

The Delay and Worry Experience of African American Women With Breast Cancer

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Purpose/Objectives: To examine the delay in seeking treatment and worry experiences of African American women with breast cancer.

Design: Descriptive, correlational.

Setting: Urban northeastern United States.

Sample: 60 African American women diagnosed with breast cancer.

Methods: Consenting participants completed the worry subscale of the Ware Health Perception questionnaire and a Demographic and Illness-Related Information Sheet during a one-hour personal interview. Data analysis consisted of descriptive statistics and Pearson correlations.

Main Research Variables: Delay in seeking treatment, worry about breast cancer and symptoms, and sociodemographic characteristics.

Findings: Contrary to the literature, participants reported short patient and provider delay. As a result of little variability in delay, predicting those for whom worry was a deterrent or a motivator to seek prompt treatment was not possible.

Conclusions: Although delay does exist, African American women with sociodemographic characteristics similar to white women who do not delay are likely to have similarly short symptom durations. Further study to determine who is helped and who is hurt by worry and other possible intervening factors would be useful. Including biologic characteristics such as tumor staging and hormone receptor information in future studies would allow for a closer examination of stage at diagnosis and biologic influence.

Implications for Nursing: Interventions with African American women cannot assume that delay exists. Strategies that consider both individual and cultural group differences are essential to the early seeking of a diagnosis and treatment for breast cancer symptoms among African American women.

African American women with breast cancer continue to die more often than other groups of women despite efforts to improve survival through the development of effective detection techniques and increased numbers of viable treatment options (American Cancer Society [ACS], 2005; Joslyn & West, 2000). The most prevalent finding concerning decreased survival for African American women has been their presentation for diagnosis and treatment at a more advanced stage of the disease, as evidenced by increased tumor size and an increased frequency and number of positive axillary lymph nodes (Caplan, Helzlsouer, Shapiro, Wesley, & Edwards, 1996; Coates et al., 1992; Li, Malone, & Daling, 2003; Moormeier, 1996; Trock, 1996). African American women's advanced stage of disease at diagnosis has been attributed largely to a delay in seeking treatment (Hunter et al., 1993; Lannin et al., 1998).

Key Points . . .

- ▶ African American women's advanced stage of disease at diagnosis has been attributed largely to a delay in seeking treatment.
- ▶ Nurses must consider multiple system-, patient-, and biologic-related factors that might influence delay and advanced-stage disease.
- ▶ Future studies are needed to better understand the relationship between worry and delay in seeking treatment.

The study reported in this article was part of a larger project examining the relationship of causal attributions to psychosocial adjustment in African American women with breast cancer in which attribution theory was used as a guide in examining the delay and worry responses of African American women to breast cancer symptoms (Bradley, 1999). What is being described is the existence of delay in seeking treatment and worry for breast cancer symptoms among African American women. Additionally, the association of delay with worry about breast cancer and selected sociodemographic and illness-related variables was examined.

Literature Review

For more than 40 years, various disciplines have investigated the association of demographic and psychosocial factors with delay in seeking treatment, particularly for cancer symptoms, from a variety of perspectives in retrospective studies (see Long [1993] and Facione [1993] for comprehensive reviews). Delay has been attributed primarily to patient characteristics such as fatalistic attitudes and distrust of the healthcare system (Conrad, Brown, & Conrad, 1996; Powe & Finnie, 2003).

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Practitioner- and system-related barriers such as lack of accessibility to preventive health care and medical treatment, inadequate continuity of care, and insufficient access to detection, diagnosis, treatment, and rehabilitation often are not examined as contributing to delay (Phillips & Smith, 2001). Despite widespread investigation of the delay phenomenon, research findings to date have been inconsistent. Furthermore, whether delay exists as a distinct component of healthcare seeking for breast cancer symptoms and the extent of the delay's existence in African American women are unknown.

The idea that delay in seeking treatment for breast cancer might be associated with an underlying cognitive process such as worry is not new, although this association has not been investigated adequately. Delay and worry appear to be culturally influenced (Facione, 1993; Facione & Katapodi, 2000; Hoffman-Goetz & Mills, 1997), yet the majority of studies in which investigators have examined delay or worry have not had an adequate representation of African American women in the sample.

