Breast Cancer Screening among Relatives of Women with Breast Cancer

ABSTRACT

Background. National surveys indicate that only 15% to 30% of all women in the general population 50 years of age or older have an annual mammogram.

Methods. We studied first-degree female relatives of women with breast cancer, who are at elevated risk of disease, to describe the breast cancer screening practices of these relatives and to improve their practices through a program of intensive education. We report here the screening behaviors of 2471 relatives of women with breast cancer.

Results. Self-reported behaviors were as follows: 49% performed monthly breast self-examination and 70% had annual breast examinations by a medical professional. Of 983 women 50 years of age or older, 49% had had a mammogram, but only 14% have a mammogram annually. Of women 50 years of age or older who had never had a mammogram, 92% reported never having had one recommended by a medical professional.

Conclusions. Our findings indicate that screening behaviors in relatives of breast cancer patients are not substantially different from those of women in the general population. Enhanced efforts both to educate medical professionals and to encourage women to demand screening mammography are necessary to reduce breast cancer mortality. (Am J Public Health. 1991;81:1174–1179)

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Introduction

Nearly one in nine women in the United States will have breast cancer in her lifetime. An estimated 175 000 new cases will be diagnosed and an estimated 44 500 deaths from this disease will be recorded during 1991. Breast cancer ranks second only to lung cancer as a cause of cancer mortality in women; yet despite biomedical advances in breast cancer therapy, mortality has remained fairly constant and has even increased slightly in recent years. ¹

Routine breast examination by a physician and breast self-examination (BSE) both have been shown to be more effective than accidental discovery in detecting the disease at an early stage. 2,3 Moreover, detection of early lesions using a combination of professional breast examination and mammography for women ≥ 50 years of age, and more recently for women 40 to 49 years of age, has been shown to improve survival from breast cancer. 4

Despite the potential reduction in morbidity and mortality using available breast cancer screening methods, screening measures are underutilized. Recent population-based surveys indicate that 50% of women ≥50 years of age perform monthly BSE, 50% have annual professional breast examinations, and no more than 15% to 30% have annual mammograms. ⁵⁻⁸.

A total of 8% of women 40 years of age or older in the United States have at least one first-degree female relative (mother, daughter, or sister) who has had breast cancer. Nevertheless, little is known about the screening behaviors of these relatives, women whose risk of disease is estimated to be twofold to four-fold higher than that for women in the gen-

eral population. ¹³ Krischer and colleagues studied the breast cancer screening behaviors of 138 first-degree and 70 seconddegree relatives of women with breast cancer and found low prevalence rates of breast cancer screening overall, rates comparable to those of women in the general population. 10 To further investigate this group of high-risk women, the Pennsylvania Cancer Program of the Pennsylvania Department of Health supported six pilot projects from 1984 to 1987. The projects were designed to identify relatives of women with breast cancer, to describe the breast cancer screening behaviors of these relatives, and to improve their behaviors through a program of intensive education.

We report here the screening behaviors of these relatives in five of the pilot projects. We hypothesized that health care providers would more effectively screen women who were known to be at elevated risk of breast cancer and that the prevalence of screening behaviors among this population would be higher than that among women in the general population.

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TABLE 1—Prevalence of Breast Self-Examination (BSE), Professional Breast Examination (BE), and Mammography (MAM) by Selected Characteristics, Relative Breast Cancer Screening Project, Pennsylvania, 1984–1987

