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Knowledge and prevention practices before breast cancer diagnosis in a cross-sectional study among survivors: impact on patients' involvement in the decision making process

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Abstract

Disparities exist in breast cancer knowledge and education, which tend to influence symptom interpretation and decision to seek screening/care. The present project describes a cohort of women's experiences, knowledge and health behavior prior to and after a diagnosis of breast cancer. It also studies how knowledge and demographic factors are associated with level of involvement participants had in the treatment of their breast cancer. Women > 18 years who have being diagnosed and treated for breast cancer within 10 years were recruited in Pittsburgh, PA, through the Healthy People Cohort Registry, a data base of volunteers from the community, and Brooklyn, NY through the American Cancer Society breast cancer survivor database. Subsequent to institutional ethics approvals, a questionnaire was administered by mail, and through an electronic interactive format.

The study included 124 breast cancer survivors, one quarter of whom were of African ancestry. Roughly half of women indicated that their overall knowledge of breast cancer was limited before diagnosis; no significant association between overall knowledge before diagnosis and stage at diagnosis or an active role of the patient in treatment choices was observed. Two-third of women reported using personal research on internet, books and other media to increase knowledge on breast cancer after diagnosis; the improvement of knowledge was associated with an active role in therapy choice. White women's self report of breast cancer knowledge prior to diagnosis was higher than that of women of African origin ($p=0.03$); the latter experienced more delays in getting results about the diagnosis ($p=0.002$), in starting treatment ($p=0.03$), and in having treatment available at local facilities ($p=0.007$) than White women. White women were more

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GRJ, SE designed and administered the questionnaires; LR participated in patients' recruitment and manuscript drafting. ET participated in the design of the study and performed the statistical analysis. CR conceived the study, and participated in its design and coordination and helped to draft the manuscript.

All authors read and approved the final manuscript.

likely to improve their knowledge through their own research ($p=0.08$) and through the contribution of their physician ($p=0.06$) than women of African origin.

There is still a need for addressing breast cancer knowledge among black women, and that improvement in physician emotional support and in their contribution to the patient's knowledge is necessary. These efforts may have a positive impact on breast cancer knowledge among black women in the United States.

Keywords

cancer prevention; cancer education; mammography; cancer therapy; African ancestry

Introduction

Although breast cancer incidence and mortality has declined over time, there are persistent disparities in both incidence and mortality among racial minorities, underserved and economically disadvantaged groups [1]. Furthermore, women within these groups have higher incidences of risk factors and are less likely to be screened for cancer. In addition to limited resources, disease knowledge and educational background, which tend to influence symptom interpretation and decision to seek screening/care, are often limited in these population [2]. Health behavior theories, such as the Theory of Reasoned Action and the subsequent Theory of Planned Behavior [3-5] show promise in their applicability to the role of knowledge, attitudes, and self-efficacy in explaining African American women's engagement in breast cancer screening and treatment [6]. Previous studies have linked screening practices to knowledge and attitudes towards prevention, age, and socioeconomic status [7]. Lower screening rates, erratic follow-up, and differences in tumor pathology all impact on the stage of cancer at initial diagnosis and subsequent medical treatment [8]. Breast cancer patients have shown that informational needs are primary for making appropriate decisions on their medical treatment [9]. A recent study showed that breast and colorectal cancer survivors had limited knowledge on the details of their diagnosis and cancer treatment course [10], and this could affect their follow-up and the continuity of appropriate care. It is conceivable that an active involvement in care would result in a better understanding on the medical procedures and therapeutic schemes, which in turn would lead to better cancer outcomes [11].

The intent of this research project is to describe a cohort of women's experiences, knowledge and health behavior prior to and after a diagnosis of breast cancer. In addition, we aim to study how knowledge and demographic factors may be associated with level of involvement participants had in the treatment of their breast cancer, with a particular emphasis on racial and socioeconomic differences. This research study will help to define the interventions needed to promote breast cancer awareness, increase knowledge of risk factors and promote screening, and to encourage proactive behavior as it applies to the process of breast cancer diagnosis and treatment among low-income, ethnic minority women, in particular.