Worry as a motivating force in seeking treatment is not fully understood. Borkovec, Robinson, Pruzinsky, and DePree (1983) defined worry as a cognitive process stimulated by a threatening event that has the possibility of a negative outcome. Breast cancer symptoms would appear to fit this description, and several studies on delay in seeking treatment have included a measure of worry or anxiety about cancer. The association of worry and delay behavior continues to be unclear, although the literature suggests that such an association does exist.

Delay in seeking treatment has been found in individuals who worry about cancer, their health, and other things in general (Caplan et al., 1996; Miller & Hailey, 1994). In contrast, investigators have noted that a dismissal of the threat of breast cancer symptoms (i.e., nonworry) played a major factor in delay in seeking treatment (Facione & Dodd, 1995; Facione & Giancarlo, 1998; Gates, Lackey, & Brown, 2001). Other researchers (Caplan et al., 1996; Coates et al., 1992) have noted that individuals who worried were more apt to seek treatment promptly.

The conflicting findings and limited research involving the association of delay with worry suggests the need for further investigation. Limitations exist regarding the comparability and generalizability of previous studies where delay and worry have been examined because of differences in definitions and measurements of these concepts, and the inadequate representation of minority groups.

This study addressed the following research questions.

- What are the delay and worry experiences of African American women seeking treatment for breast cancer symptoms?
- What is the relationship of delay to worry?
- What is the relationship of delay to demographic and illness-related variables?

Methods

Sample

Participants were 60 African American women who were 18 years of age or older and diagnosed with breast cancer. The sample size of 60 was determined by Cohen's (1988) power analysis for the regression analysis in the larger study using an alpha level of 0.05 to detect a medium effect size

($R^2 = 0.13-0.25$). The sample included pre- and postmenopausal women who were receiving or had completed breast cancer treatments, including radiation, chemotherapy, or surgery. Although other active major illnesses such as heart disease might affect delay, because of the high degree of comorbid medical conditions in the African American population (Freeman & Wasfie, 1989), individuals with other illnesses were not excluded from this study. Participants who reported other illnesses were asked to direct their answers to their breast cancer experience only.

Instruments

Sociodemographic and clinical characteristics: The Demographic and Illness-Related Information Sheet was a questionnaire designed by the investigator to obtain information about personal characteristics such as age, marital status, occupation, income, employment status, and religiosity. The illness-related information gathered included descriptions of treatment characteristics and breast cancer symptoms.

Delay measures: For the purposes of this investigation, delay in seeking treatment was measured by self-report and verified, when possible, with patient chart information. Questions measuring delay were incorporated into the Demographic and Illness-Related Information Sheet. Participants were asked for several dates: the date their symptom was discovered, the date they first sought consultation with a healthcare provider for their symptom, and the date of diagnosis.

Consistent with the literature reviewed by Facione (1993) and previous investigators who have examined delay in seeking treatment, delay was categorized into two types: patient delay and provider delay. Patient delay in this study was measured as the time, in weeks, from discovery of a breast symptom to the time the woman sought evaluation of the symptom by a healthcare provider. Provider delay was measured as the time from a woman seeking a healthcare evaluation of a breast symptom to initiation of treatment.

Worry measures: The Ware Health Perceptions Questionnaire (HPQ) subscale of health worry/concern (Ware, 1976) was used to measure general health worry. The HPQ consists of eight self-administered scales constructed from 32 items designed to measure individuals' opinions about personal health or health-related perceptions. Statements for each scale were worded favorably or unfavorably. Participants were given a choice of five responses: definitely true, mostly true, don't know, mostly false, and definitely false. The possible score on the health worry/concern subscale (4 items) ranged from 4–20, with a higher score indicating greater worry. According to Ware, replications of the findings of successful scaling studies across five field tests in general population samples that differed widely in socioeconomic and racial characteristics supported generalization of the findings regarding scale development. Both internal consistency and test-retest stability estimates (median coefficient = 0.60) indicated that the HPQ scale relevant to this study, the health worry/concern subscale, was sufficiently reliable (Ware).

Two other worry measures designed by the investigator from a literature review were used to determine the existence of worry about the initial breast cancer symptom and the breast cancer diagnosis. Each measure of worry was a single-item rating scale included on the Demographic and Illness-Related Information Sheet. Each scale ranged from 1 (not at all) to 10 (a lot) in response to the questions "When you first

noticed your symptom(s), did you worry?" and "When you were first diagnosed, did you worry?" A higher score indicated a greater degree of worry.