| Characteristic ^a | Total | Ever BSE (%) | Monthly BSE (%) | Ever BE (%) | Annual BE (%) | Ever MAM (%) | Periodic MAM (%) ^b |
|-----------------------------|-------|-----------------|-----------------------|----------------|---------------------|-----------------|----------------------------------|
| Overall | 2471 | 83 | 49 | 96 | 70 | 37 | 15° |
| Age (years) | | | | | | | |
| <40 | 1059 | 84 | 49 | 96 | 77 | 42 ^d | NAe |
| 40-49 | 424 | 86 | 54 | 97 | 70 | 53 | 17 |
| >50 | 983 | 82 | 47 | 96 | 61 | 49 | 14 |
| Race | | | | | | | |
| White | 2362 | 82 | 47 | 96 | 61 | 48 | 15 |
| Non-White | 106 | 79 | 41 | 97 | 74 | 58 | 11 |
| Residence | | | | | | | |
| Urban | 1091 | 84 | 55 | 97 | 76 | 42 | 19 |
| Mixed | 1268 | 83 | 46 | 95 | 65 | 33 | 13 |
| Rural | 112 | 89 | 24 | 96 | 61 | 31 | 4 |
| Relation | | | | | | | |
| Daughter | 1231 | 85 | 50 | 96 | 74 | 26 | 17 |
| Sister | 1159 | 82 | 49 | 96 | 65 | 47 | 15 |
| Mother | 81 | 78 | 38 | 98 | 68 | 54 | 11 |
| Education (years) | | | | | | _ | • • |
| <12 | 441 | 79 | 44 | 93 | 53 | 39 | 10 |
| 12 | 1119 | 84 | 48 | 96 | 69 | 50 | 15 |
| >12 | 858 | 81 | 52 | 98 | 78 | 59 | 23 |
| Income(\$) | | _ | | | | | |
| <20.000 | 843 | 79 | 46 | 95 | 61 | 41 | 11 |
| 20.000-40.000 | 1001 | 86 | 51 | 96 | 74 | 55 | 17 |
| >40,000 | 414 | 85 | 53 | 100 | 80 | 73 | 27 |

^aData are not available for all behaviors stratified by all characteristics.

Methods

All women diagnosed with breast cancer from 1980 to 1986 were identified from cancer registries in eight Pennsylvania hospitals and from the Pennsylvania Cancer Registry in the south-central region of the state. Only women known to be alive at the time of the study were included. The physician who completed the cancer registry data form was contacted for permission to contact the patient; women whose physicians granted permission received letters describing the study and inviting their participation. Women with breast cancer were asked to identify and give permission to contact their mothers, sisters, and daughters, ≥18 years of age, for enrollment in the study.

Data were collected either by telephone or in face-to-face interviews using a structured questionnaire that included demographic characteristics and information about three breast cancer screening behaviors: performance of BSE, breast examinations by a medical professional, and mammography. All information was self-reported; no attempt was made to ver-

ify the reported frequencies of screening behaviors by review of medical records.

Because the majority of participating relatives lived in the area of the hospital and because no specific information on residence was collected, the catchment area of the hospital was used as a surrogate for characterizing residence.

The Statistical Analysis System (SAS Institute, Cary, NC) was used for data analysis. Categorical data were compared using χ^2 and the χ^2 test for trend. In reporting stratified data on screening behaviors, only participants with complete risk factor and outcome information were included. To compute the odds ratio for each of the three screening behaviors while simultaneously controlling for the potentially confounding effects of other characteristics, we used unconditional logistic regression (SAS CATMOD with the CLOGITS option).

Results

Demographics

A total of 4012 women with histologically confirmed breast cancer were iden-

tified. At the time of the study, 3229 were still alive and were well enough to participate. The physicians of 2975 (92%) of these gave consent for their patients to be contacted. A total of 2050 women (64%) agreed to participate, and 1862 (58%) were interviewed.

Women with breast cancer identified 3860 relatives, of whom 2865 (74%) were invited to participate. A total of 2540 relatives (66%) agreed to participate, and 2539 were interviewed. Data on 68 of these women (2% of the total group of relatives) who reported that they also had had breast cancer were excluded from the analysis. The analysis thus consists of 2471 women, 64% of the relatives of participating women with breast cancer.

Characteristics of participating relatives are summarized in Table 1. The majority were <50 years of age, White, had completed at least 12 years of education, and had a household income >\$20,000. A total of 44% of participants were from urban areas, 51% were from areas of mixed type (urban and rural), and 5% were from rural areas. Information about relatives who declined to participate was not available.

Screening Behaviors

A total of 83% of women have done BSE, and 96% have had at least one breast examination by a medical professional (Table 1). A total of 42% of women 35 to 39 years of age, 53% of women 40 to 49 years of age, and 49% of women \geq 50 years of age have had at least one mammogram. A total of 28% of women \geq 50 years of age reported having had a mammogram within the previous 12 months.

