reach. Clinical supervision was provided, and nurse clinical competence was assessed by observation and written examination. In all, seven nurse clinicians, two public health nurses, and two public health advocates received some or all aspects of the training, depending on their ultimate duties.

A quality assurance program was developed to assure high-quality screening. Each nurse had clinical evaluations every 6 months by the nurse administrator and physician coordinators of the program as to the adequacy of their screening techniques. All normal mammograms and Pap smear reports were routinely reviewed by the nurse coordinators and, when necessary, by the physician coordinators. All patients with abnormal tests were referred for consultation as required, and all abnormal mammograms received a second review by an experienced breast specialist. All women with significantly abnormal Pap smears were referred for colposcopy.

The CDOH laboratory processed all the CDOH Pap smears. The CCH laboratory processed all the CCH Pap smears. A one-time joint blind reading of 100 abnormal Pap smears from each institution by the other institution's laboratory yielded a 96-percent concordance rate for the specific abnormality.

Each experimental clinic had a corresponding nonintervention control clinic where no such screening program was located, although these control clinics could refer clients if they desired. Similarly, the community outreach component specifically targeted designated experimental commu-

Classroom Survey Instrument (Requires true or false answers)

1. Women who have had multiple sexual partners increase their risk of cervical cancer.

2. Bumping or bruising your breasts can cause breast cancer.

3. Shortness of breath is not a warning sign for breast cancer.

4. A chest X-ray can not help discover breast cancer early.

5. Women over 40 should have a breast exam about once every 3 years.

6. All women, regardless of age, should have an annual mammogram.

7. All women, regardless of age, should have an annual Pap smear.

8. Diets high in fat may increase a woman's risk for breast cancer.

9. If you have a lump in your breast, it is likely to be cancer.

10. Pain is usually an symptom of early breast cancer.

11. Pain in both breasts which comes and goes is normal for women even after menopause.

12. An experienced physician can diagnose breast cancer by feeling a lump.

13. When you are examining your breasts, you should always use the palms of your hands.

nity areas, and there were corresponding nonintervention control communities. The experimental design has been described in detail elsewhere (9).

Women were eligible for breast examinations and Pap smears if they were ages 20 or older. Mammograms were offered yearly to women ages 40 and older. The National Cancer Institute's guidelines for breast and cervical screening were followed (10). Because the intervention continued for 18 months at most, women could get two screens. Symptomatic women were included in the program. For the purposes of this study, their test results were included with other screening results.

The intervention was designed to address four barriers to breast and cervical cancer detection that the authors had identified (in previous experience and research) as preventing low-income women attending public institutions and living in lowincome communities from receiving adequate screening. These were accessibility (which included cost and awareness), knowledge about screening, followup, and access to treatment.

Accessibility. Two components of accessibility were addressed by the intervention—cost and awareness.

The cost barrier was removed when all screening and followup services were free. Lack of awareness was overcome by active recruitment efforts within the experimental clinics and outreach efforts into the experimental communities.

Women were recruited to come for screening examinations by the program nurses. At the hospital site, recruitment took place in the general medicine clinic and a group of medical subspecialty clinics. Women were approached by a program nurse while they were sitting in the waiting area before a scheduled appointment with the physician. The nurse briefly explained the program and the importance of screening. The women were then invited to attend the program and, if interested, were given an appointment to come in for screening on their next clinic appointment day. Additionally, women's friends, relatives, and physicians were another referral source.

At the community-based clinic site, the community outreach effort was an additional source of referrals. Public health workers in the program visited such institutions and facilites in the community as churches, beauty parlors, laundromats, businesses, libraries, and community agencies to recruit women for the program.

Randomized surveys of knowledge, attitudes, and practice were performed before and after the intervention in all the clinic and community sites. Among the questions asked were those specifically about women's awareness of the screening programs.