A fourth single item was used to determine the perceived helpfulness of worry in motivating women to take action about their symptoms. Participants were asked to rate the helpfulness of worry on a scale of 1 (not at all helpful) to 10 (very helpful).

Procedure

African American women who were being treated in the oncology, radiation, or outpatient breast cancer detection units at two inner-city hospitals in the northeastern United States were approached in person or via telephone to ascertain interest in the study. Appropriate institutional review board approval was obtained. Additional recruitment was done at breast cancer conferences and health fairs. The investigator also used "word of mouth" as a recruitment technique, whereby study participants referred friends and coworkers to the study.

Consenting participants completed the worry subscale of the Ware HPQ and a Demographic and Illness-Related Information Sheet during a one-hour personal interview conducted in a place of convenience for them, such as a room in the outpatient clinic or the participants' homes.

Initially, recruitment was limited to participants with a length of diagnosis of less than two years because participants were asked to recall information. Because of the difficulty in recruiting participants within two years of diagnosis and the willingness of participants at later time periods postdiagnosis to discuss their experiences, recruitment was subsequently extended to African American woman at any point postbreast cancer diagnosis. In consideration of the limitation regarding recall of information for women beyond two years postdiagnosis, Owens and Heron's (1989) suggestion regarding the accuracy of estimates of delay in seeking breast cancer diagnosis and treatment was followed. Participants having difficulty with the recall of dates measuring delay were questioned using a guided recall procedure: They were asked to recall significant events (such as birthdays and holidays) that coincided with the time period in question as a way of increasing the accuracy of the delay measures.

Results

Sample

Personal characteristics: Table 1 summarizes the personal characteristics of the 60 women. The mean age was 49.3 years (SD = 9.9, range = 24–75). The time since diagnosis ranged from 2–348 months. Participants were interviewed within two years (60%) of their diagnosis to more than five years (22%) after diagnosis. Although more than half of the participants (63%) were divorced, widowed, or never married, 80% lived with a significant other. Significant others were primarily identified as college-aged children or an older parent. The majority of women (95%) had graduated from high school, partially attended college, or graduated from college. Of these women, 10 participants had obtained graduate degrees. Only 3 women reported partial high school education.

Seventy-five percent of the sample was employed in occupations ranging from clerical to professional, such as nurses or teachers. Approximately 80% of the sample had an annual income more than \$20,000, with 92% of the women in the

sample having health insurance at the time of symptom discovery. More than 98% (n = 59) reported an affiliation with an organized religion. The most frequent affiliation reported was Baptist (43%). Church attendance was high, with 95% (n = 57) reporting occasional to regular attendance.

Dimensions of breast cancer symptoms: The primary symptom for 70% of the sample was a painless lump. Symptoms were discovered by 43% of the sample through breast self-examinations (n = 26). Another 32% (n = 19) were found by accident, which included warming fingertips under the arm, washing the breast during a shower, or discovery by a relative or friend. A healthcare provider discovered symptoms in 25% of the women through a clinical breast examination (n = 8) or mammogram (n = 7).

Table 1. Sample Characteristics of African American Breast Cancer Survivors

Characteristic	n	%
Age (years)		
\bar{X} = 49.3; SD = 9.9	–	–
24–42	13	22
43–50	22	37
More than 51	25	42
Time since diagnosis (months)		
2–24	36	60
25–36	12	20
More than 60	12	20
Marital status		
Married	22	37
Divorced, widowed, or never married	38	63
Living arrangement		
Alone	12	20
With someone	48	80
Education		
Partial high school	3	5
High school graduate/partial college	36	60
College graduate	21	35
Employment status		
Employed	45	75
Unemployed	15	25
Income		
Less than \$20,000	11	18
\$20,001–\$40,000	31	52
More than \$40,001	17	28
No response	1	2
Health insurance		
Yes	55	92
No	5	8
Religious affiliation		
Baptist	26	43
Other	33	55
None	1	2
Church attendance		
Regular	38	63
Occasional	19	32
Never	3	5

N = 60

Note. Because of rounding, not all percentages total 100.

Treatment characteristics: The major treatment characteristic for more than 98% of the sample involved a surgical procedure such as mastectomy, lumpectomy, or biopsy. Other treatments included chemotherapy (67%), radiation (60%), and hormone therapy (46%).