In order to more accurately distinguish routine screening behaviors from breast examinations or mammography done because of breast abnormalities, we also examined periodic performance of breast cancer screening. Table 1 shows the proportions of women reporting monthly BSE, annual breast examinations from a professional, periodic mammography (biennial mammograms for women 40 to 49 years of age and annual mammograms for women ≥50 years of age) for women overall and stratified by age, race, residence, relationship, education, and income. Younger women, women from urban areas, daughters of women with breast cancer, more highly educated women, and women of higher income more often performed monthly BSE, had annual breast examinations from a professional, and had periodic mammography. Although the numbers of non-White

^bBiennial mammograms in women 40–49 and annual mammograms in women ≥50.

[°]Women ≥40 only

dWomen 35-39 only

^eNA = not applicable.

| | Mammogram w | | | |
|---------------------|-------------|----------|-----------|--|
| Professional breast | Yes No. (%) | No | Total | |
| exam within 12 mo. | | No. (%) | No. (%) | |
| Yes | 263 (41) | 375 (59) | 638 (67) | |
| No | 6 (2) | 315 (98) | 321 (33) | |
| Total | 269 | 690 | 959 (100) | |

| | | ars Having I sylvania, 19 | Mammograms, 184–1987 | Relative E | Breast Canc | er Screening |
|----------------------|---------------|------------------------------|-------------------------|------------------|----------------|--------------|
| | Any Mammogram | | | Annual Mammogram | | |
| Medical specialist | Yes | Total patients | Percentage | Yes | Total patients | Percentage |
| OB/gyn | 194 | 323 | 60 | 66 | 321 | 21 |
| Internist | 38 | 67 | 57 | 16 | 67 | 24 |
| General practitioner | 138 | 356 | 39 | 27 | 356 | 8 |
| Others ^a | 99 | 178 | 56 | 30 | 178 | 17 |

women in the study population were small, White women performed BSE and had periodic mammography more frequently. Non-White women more frequently had annual professional breast examinations.

Medical Care Encounters

Of 700 women >40 years of age who had never had a mammogram, 89% reported that a mammogram had never been recommended to them by a medical professional. Stratified by age, 83% of women ages 40 to 49 and 92% of women \geq 50 years of age reported never having had a mammogram recommended.

The 75 women who had never had a mammogram, but to whom a mammogram had been recommended, were asked why they had not had one. A total of 19% responded "no particular reason," 17% cited high cost as the primary reason, and 13% said that they planned to have a mammogram.

Of 959 women ≥50 years of age for whom information was available, 67% had had a professional breast examination within the previous 12 months. Of these women, 41% had had a mammogram within that period of time compared with 2% of women who had not had a breast

examination within 12 months (χ^2 = 163.58; P < .001) (Table 2). Nevertheless, 59% of women who had a breast examination by a professional within the previous 12 months had not had a mammogram within that period of time.

In the same group of 959 women \geq 50, we noted the type of medical specialist usually seen for a breast examination stratified by mammography use and annual mammography use (Table 3). A total of 60% of women who usually have a breast examination by an obstetrician/ gynecologist had had a mammogram, compared with 57% seen by internists and 39% who usually have breast examinations by a general practitioner (χ^2 for trend = 34.31; P < .001). Moreover, only 8% of women usually seen by a general practitioner for breast examinations have annual mammograms, compared with 21% seen by obstetrician/gynecologists and 24% seen by internists ($\chi^2 = 28.24$; P <.001). Some women were seen for breast examinations by surgeons, oncologists, or physicians whose specialties were unknown or unreported. These medical practitioners make up the "other" category. The extent to which the practices of physicians in this category are comparable is not known. The differences by medical

specialty persisted when the data were stratified by age groups, education groups, and income groups. When we stratified the data by residence, we found the same differences in mammography use based on the type of physician seen for a breast examination among residents of both urban and mixed (urban and rural) settings. There were too few observations for women living in rural areas to make meaningful comparisons among the three types of residences, however.