Knowledge. Upon entering the program, women were asked to attend a 20-minute class on breast and cervical cancer screening given by the nurses who used a scripted outline. During this session, the importance of breast and cervical cancer screening was explained, and the women were taught breast self-examination. A pre- and post-class determination of the clients' knowledge was conducted on a sample of 450 (227 at CCH and 223 at CDOH) participants by a program nurse using a 13-item questionnaire (see box).

After the class, a client screening history was taken that included questions about demographics, outreach, risk factors, previous cancer screening, and symptomatology. Breast or cervical cancer screening examinations, or both, were performed by the nurse clinicians immediately after the class. If a clinical abnormality was detected on the initial examination, the client was given an appointment for a consultation by a physician, and diagnostic tests were performed as indicated. If no abnormality was present, the client was scheduled to return for routine screening (as determined by the ageappropriate guidelines) in the future. She was also scheduled for a mammogram when indicated and told that she would be notified if there were any abnormalities present.

Followup and treatment. A computerized management data base was developed specifically to support this intervention by ensuring adequate client tracking and followup. Demographic, risk factor, symptom, examination, consultation, and test results were included in this data base, which allowed us to track appointments, test results, outreach measures, and compliance over time. It also generated reminder letters 2 weeks before an upcoming appointment and letters to inform women of their test results.

The dates of all tests and appointments were stored so that each woman's screening history could be tracked through diagnosis and treatment. At the time of entry into the program, contact names, addresses, and telephone numbers were obtained to facilitate followup. Women with abnormal findings received reminder letters as well as telephone followup. The data base allowed the nurse and administrative staff members quick access to a patient record for checking test results or making appointments.

The letter reminder system linked client results with specific computer-generated letters that recommend specific followup. When women did not return for appointments for suspected abnormalities, they were sent a letter and telephoned. When clients required a breast or cervical biopsy, they were notified by letter, telephone, telegram or, when necessary, a home visit to ensure that the followup occurred. Second opinions were offered to all women with breast abnormalities requiring biopsies.

For clients requiring breast evaluation by a physician, the nurse clinicians accompanied them to the consultation and arranged for the biopsy when indicated. Women requiring followup for Pap smear abnormalities were given appointments with the gynecologist and received counselling about the importance of keeping that appointment. These women were not accompanied to that appointment by the nurse clinician because other staff duties prevented it.

Results

The demographic characteristics of the women

Table 1. Demographic characteristics of women attending the screening clinics at Cook County Hospital (CCH) and the Chicago Department of Health (CDOH); percentages by age¹ and race

Characteristic	ссн	CDOH
Age (years):		
Older than 40	81	70
Older than 60	36	25
Race:		
African American	80	99
Latino	14	
White	6	1

¹ Average ages were 53 at CCH and 49 at CDOH.

Table 2. Results of telephone survey of knowledge of the breast and cervical cancer screening program offered at Englewood Health Center and Cook County Hospital before and after intervention

Location	Sample size	Before (percent)	Sample size	After (percent)	P
Englewood health					
center:					
CDOH-E	192	46	152	72	0.001
CDOH_C	251	14	201	38	0.001
СМТҮ-Е	257	15	227	31	0.001
СМТҮ-С	184	17	276	24	0.05
Cook County hospital:					
CCH-E	317	61	292	69	0.05
ССН-С	292	55	179	57	NS
CMTY-E	280	19	284	26	0.05
CMTY-C	316	19	216	21	NS

NOTE: CDOH-E—Chicago Department of Health Experimental Clinic; CDOH-C—Chicago Department of Health Control Clinic; CMTY-E—Experimental Community Areas; CMTY-C—Control Community Areas; CCH-E - Cook County Hospital Experimental Clinic; CCH-C—Cook County Hospital Control Clinic. NS = Not significant.

attending the community (CDOH) and the hospitalbased (CCH) screenings over the first 18 months of the program are shown in table 1. The average age of women was 49 at the community clinic and 53 at the public hospital clinic. Seventy percent of the women at the community clinic site and 81 percent at the public hospital site were older than age 40; 25 percent at the community site and 35 percent at the hospital site were older than age 60. The overwhelming majority of women at both sites were African American (99 percent at the community clinic and 80 percent at the hospital). Of the women attending the screening program for the first time, 82 percent reported not having had a mammogram in the prior year. Moreover, 25 percent of the women reported not having had a Pap smear in the preceding 3 years.