Delay Characteristics

Delay in seeking treatment was categorized into two types of delay (see Figure 1). The length of patient delay ranged from 2 days to 36 months. More than 86% (n = 52) sought treatment within one to four weeks of recognition of the symptom. The length of provider delay ranged from within 1 week to 15 months. Almost 95% (n = 57) of the participants received a diagnosis within one month of seeking treatment from a healthcare provider.

Worry Characteristics

General health worry scores (see Figure 2) ranged from 4–16 (\bar{X} = 10; SD = 2.5). Fifty percent of the group tended to worry somewhat (score of 9–12) about their health; only 28% worried a little (score of 4–8), whereas the other 22% had moderately high levels of worry (score of 13–16). No one reported worrying “a lot” (score of 17–20) about her health. The scores for worry about breast cancer symptoms ranged from 1–10 (\bar{X} = 5.5; SD = 2.9). Thirty-seven percent (n = 22) described their worry levels as 7 or more. Worry scores about breast cancer diagnosis also ranged from 1–10 (\bar{X} = 7.1; SD = 3.06). In contrast to the 37% who reported high levels of worry about the symptom, after diagnosis, almost 67% (n = 40) scored their worry as 7 or more (see Figure 3). The scores for perceived helpfulness of worry in seeking treatment also ranged from 1–10 (\bar{X} = 5.7; SD = 3.7). This distribution was U shaped (see Figure 4). That is, approximately one-third of the group perceived worry to be either not at all helpful (37%) or very helpful (33%), whereas the other one-third in the middle (30%) perceived worry as neutral.

Relationship of Worry and Delay

Using Pearson correlations, no relationship was found between the worry measures and either patient delay or provider delay. In addition, cross-tabulations showed no curvilinear relationship. The women scoring highest on worry had delay scores comparable to women scoring low on worry.

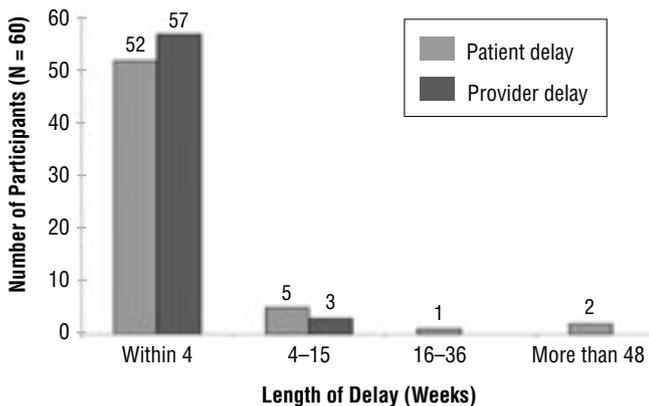


Figure 1. Distribution of Patient and Provider Delay

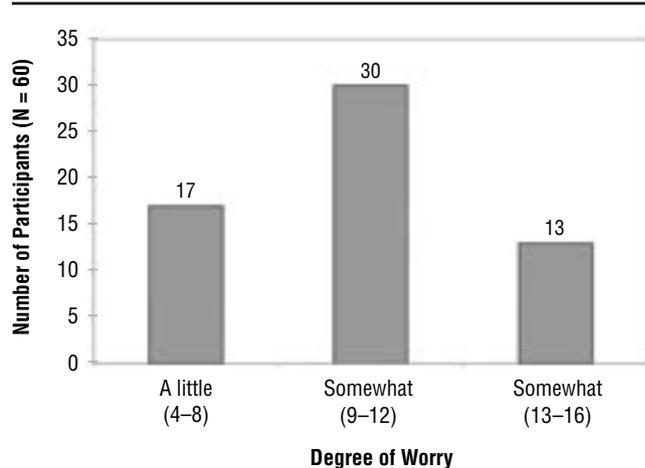


Figure 2. Degree of General Health Worry

Relationship of Demographic Variables and Delay

No relationship was found between the demographic variables of age, education, employment status, occupation level, income, and patient or provider delay (r = 0.03–0.15). Similarly, marital status, living arrangement, health insurance, and religious affiliation were not associated with delay. In general, the differences in delay tended to be only one week, which was not clinically significant. Instances where the differences were greater resulted from the effect of a few moderate outliers given the small sample size. Little clinically significant variability was noted in patient or provider delay. Regarding patient delay, 77% of the participants had one- or two-week delays, and 84% had one week or less provider delay. How the breast cancer was discovered (i.e., through breast self-examination, clinical breast examination, mammogram, or by accident) did not relate to patient or provider delay.