Multivariate Analyses

We examined BSE, breast examination by a professional, and annual mammography using unconditional logistic regression. The importance of age, income, education, urban setting, family relation, and type of medical professional seen for a breast examination were all analyzed in connection with the three outcome behaviors mentioned above (Table 4). Controlling for the other variables in the model, monthly BSE was significantly associated with urban residence. For the outcome of annual breast examination by a professional, the variables of most importance when controlling for other factors were younger age, higher income, urban residence, and type of medical professional seen for a breast examination. (Women usually seen by obstetrician/gynecologists were more likely to have annual examinations than women seen by general practitioners.) When these same independent variables were analyzed with annual mammograms as the outcome variable, older age, higher income, urban residence, and type of medical professional seen for a breast examination were the variables of most importance. Women usually seen by obstetrician/gynecologists, internists, or physicians in the "other" category were more likely to have annual mammograms than women usually seen for breast examinations by general practitioners.

Adherence to American Cancer Society Screening Guidelines

We examined the behaviors of women in the two age groups 40 to 49 and ≥50 to determine what proportions adhere to American Cancer Society (ACS) guidelines: monthly BSE; annual breast examinations by a professional; and mammography, biennially for women 40 to 49 and annually for women ≥50 years of age. ¹⁴ Seventeen percent of women ages 40 through 49 have biennial mammograms, and 14% of women ≥50 have annual mammograms (Table 1). A total of

TABLE 4—Prevalence of Annual Mammogram (MAM), Annual Professional Breast Examination (BE), and Monthly Breast Self Examination (BSE) by Selected Characteristics, Logistic Regression Model, Relative Breast Cancer Screening Project, Pennsylvania, 1984–1987

| | Anı | nual MAM | A | nnual BE | Mo | nthly BSE |
|-----------------------------|-------|-------------|-------|-------------|-------|-------------|
| Variable | OR | 95% CI | OR | 95% CI | OR | 95% CI |
| Relation (base = daughters) | | | | | | |
| Sisters | 1.743 | 1.110-2.735 | 1.276 | 0.943-1.725 | 0.906 | 0.703-1.168 |
| Mothers | 1.130 | 0.452-2.826 | 1.519 | 0.798-2.891 | 0.516 | 0.289-0.92 |
| Age (years) (base = <40) | | | | | | |
| 40-49 | 3.975 | 2.352-6.718 | 0.706 | 0.5070.982 | 1.446 | 1.096-1.91 |
| 50 and older | 5.212 | 3.011-9.021 | 0.494 | 0.353-0.691 | 1.156 | 0.866-1.54 |
| Residence (base = urban) | | | | | | |
| Mixed | 0.661 | 0.475-0.920 | 0.697 | 0.556-0.875 | 0.695 | 0.575-0.84 |
| Rural | 0.141 | 0.018-1.087 | 0.693 | 0.417-1.151 | 0.320 | 0.193-0.53 |
| Education (base = <12 | | | | | | |
| 12 | 0.940 | 0.593-1.488 | 1.202 | 0.902-1.600 | 0.907 | 0.686-1.200 |
| >12 | 1.200 | 0.709-2.030 | 1.400 | 0.985-1.991 | 0.989 | 0.719-1.36 |
| Income (base = <\$20,000) | | | | | | |
| \$20,000-\$40,000 | 1.794 | 1.214-2.653 | 1.394 | 1.098-1.770 | 1.202 | 0.973-1.486 |
| Over \$40,000 | 2.711 | 1.679-4.375 | 1.799 | 1.277-2.533 | 1.147 | 0.869-1.512 |
| Physician specialty (base = | | | | | | |
| general practice) | | | | | | |
| Ob/gyn | 1.774 | 1.145-2.748 | 1.608 | 1.240-2.086 | 1.165 | 0.923-1.472 |
| Internal medicine | 2.784 | 1.417–5.471 | 1.783 | 0.977–3.253 | 0.856 | 0.514_1.426 |
| Other | 2.751 | 1.666-4.541 | 1.009 | 0.727-1.400 | 1.113 | 0.820-1.510 |
| Total n | | 2003 | | 2024 | | 2068 |