Methods

Study population: Women over the age of 18 who are currently receiving care for, or who, within the past 10 years, have being diagnosed and treated for breast cancer were recruited from the cities of Pittsburgh, PA, and Brooklyn, NY; both cities with direct access to major medical centers and any outreach measures directed at the community by these centers. In Brooklyn, women were identified through the American Cancer Society breast cancer survivor database and the cancer survivor support groups at Downstate Medical Center. In

Pittsburgh, women were identified through the Healthy People Cohort Registry, a data base of volunteers recruited through community housing, health fairs, and other public events.

Data collection: Subsequent to institutional ethics approvals at both the University of Pittsburgh and Downstate Medical Center, a questionnaire was administered by mail, and was converted into an electronic interactive format housed on the African-Caribbean Cancer Consortium's website (www.ac3online.org). No restriction criteria for participation was imposed, and as all the women included in each registry were invited to participate. Each woman was mailed either a concealed flyer or postcard inviting them to take part in the study by accessing the questionnaire on line, or requesting that a hard copy be mailed to them which they would then return anonymously. Each piece of mail had a randomly generated and untracked unique key code attached to it. The purpose of the code was to help tracking where each participant completing the survey was geographically located, and as well ensure that each woman who accessed the website to respond to the questionnaire only did so once.

Statistical Analysis

Descriptive statistics of the study population were calculated to assess pre-diagnosis health status, physical activity, diet, socioeconomic status, educational background, lifestyle, reproductive history, family history, and patients' interpretation of symptoms, decision to seek care, their involvement in and interpretation of the care they received, among other parameters. A change in overall knowledge of breast cancer was measured by comparing knowledge after diagnosis – knowledge before diagnosis through a paired-t test. For some indicators of breast cancer knowledge prior to diagnosis and overall experience during diagnosis and treatment, a comparison between white women and women of African origin was performed by a chi-square test. A multivariate analysis was conducted to assess the independent predictors of the patient's active role in her breast cancer treatment options. The SAS statistical package was used to perform all statistical analyses.

Results

The study included 124 breast cancer survivors, whose characteristics are presented in Table 1; 26% of the women defined themselves as of African origin, and roughly half had a breast cancer diagnosis within 5 years from the current interview. Table 2 presents descriptive information regarding the factors that directly or indirectly indicate breast cancer knowledge prior to diagnosis. Most of the women had a yearly mammogram and conducted a breast self-exam every few months. Half of the women reported healthy habits, such as consumption of the recommended quantity of daily fruit and vegetables, the avoidance of fried foods, and an adequate level physical activity. Despite that almost all women reported knowing of the existence of breast cancer prior to diagnosis, roughly half of them indicated that the overall knowledge of breast cancer as a disease was limited before diagnosis; no significant association between overall knowledge before diagnosis and stage at diagnosis was observed.

There was an improvement in overall knowledge after diagnosis ($p=0.07$ for paired comparison) of knowledge after – knowledge before diagnosis).

Overall experience during diagnosis and treatment (Table 3): Two-thirds of breast cancer patients waited less than a week to get results about their diagnosis; one-third of them asked for a second opinion before starting the course of treatment, despite the fact that an overwhelming percentage judged their health care provider to be knowledgeable about their disease and compassionate. The treatment was started within a few weeks for most of patients, who rated the experience above average in 70% of cases; patients participated in

the decisional process of their treatment course in 79% of cases, however there was no significant association between previous knowledge about breast cancer and an active role of the patient in treatment choices. At multivariate analyses, race, previous knowledge of breast cancer, education, family history of breast cancer, frequency of breast self exam, and healthy diet (as measured by number of daily servings of fruit and vegetables) had no significant association with an active role of the patient in treatment choice. Two-third of women reported using personal research to increase knowledge on breast cancer after diagnosis. The improvement of knowledge obtained through personal research on internet, books and other media was associated with an active role in therapy choice.