The results of one aspect of a randomized telephone survey conducted in the control clinics and control community areas are shown in table 2.

Awareness regarding the presence of the cancer screening programs increased significantly at both of the experimental clinics and at one control clinic as measured by the post intervention surveys. For example, the proportion of women at the community experimental clinic (CDOH-E) who reported hearing about the community based screening program increased from 46 to 72 percent (P < 0.001). The proportion at the community control clinic (CDOH-C) also showed a significant increase from 14 to 38 percent (P < 0.001). At the same time, the proportion of women who were aware of the screening program at the hospital based experimental clinic (CCH-E) increased from 61 to 69 percent (P < 0.05) but there was no significant increase in awareness about the program as measured at the hospital based control clinic (CCH-C). Awareness of the community based screening clinic increased significantly in both the experimental (CMTY-E) and control (CMTY-C) communities. Awareness of the hospital-based program increased significantly only in the experimental community.

Average scores on the pre- and post-class 13-item questionnaire that was used to evaluate the effectiveness of the class experience increased significantly from 6.8 true out of 13 to 10.5 (P < .001) at the community clinic site and from 6.6 to 9.1 (P < .001) at the hospital based site.

Evaluation of one aspect of the computerized client tracking system is detailed in table 3. The proportion of women keeping appointments at the hospital-based screening clinic within 60 days of receiving computer generated reminder letters is reported by month. Of the 1,361 women who were sent a reminder letter, 86 percent actually visited the program.

Followup rates for women with suspected breast and cervical abnormalities were similar at both the community and the hospital clinic based screening sites, with about 90 percent of women with suspected breast abnormalities keeping appointments for further followup and almost 70 percent keeping appointments for suspected cervical dysplastic lesions.

The program results are presented in table 4. During the 18 months of the intervention, 10,829 visits were made for breast and cervical cancer screening by 7,654 women. There were 7,205 visits for breast screening and 3,624 visits for cervical screening. At the CDOH site, 4 percent of all mammmograms were abnormal; at the CCH site 11 percent were abnormal. At CDOH, 2 percent of all the Pap smears were abnormal; at CCH, 1 percent were abnormal. An additional 1,449 visits were made to evaluate 1,151 suspected breast and 298 cervical abnormalities. Breast biopsies were done on 305 women and cervical biopsies on 59. Eightyfour (28 percent) of the breast biopsies and nine (15 percent) of the cervical biopsies identified cancers.

Table 5 shows the American Joint Committee on Cancer (11) stage of breast cancers discovered during the project by clinic site. Stage was not available for five diagnosed breast cancers and were not included. Only 18 percent of the breast cancers detected in the 18-month intervention were Stage 0 or Stage 1. A breakdown of the staging by time period, however, showed that during the first 12 months of the intervention, 7 percent of the breast cancers were Stage 0 or Stage 1, and during the final 6 months of the intervention. 31 percent Stage 0 or Stage 1. Of the nine cervical cancers detected during the intervention, two were carcinoma in-situ, four were Stage 1, and one was Stage 3. The final staging for two patients with cervical cancer was not known.

The breast cancer detection rate per 100,000 population for this project was among the highest when compared with other breast cancer detection projects reported in the literature (12-20).

Study	Detection rate on first screen
Shapiro, 1971, NYC (HIP)	273
Gohagen, 1980, Columbia BCDDP	506
Canadian Study, 1986	520
Baker, 1982, All BCDDP	558
George, 1980, Liverpool	602
Roberts, 1990, Edinburgh	620
Carlile, 1981, Seattle BCDDP	780
This Study, CDOH	791
Chamberlain, 1984, London	970
This Study, CCH	1,306
Tabar, 1985, Sweden	1,370

Discussion

This intervention, developed to overcome four identified barriers to cancer screening in public sector clinics in Chicago, was successful in attracting women not likely to receive early detection for breast or cervical cancer. The vast majority of women were older than age 40 at both program sites, and most were poor African American women. Of the women making an initial visit to the screening program, 82 percent reported not having had a mammogram in the past year, suggesting that a high-risk group was being reached by the screening program. In addition, 25 percent reported not having had a Pap smear within the last 3 years. More than half the women at the CCH site and almost all the women at the CDOH site were not active clients of the clinics where the screenings were performed.