| ination (BE), and Mammography (MAM), Pennsylvania, 1984–1987, vs Studies of Women in the General Population | | | | | |
|--|----------------------------|-------------------------------------|--|--|--|
| Behavior | Percentage Pennsylvania | Percentage General Population | | | |
| Monthly BSE | 49 | 47–50 ^{5,9} | | | |
| Annual BE | 70 | 50-55 ⁵⁻⁷ | | | |
| MAM ^a | 50 | 40-67 ^{7-9,16} | | | |
| Annual MAM ^b | 14 | 15-30 ⁶⁻⁸ | | | |
| MAM ≤1 yr ^b | 28 | 20-417,15,17,21 | | | |

41% of women 40 to 49 and 32% of women ≥50 adhere to the recommended screening for two of the three practices, monthly BSE, and annual professional breast examinations. Only 11% and 8%, respectively, adhere to all three screening guidelines for their age group.

We compared our findings with those of other surveys of breast cancer screening among women in the general population (Table 5). The prevalence of monthly BSE and mammography use reported in our study is similar to that of women in the general population. 5-8,15-19 The prevalence of annual professional breast examination, 70%, is higher than generally reported. 5-7,9 The proportion of women in

the general population who practice a combination of these three screening methods is not known.

Discussion

Our findings indicate that BSE and mammography use in relatives of women with breast cancer, who are at elevated disease risk, do not differ substantially from the behaviors of women in the general population. Despite the higher rates of professional breast examinations reported for this population, barriers to more widespread use of screening mammography exist. Our data do not support the hypothesis that physicians screen selectively and

comprehensively those women known to be at elevated risk of breast cancer. Nearly 90% of women who had never had a mammogram reported that a medical professional had never recommended one.

Older women, women of lower socioeconomic status, and women living in rural areas were less likely to report adherence to current ACS breast cancer screening guidelines. Similar risk factors for inadequate preventive health practices in general and for breast cancer screening in particular have been found in national surveys. 9,19-21

Not surprisingly, we found that women who reported having had a recent professional breast examination more often reported having had a recent mammogram. Yet the majority of women ≥50 seen for a breast examination within the previous year who would have been eligible for screening mammography were not screened, most often because their physicians had not recommended it.

We found differences in compliance with guidelines for mammography use among medical specialties: women who usually had breast examinations by internists or obstetrician/gynecologists were more likely to have mammograms than women who usually had breast examinations by general practitioners. Reasons for the apparent differences in practices

among medical specialists are not clear, but such differences may in part reflect type or recency of medical training or participation in continuing medical education. It is also not known whether women in the study population who have breast examinations by general practitioners were less likely to have health insurance that covers screening mammography than were women seen by internists or obstetrician/gynecologists. Bergner and colleagues²² found that recent medical school graduates and medical school faculty members were more likely to perform a series of cancer screening procedures among asymptomatic patients over the age of 50 for whom they provided primary care. In their survey, obstetrician/ gynecologists followed by oncologists most often performed breast examinations and screening mammograms. Information on years since graduation from medical school or faculty status was not available for the physicians of participants in our study.

The failure of physicians to follow established guidelines for breast cancer screening in asymptomatic women was documented in a 1989 Ohio survey of more than 1000 practicing primary care physicians.23 The survey found that although 98% advise their patients to do BSE, and 78% followed published ACS guidelines for periodic breast physical examinations, only 37% followed guidelines for screening mammograms in asymptomatic women.²³ A similar survey conducted in 1984 found 80% and 11% of physicians adhering to ACS guidelines for breast physical examinations and screening mammography, respectively.24

The National Cancer Institute (NCI) has developed the following objective for breast cancer screening for the year 2000: 80% of women 50 to 70 years of age will have both annual breast examinations by a medical professional and annual mammograms.25 The authors of Healthy People 2000 suggest that the NCI breast cancer screening goals be incorporated into the Nation's Year 2000 Health Objectives.26. To achieve these goals, enhanced educational efforts are needed, particularly in promoting mammography. These efforts should target both primary health care providers and women ≥50 years of age. Medical school, residency training, and continuing medical education programs should include instruction on the current approaches to breast cancer screening. The 1989 survey of practicing primary care physicians suggested that misinformation about radiation risks from

mammography may deter some physicians from ordering screening mammograms for their patients.²³ In addition, women should be encouraged to demand screening mammography, an approach that has shown utility in stimulating physicians to provide other preventive services.^{27–29}

Several limitations of the study design should be noted. First, participation rates were low for women with breast cancer (58%) and their relatives (64%); yet there was no information by which to compare characteristics of participants and nonparticipants. We believe that nonparticipants are unlikely to have better screening behaviors than participants.