Patients acknowledged the availability of support services in roughly half of the cases, but only used them in less than half of the cases. Overall, women were satisfied with the outcome of their disease (87%).

Stratified analysis according to ethnicity (table 4): There was no significant difference between White women and women of African origin in age and education level; similarly, a comparison between knowledge about breast cancer prevention and risk factors showed no significant differences with race. However, White women's self report of breast cancer knowledge prior to diagnosis was higher than that of women of African origin ($p=0.03$). Women of African origin experienced more delays in getting results about the diagnosis ($p=0.002$), in starting treatment ($p=0.03$), and in having treatment available at local facilities ($p=0.007$) than White women. White women were more likely to improve their knowledge through their own research ($p=0.08$) and through the contribution of their physician ($p=0.06$) than women of African origin.

Discussion

With this study we examined knowledge and prevention practices among breast cancer survivors, as well as how knowledge impacted their involvement with medical treatment. Knowledge of breast cancer, screening with regular mammograms and breast self-exams are expected to be associated with earlier decision to seek medical care and earlier stage of breast cancer at initial diagnosis. Higher knowledge will also be associated with more involvement in the treatment process and in better outcomes [12]. Breast cancer survivors in this study reported limited breast cancer knowledge in half of the cases; knowledge was not associated with stage at diagnosis or in an active role in the treatment decision. Previous studies have indicated that breast cancer knowledge is greater in women who access the Internet and read health pamphlets and for those women who discuss a greater number of breast cancer topics with their physician [13]. Although several factors were analyzed as predictors of women's active role in treatment, none of them were found to be statistically significant in our study. Our study indicates that overall breast cancer knowledge was better among white than black women, despite the fact that the two groups were similar in mammography rates, and in the distribution of behavioral risk factors. African descended populations have traditionally faced a dilemma with regard to the dissemination of information, which has neither been well managed nor even as well received when compared to other populations [9, 10]. One could possibly attribute this to cultural and educational differences across populations.

Other interesting differences between black and white women were the fact that compassion of the health professional was rated lower by black versus white women, and so was the contribution of the physician to increasing the woman's knowledge on breast cancer. A study among low-income minorities showed a significant association of patient self-efficacy and physician emotional support with breast cancer knowledge; physician emotional support appeared to be more important than physician informational support [12]. In our study,

physician contribution to improving knowledge was not statistically significant for either whites or blacks women; providing appropriate emotional support during patient education about breast cancer may increase informational uptake in minorities, but more studies are needed on this subject.

Spiritual beliefs were important to all participants and did seem to help them cope with and reframe their illness experiences. The patient–provider relationship was the most notable factor that influenced treatment decisions. Women with early stage breast cancer and cancer physicians shared some views of how physicians involve patients in treatment decision making, although there were important differences. Physicians may underestimate the importance that women place on understanding the rationale for their involvement in treatment decision making and on feeling comfortable during the consultation [14].

Another key findings is that the treatment modalities seem to differ with race: black women experience more delays in starting the treatment, and less frequent availability of treatment at their local health facility: this may indicate that financial and geographical barriers may prevent timely treatment among minorities. These findings underline the importance of addressing these barriers in order to improve both screening and disease outcome.

One limitation of this study is that the assessment of breast cancer knowledge prior to diagnosis may be subject to recall bias. Another challenge that must be addressed by future studies is the fact that black populations comprise more than one ethnic subgroup, with potential heterogeneity in cultural and religious beliefs; this requires outreach and dissemination of information that is culturally sensitive to these needs.

Our overall findings suggest that there is still a need for addressing breast cancer knowledge among black women, and that improvement in physician emotional support and in their contribution to the patient's knowledge is necessary. These efforts may have a positive impact on breast cancer knowledge among black women in the United States.