Discussion

The most important finding of this study was that, contrary to the literature, the African American women in this sample reported short patient and provider delay. These findings are similar to results reported from the National Cancer Institute’s (NCI’s) Black/White survival study (Caplan et al., 1995) that indicated that women with income levels more than \$20,000, at least a high school education, presenting symptoms including a palpable lump, health insurance, and a high degree of organization participation were less likely to delay seeking treatment. In the NCI Black/White Survival Study, however, white women were more likely than black (African American) women to have these characteristics.

Based on the findings of the NCI survival study (Caplan et al., 1995) and the similarities in personal characteristics and types of breast cancer symptoms of the current sample, the findings regarding short delay should not be surprising. This was a relatively educated, employed group with a high degree of organization participation, such as church attendance. Income level was middle range, and an overwhelming majority had health insurance at the time of symptom detection. More than three-quarters of the participants had a symptom found

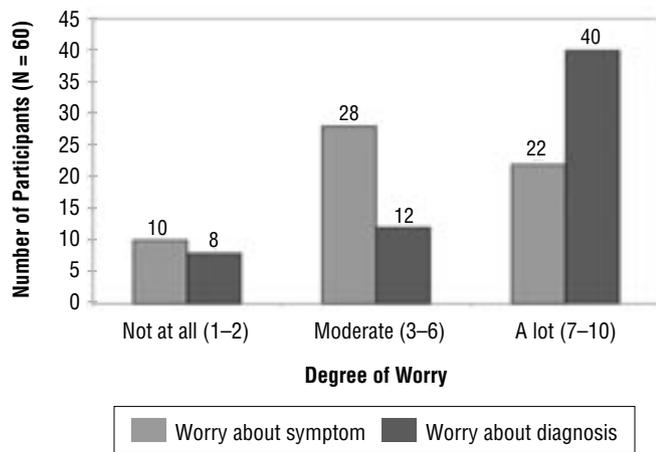


Figure 3. Degree of Worry About Symptoms and Diagnosis

through the standard detection methods (ACS, 2005) of breast self-examination, clinical breast examination, and mammogram, indicating that these women were knowledgeable about, had access to, and used these detection procedures.

Similarly, Mitchell, Lannin, Mathews, and Swanson (2002) found that women who reported timely breast cancer screenings were more likely to have full health insurance coverage, knowledge about breast cancer risk factors, and involvement in the healthcare system. The finding of short symptom duration in African American women who have personal and breast cancer symptom characteristics comparable to white women with short symptom duration in other studies supports Lannin et al.'s (1998) recommendations that socioeconomic differences and associated factors be examined for their role in the delay in seeking treatment phenomenon.

African American women in this study reported moderate levels of worry about their general health. An interesting observation is that no one reported worrying a lot about her health. Two of the four items asked participants to compare their level of worry to others. All of the women were reluctant to do this. Additional study is necessary to ascertain methodologic considerations regarding the reluctance of African American women to compare themselves to others.

Participants reported varying degrees of worry about breast cancer symptoms and the breast cancer diagnosis. Although only one-third of the participants described their worry levels about the symptom as high, three-quarters of the women reported "knowing" that their symptom was cancer. Additionally, contrary to other studies reporting fatalistic beliefs of African Americans about cancer (Conrad et al., 1996; Jennings, 1996; Phillips, Cohen, & Moses, 1999; Powe, 1996), the majority of participants believed that their symptom was something that could be taken care of. This feeling of confidence might account for the lower degree of worry about the symptoms reported.

After diagnosis, in contrast to the 37% who worried about the symptom, almost 67% scored their worry as seven or higher. This increased worry score is consistent with findings described by Easterling and Leventhal (1989) in an investigation of threat cognitions and worry. They found that a definitive diagnosis was more likely than generic symptoms to stimulate worry.