Most of the women we were attempting to reach were not going to be able to pay out of pocket for mammography services. The screening clinics and services were free, and much of the diagnostic and treatment services were also free or priced on a sliding scale. These were the only free breast and cervical cancer screening programs in Illinois. We have no direct evidence, however, that women would not have come if there were charges for the services.

Before using a screening program, a potential client has to know where the services are located. Our recruitment strategies were successful, as evidenced by the significant increase in the level of awareness about the screening programs during post intervention surveys over that measured at baseline. Although awareness levels were greatest in women attending the experimental clinics, there was a corresponding increase in the community control clinic and in the experimental communities.

Our classroom educational intervention proved to be an effective means of addressing the informational barriers to screening. The women were effectively informed by the classes, as evidenced by their scores on the pre and post class questionnaire. Women at both experimental clinic sites scored significantly higher on the questionnaire after attending the class, suggesting that this is a useful method of teaching women about the importance of screening. The data are limited, however, since no long-term followup survey was performed.

Once women get an initial screen for cancer, it is important for them to get rescreened in the future and keep referral appointments for followup evaluations when indicated. Our computerized tracking system allowed us to follow a complicated array of tests and appointments for large numbers of patients. In this study, 86 percent of women who received computer-generated letter prompts to remind them of upcoming appointments actually received an examination within 2 months of the reminder. This finding is quite remarkable and suggests that this method of cueing women about upcoming screening and followup appointments should be explored in programs serving populations similar to the ones examined in this report. There is a body of literature in which the success of appointment reminders as a mechanism for improving followup rates for clients in medical clinics (21,22) and for cancer screening has been examined (23). Our results are consistent with the findings of these prior studies.

Table 3. Percentage of women returning to the Cook CountyHospital clinic for followup screening examinations within 60days of receiving a reminder letter, November 1989 toOctober 1990

Number of women returning	Percentage	
146 of 168	87	
175 of 192	91	
	85	
213 of 254	84	
230 of 278	83	
	86	
1,165 of 1,361	86	
	returning 146 of 168 175 of 192 150 of 176 213 of 254 230 of 278	

Table 4. The number of breast and cervical cancer screening examinations and biopsies performed and cancers discovered from June 1989 to November 1990 at the Cook County Hospital (CCH-E) and the Chicago Department of Health (CDOH-E) sites

Procedure	CCH-E	CDOH-E	Total
Breast screenings	5,513	1,692	7,205
Breast biopsies	234	34	268
Breast cancers	72	12	84
Cervical screenings	2.814	810	3.624
Cervical biopsies	45	14	59
Cervical cancers	6	3	9

Table 5. American Joint Committee on Cancer stage of breast cancers detected by the two screening programs during the first 12 months of the intervention (June 1989–May 1990) compared with the last 6 months of the intervention (June–November 1990¹)

	June 1989- May 1990		June- November 1990		Total	
	Number	Percent	Number	Percent	Number	Percent
0/1	3	7	11	31	14	18
2	27	63	20	56	47	59
3/4	13	30	5	13	18	23
Totals	43	100	36	100	79	100

¹ Five cases that were not staged are not included in this analysis.

Much care was taken at the initial presentation to gather accurate information regarding the client's address and telephone number. Other contact addresses and telephone numbers were also collected to maximize the chances of obtaining good followup rates. All of this information was maintained on the tracking system's master file. Additional investigations need to be done to see if computer generated reminder letters can influence appointment-keeping behavior over longer periods.