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Table 1
Characteristics of the study population of breast cancer survivors (n =124)

RACE	N (%)
African origin	31 (26.27)
White	77 (65.25)
Latino	7 (5.93)
Native /Pacific islander/Asian	3 (2.54)
AGE (years)	
< 35	12 (10)
36-65	69 (57.5)
>65	39 (32.5)
PLACE OF BIRTH	
US/outside	98 (80.99)/23 (19.01)
EDUCATION	
≤ High School	40 (33.06)
Technical school	18 (14.88)
College	44 (36.36)
Graduate school	19 (15.70)
CURRENTLY EMPLOYED	
No/yes	69 (58.47)/49 (41.53)
SMOKING HISTORY	
Never/ever	103 (84.43)/19 (15.57)
ALCOHOL	
Never	60 (52.63)
Yes currently	34 (29.82)
Yes in the past	20 (17.54)
AGE AT MENARCHE (years)	
< 11	25 (21.19)
12	27 (22.88)
13-14	48 (40.67)
>15	18 (15.26)
EVER BEING PREGNANT	
No/yes	24 (20.34)/94 (79.66)
PAST USE OF ORAL CONTRACEPTIVES	
No/yes	51 (43.59)/66 (56.41)
YEARS SINCE BC DIAGNOSIS	
1-2	25 (20.66)
2-5	41 (33.88)
5-10	35 (28.93)
>10	20 (16.53)

Previous breast biopsy for benign condition	
Yes/no	84 (70.59)/35 (29.41)
FAMILY HISTORY FOR BC	
No/yes	70 (59.32)/48 (40.68)
Weight (pounds)	Mean + SD (range)
	160.8 (38.0) 105- 294

Table 2
Breast cancer risk factors and knowledge before diagnosis

Had a prior mammography	N (%)
No/yes	12 (10.0)/ 108 (90.0)
Mammography frequency	
every year/ Every 2 years/ Sometimes	86 (87.8)/ 7 (7.1)/ 5 (5.1)
Reporting a healthy weight at time of diagnosis	
No/yes	37 (31.1)/ 82 (68.9)
Had dense breasts at mammography	
No/yes/Don't Know	51 (44.7)/ 58 (50.9)/ 5 (4.4)
Consumption of recommended fruit and vegetables	
No/yes	65 (54.6)/ 54 (45.4)
Consumption of fried food (times x week)	
1-2	74 (66.1)
>2-5	30 (26.8)
6-7	6(5.4)
>7	2 (1.8)
Physical activity (hr x week)	
None	7 (6.0)
<1	14 (12.0)
1-3	54 (46.1)
3-7	32 (27.4)
>7	10 (8.5)
Breast self exam	
No/yes	9 (9.4)/ 90 (90.6)
Frequency of self exam (among yes, n=90)	
Once a month	41 (45.6)
Every few months	29 (32.2)
Once a year	2 (2.2)
Only during doctor's visit	16 (17.8)
Knowledge of breast cancer as disease	
No/yes	8 (6.6)/ 114 (93.4)
Overall breast cancer knowledge	
Non existent	2 (1.7)
Very limited	24 (20.3)
Somewhat knowledgeable	43 (36.4)
Moderately well informed	29 (24.6)
Extremely well informed	20 (17.0)
Knowledge about treatment	
Non existent	8 (6.7)

Very limited	33 (27.7)
Somewhat knowledgeable	41 (34.5)
Moderately well informed	25 (21.0)
Extremely well informed	12 (10.1)