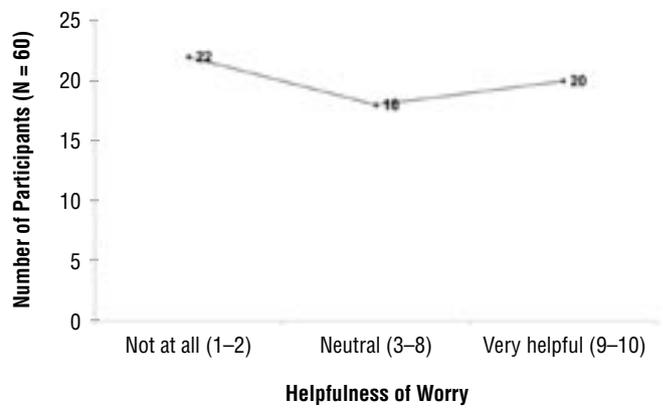


Figure 4. Perceived Helpfulness of Worry

A mixed effect of the influence of worry on delay was found in this study. Consistent with findings in other studies, worry appears to be helpful to some and detrimental to others. Worry about breast cancer was reported as very helpful as a motivator in seeking treatment for a third of the sample, whereas another third perceived worry as not at all helpful, and the middle third described worry as not making a difference. The percentage of women scoring the highest worry levels had comparable delay scores to the percentage of women scoring the lowest levels of worry.

Gates et al. (2001) also found a mixed response to worry. Several women reported that they did not follow-up on diagnosis and treatment because of an intense fear. In this case, similar to Phillips' (1999) findings, fear (worry) was paralyzing. Others in the Gates et al. study reported delaying after dismissing the seriousness of their symptom.

Several investigators (Loescher, 2003; McCaul, Branstetter, O'Donnell, Jacobsen, & Quinlan, 1998) have suggested that moderate levels of worry are the most beneficial because women are more likely to seek information and engage in risk-reducing behaviors. Other investigators have suggested that high levels of worry may hinder positive health-seeking behaviors (Diefenbach, Miller, & Daly, 1999). As a result of little variability in delay, predicting those for whom worry was a deterrent or motivator to prompt help-seeking was not possible. Further study to determine who is helped and who is hurt by worry and other possible intervening factors would be useful.

Limitations

The primary limitation of this study is the use of a retrospective self-report measure for delay in seeking treatment. Distortions of memory, selective recall, and a natural tendency to provide a rational explanation to past events because of the social desirability of participants could have potentially biased this self-report. However, some investigators have observed that women mark the timing and exact circumstances of breast symptom discovery (Lierman, 1988), making distortions of memory and selective recall less likely.

Another important limitation was the unavailability of histologic tumor data, limiting the examination of a possible biologic influence of tumor size on diagnosis. More recently, investigators have suggested the addition of biologic determinants of

advanced stage in African American women with breast cancer as another factor to consider (Rose & Royak-Schaler, 2001; Simon & Severson, 1997).

The generalizability of this study's findings, although limited because of the small sample size, purposive sampling, and the sample homogeneity, do add important information regarding the responses of this particular group of African American women to breast cancer symptoms. Further research including various socioeconomic and geographic groups, such as rural and poor populations, would be useful for possible comparisons (Jones & Chilton, 2002; Kreiger, 2002).

Nursing Implications

Researchers, clinicians, and educators must consider multiple factors that might influence delay or advanced-stage disease presentation. System-related barriers must be examined as well as the patient's action or inaction (Caplan et al., 1995; Smith, Phillips, & Price, 2001).

Given the prevalent assumption that African American women's presentation at an advanced stage of disease is a result of delay in seeking treatment and the relatively short delay periods of this sample, inclusion of biologic characteristics such as tumor staging and hormone receptor information in future studies would allow for a closer examination of stage at diagnosis and biologic influence.

Phillips and Smith (2001) and Kreiger (2002) underscore the importance of the intra- and intercultural differences and

similarities of the group being studied. For example, when doing assessments, researchers cannot assume that all African American women delay seeking treatment, as indicated by the short symptom duration of African American women in this study, contrary to the literature.

Prior to creating health messages, individual differences also must be considered regarding worry and its role in care seeking because worry in this study served as a motivator for some and a deterrent to others in seeking treatment. More precise assessments enlisting perceptions and considering individual beliefs will enable nursing goals and interventions to be culturally sensitive and tailored to the specific needs of the individual (Farmer & Smith, 2002; Moore, 2001; Rajaram & Rashidi, 1998). Strategies that take into consideration both individual and cultural group differences are essential to the early seeking of a diagnosis and treatment for breast cancer symptoms among African American women, making it more likely that women will participate in early detection and diagnostic activities.

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