Problems with access to appropriate treatment is an important barrier to breast and cervical cancer 'Our computerized tracking system allowed us to follow a complicated array of tests and appointments for large numbers of patients. . . . 86 percent of women who received computer-generated letter prompts . . . actually received an examination within 2 months of the reminder. This finding is quite remarkable. . . .'

early diagnosis among women in populations like the ones we serve (24). A recent study using a population of women attending the same community clinic where we placed our intervention found that delayed followup for cancer related referrals was an important barrier to cancer control efforts (8). We attempted to address this barrier by linking screening services with treatment facilities. The overwhelming majority of women who were diagnosed with breast or cervical abnormalities had their diagnosis and treatment performed at Cook County Hospital in Chicago. Project nurses accompanied women with breast abnormalities to consultations with surgeons. Contact was maintained with clients through diagnosis.

The adherence rates for appointments for suspected breast abnormalities was 92 percent among women attending the community based screening program and similar in the hospital program. Of the women diagnosed with breast cancer during the intervention, only one refused treatment.

Followup rates for women referred for cervical abnormalities was only 70 percent. These women were directly referred to colposcopy but not accompanied by project nurses. The differences in these methodologies may explain the different followup rates. These findings are explored in detail elsewhere (25).

The two screening programs had more than 10,000 visits in 18 months. There were an additional 1,449 visits for further diagnostic evaluations. Of those referred for breast biopsy, compliance was high (more than 90 percent), a rate higher than that reported from the Breast Cancer Detection and Demonstration Project (28,200 out of 37,200, or 76 percent) (15). Of those biopsied in our program, 31 percent had malignancies. Only 18 percent of the breast cancers were classified as early (Stage 0 or Stage 1). This compares unfavorably with the results that have been found in other studies but must be viewed cautiously because it reflects cancers detected in slightly more than one cycle of screening and includes women who presented with symptomatic disease.

Most screening programs exclude women with symptoms or breast findings from participation (15). We decided to include all women who presented to the program for evaluation because we provided quick access to diagnosis and treatment for women who had difficulty finding such services. It is postulated that much of the breast cancer that was discovered during the first 18 months represented existing (prevalent) rather than new (incident) cases. The fact that the proportion of Stage 0 and Stage 1 breast cancer increased more than four-fold during the final 6 months of the intervention was encouraging.

In contrast to the results for breast cancer, most of the cervical cancers were in situ or Stage 1. These differences can probably be attributed to the history of prior adequate cervical cancer screening in 75 percent of the women screened, whereas only 18 percent of the women had had prior mammographic screening.

The detection rates for breast cancer experienced at both sites of this program were relatively high compared with other studies. These rates, because they are not population based, probably reflect referral patterns in Chicago rather than true increased rates of disease. Because indigent minority women do not have many screening and treatment sites available, it is likely that many made their way to our programs for evaluation. More breast cancers were diagnosed in the 18-month intervention by these two screening programs than are routinely diagnosed by the average Illinois hospital (24).

This study has a number of limitations. We were only able to address a limited number of barriers to breast cancer screening that we had identified through our previous work and a review of the literature as being important (4-8). We did not address explicitly other important barriers to cancer screening, such as women's reluctance to participate in breast cancer screening or physician barriers to screening. These client attitudinal and physician barriers to cancer screening are important (26,27) but were not directly addressed by this intervention.

This study is also limited by the fact that it was not a randomized trial. The intervention had a number of different components that were applied in a quasi-experimental setting. For this reason, it is difficult to identify with certainty which aspects were specifically successful. Finally, while successful in the setting of public hospital and community based public clinics in Chicago, this intervention may not be generalizable to other settings. We were able to provide free services from screening to treatment where necessary. Certainly, the importance of this factor cannot be minimized and may limit the replicability of this program in other settings.

In conclusion, this breast and cervical cancer screening intervention was successful in addressing and overcoming certain barriers to screening and followup in public sector clinics in Chicago. The programs attracted a high-risk, low-income population. The use of the computerized patient tracking system to follow clients and their test results was a useful method to maximize followup. Whenever possible, such a model should be replicated in other settings.

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