Table 3
Overall experience after breast cancer diagnosis and treatment

Testing at Local Laboratory	N (%)
Yes	69 (71.9)
No	4 (4.2)
Don't know	23 (23.9)
Waiting time to get results	
< 1 week	63 (67.7)
1–2 weeks	27 (29.0)
>1 month	3 (3.3)
Asked for a second opinion	
No/yes	63 (66.3)/32 (33.7)
Knowledge of the person who delivered the news	
Non existent	1 (1.1)
Poor	5 (5.3)
Somewhat knowledgeable	4 (4.2)
Moderately knowledgeable	12 (12.6)
Extremely knowledgeable	73 (76.8)
Compassion the person delivering the news	
Don't remember	1 (1.0)
Lacked any compassion	14 (14.4)
Somewhat compassionate	9 (9.3)
Very compassionate	35 (36.1)
Above and beyond the call of duty	38 (39.2)
Received counseling	
No/yes	63 (67.0)/31 (33.0)
Availability of treatment at local facility	
Did not know they treated cancer	21 (23.4)
Treatment was non existent	3 (3.3)
Treatment was very limited	2 (2.2)
Treatment was moderately specialized	36 (40.0)
Treatment was highly specialized	28 (31.1)
Treatment delay	
Few days	32 (33.3)
Few weeks	45 (46.9)
Few months	19 (19.8)
Quality of experience during treatment	
Extremely poor	3 (3.2)
Poor	5 (5.3)
Average	23 (24.2)

Above average	64 (67.4)
Exceptional	3 (3.2)
Patient's role in deciding treatment course	
None	6 (6.2)
Very little	13 (13.4)
Moderate	40 (41.2)
Actively involved	37 (38.2)
Availability of support services	
Never looked into it	34 (36.2)
Non existent	6 (6.4)
Very limited	4 (4.3)
Moderate	24 (25.5)
Abundant	26 (27.6)
Role of physician in pointing out support services	
Did not help at all	28 (30.8)
Limited	25 (27.5)
Average	19 (20.9)
Above average	12 (13.2)
Exceptional	7 (7.7)
Use of support services	
No/yes	46 (54.1)/39 (45.9)
Satisfaction with outcome (women no longer treated)	
No/Yes	10 (13.2)/66 (86.8)
Physician contribution to improving knowledge	
Did not/limited	11 (9.4)
Average	23 (19.7)
Above average	40 (34.2)
Exceptional	43 (36.7)
Personal research contribution to improving knowledge	
Did not/limited	16 (13.4)
Average	34 (28.6)
Above average	47 (39.5)
Exceptional	22 (18.5)
Role of religion in recovery	
No role	17 (14.5)
Very minimal	10 (8.6)
Moderate	24 (20.5)
Major	66 (56.4)

Table 4
comparison of selected variables between White women and women of African origin

VARIABLE	African origin (%)	White (%)	P value
Prior mammography (no/yes)	13.8/86.2	6.6/93.4	0.4
Mammography every year/ Every 2 years/ Sometimes	69.6,17.4,13.0	93.7, 3.1, 3.2	0.02
Had dense breasts at mammography (no/yes)	58.6/41.4	39.4/60.6	0.1
Previous breast biopsy for benign condition (no/yes)	82.8/17.2	66.7/33.3	0.1
Previous consumption of recommended fruit and vegetables	62.1/37.9	52.0/48.0	0.4
Prior self-exam	11.8/88.2	10.1/89.9	1
Prior breast cancer knowledge (limited/moderate/high)	25.0/53.6/21.4	20.0/32.0/ 48.0	0.03
Prior knowledge about treatment (limited/moderate/high)	46.4/32.1/21.4	28.9/38.2/ 32.9	0.1
Waiting time to get results (<1wk; 1-2wk; >1 month)	41.2/47.1/11.8	77.3/21.2/1.5	0.002
Treatment availability at local facilities (no/yes)	57.1/42.9	19.7/80.3	0.007
Delay in treatment (days/weeks/months)	17.6/41.2/41.2	37.7/49.3/13.0	0.03
Active role in treatment (no/yes)	23.5/76.5	17.1/82.9	0.5
Compassion of the person delivering the news (lacking, minimal, high, beyond call of duty)	29.4, 11.8, 35.3, 23.5	12.9, 8.6,32.9, 45.7	0.05
Improved BC knowledge through own research (no/yes)	56.7/43.3	36.4/63.6	0.08
Physician contribution to improving knowledge (no/yes)	23.3/76.7	9.1/90.9	0.06
Role of religion in recovery (no/yes)	16.7/83.3	28.6/71.4	0.2