Second, in order for women with breast cancer to provide access to their relatives, only those women still alive at the time of the study were eligible breast cancer patients. Whether relatives of women who have died from breast cancer differ from other relatives in their screening behaviors is not known. Further research is needed to better understand factors such as stage of disease at diagnosis, extent of disease, or type of therapy, all of which may affect preventive behaviors in asymptomatic relatives.

Third, all information in the study was self-reported and thus subject to recall bias on the part of the respondents. No attempt was made to verify the reported frequency of professional breast examinations or mammography use by review of medical records. It is therefore possible that some groups of women are more likely to recall breast cancer screening practices better than others.

Fourth, the population studied was primarily White and of relatively high so-cioeconomic status; the findings may be neither comparable to findings of other population surveys of breast cancer screening behaviors nor generalizable to all populations. Additional studies should focus on the breast cancer screening practices of non-White women and women of lower socioeconomic status who are at elevated risk of breast cancer.

Despite these limitations, our data confirm the findings of previous surveys of women's breast cancer screening behaviors: screening remains underutilized. 5-9,15-18 Whether any of these surveys, including our own, actually measure women's behaviors as opposed to those of their health care providers is not clear. In either case, intensified efforts are needed to enhance the early detection of breast cancer in order to reduce mortality from this disease.

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New Insights into Sudden Infant Death Syndrome

Results from a study published in the May 1 *American Journal of Epidemiology* suggest that certain labor and delivery events may increase the risk of sudden infant death syndrome (SIDS).

SIDS is the leading cause of mortality in the United States for infants 1 to 12 months old, accounting for one to three deaths per 1000 live births. SIDS has been called "a diagnosis of exclusion" because its victims can only be identified through an autopsy that rules out all other explainable causes of death.

This study "is one of the first analytic studies to focus on the intrapartum period and risk factors for SIDS," says lead author Germaine M. Buck, PhD, clinical assistant professor, Department of Social and Preventive Medicine, School of Medicine and Biomedical Sciences, Buffalo, NY.

Buck and her team found a sevenfold increased risk for SIDS associated with vaginal breech delivery and more than twice the risk for SIDS when mothers were in labor 16 hours or longer. Their study population was selected from a 1974 cohort of live births from Upstate New York that included 132 948 resident mothers. Data were abstracted from hospital delivery and vital records for 148 autopsied cases and 355 matched controls.

"The majority of breech SIDS infants were single footling deliveries (a rarer type of breech presentation with the baby emerging one foot first). The more common form of breech delivery called 'frank' presentation, with the baby emerging buttocks first, was not associated with an increased risk for SIDS," Buck says.

"We suspect that the single footling breech presentation may be an indicator for an earlier problem in the fetus' development, while a breech delivery, per se, is not the direct cause of the syndrome," she says. This speculation concurs with previous studies that have suggested SIDS victims may be compromised before birth. As Buck explains, "SIDS babies may have experienced a prior central nervous system insult in utero since they often show signs of subtle growth retardation, including reduced birth weight and length." These effects could be explained by altered blood flow or oxygen supply to the developing fetus, Buck says, but not by labor or delivery events.

"The association between long labor and SIDS must be viewed conservatively," Buck adds. "There is a lot of subjectivity in the woman's reporting of how long she has been in labor when she is first seen in the hospital."

According to Buck, the incidence of SIDS has not diminished as prenatal care has improved in the last several decades. "SIDS is a chief contributor to this nation's high infant mortality rate, and further effort to understand this syndrome should be a public health mandate," she says.