Published in final edited form as:
Health Educ J. 2014 May ; 73(3): 274–284. doi:10.1177/0017896912471048.

Breast self-examination beliefs and practices, ethnicity, and health literacy: Implications for health education to reduce disparities

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Abstract

Objective—This study aimed to quantitatively and qualitatively examine breast cancer screening practices, including breast self-examination (BSE), and health literacy among patients with chronic disease.

Design—A prospective, multi-method study conducted with a targeted purposive sample of 297 patients with diabetes and/or hypertension from four ethnic groups (Latino, Vietnamese, African American, White-American) at an urban community health center.

Setting—A federally qualified health center in Western Massachusetts.

Methods—In our four-year study, 297 participants completed cancer knowledge, beliefs, attitudes and screening utilization scales and measures of health literacy. In addition to survey data

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AUTHOR DISCLOSURE STATEMENT
No competing financial interests exist.

collection, we conducted in-depth interviews, focus groups, home visits, and chronic disease diaries (n=71).

Results—In focus groups, African American, Vietnamese and Latina participants offered interviewers an unprompted demonstration of BSE, reported regular BSE use at particular times of the month, and shared positive feelings about the screening method. In a sample where approximately 93% of women have had a mammogram, many also had performed BSE (85.2%). Women with adequate health literacy were more likely than those with inadequate health literacy to rely on it. Despite being positively inclined toward BSE, Vietnamese women, who had the lowest health literacy scores in our sample, were less likely to perform BSE regularly.

Conclusions—BSE seemed to be an appealing self-care practice for many women in our study, but we conclude that proper BSE practices may not be reinforced equally across ethnic groups and among patients with low health literacy.

INTRODUCTION

A highly political topic, there is much debate about the guidelines for breast cancer screening. Breast self-examination (BSE) was de-emphasized when research suggested that BSE has little effect on mortality reduction.[1] While the US Preventive Task Force determined that breast self-examinations show no benefit for women,[2] other evidence suggests that BSE can be beneficial for detecting breast cancer in high risk women.[3] Moreover, recently published research reveals that many breast cancers are found by women themselves.[4]

Many policy-making and health education institutions in the United Kingdom and the United States have shifted their cancer control efforts toward breast awareness (BA), which requires a vigilant attitude toward breast changes in lieu of routine BSE.[5] As public health recommendations about mammography undergo contestation and revision, BSE continues to offer a woman-controlled self-care technique to low-income patients at the federally qualified health center in Massachusetts where we conducted our study. These patients continue to conduct BSE and view it as an important aspect of their self health care. In this paper, we present data showing that this group of women uses breast self-examination (BSE) but the regularity of use varies by ethnicity and health literacy. Using quantitative and qualitative data, we describe BSE practices in our sample, explore women's retention of BSE education, and examine associations by ethnicity and health literacy. Finally, we suggest some implications of our findings for breast cancer education, which many experts argue should be focused on a breast health regimen that includes mammography, clinical exams, and BSE.

Barriers and enablers to breast health education

Much research about BSE knowledge, beliefs, attitudes, and utilization is conducted internationally, as the United States and Canada have shifted focus to other forms of early detection for breast cancer, such as mammography and clinical breast exam.[6] Particularly in limited resource contexts, it is believed that BSE is a valuable screening tool in the absence of widespread access to mammography.[7] Hence, research on breast self-examination as part of general breast health programs continues apace among underserved communities in North

America.[8] More voluminous research in international contexts has shown that breast self-examination education can effectively increase knowledge about the practice [9] and encourage attitudes that help facilitate self-screening.[10] Some of this research reveals that women who do not use BSE regularly have not been instructed how to do it.[11] Other research has found that women know how to perform BSE and do it, but do not perform it regularly.[12]

While BSE is often included as part of a general approach to breast health practices, some groups of women may not have access to all recommended screenings, such as mammography or clinical breast examination. In addition to socioeconomic barriers to screening, research suggests that literacy or education level may affect knowledge and practice of breast cancer early detection.[13] Furthermore, low health literacy has been associated with low adherence to breast cancer screening.[14] Tailoring education to particular marginalized groups can positively affect breast screening use[15], but perception of bias and discrimination in the health care system can affect a woman's likelihood of engaging in breast health practices.[16]

This perceived bias may keep women from seeking immediate assistance from a provider when they detect a change in their breast. Despite the fact that they use BSE, many women delay visiting the doctor upon finding a lump or having breast symptoms, possibly because they are unaware of cancer's symptoms [17], they are distressed by the finding [18], or they have limited access to health care.[19] One study found that Latinas and African American women who have experienced bias in the health care system might be more likely to delay a visit to their doctor to follow up on suspicious breast symptoms.[19] Moreover, researchers have found that socioeconomic status may lead to delays in cancer diagnosis [20] and later stages at diagnosis.[21] While these delays might be explained by lack of access to regular health care, they can also result from providers not recommending screening to low-income minority women.[22] By removing major economic obstacles to cancer screening and treatment and promoting inclusiveness in health care contexts, providers may play a part in mitigating these delays.

METHODS

At the federally qualified health clinic where our National Cancer Institute-funded study took place, it is up to each individual practitioner to decide if she wants to instruct and encourage her patients to conduct BSE. Caring Health Center is a federally funded, Section 330 primary care clinic that cares for predominantly low-income and minority patients. It is located in a medically underserved area in Western Massachusetts, a region defined by few primary care providers, high infant mortality, high poverty and/or high elderly population.

This five-year, prospective study combined two waves (baseline and 12 months) of epidemiological survey collection and three waves (baseline, 12 months, and 24 months) of medical chart extraction, along with four qualitative data gathering approaches to explore the sociocultural factors that shape low health literacy and to assess the effects of low health literacy on chronic disease management and cancer screening use. This paper utilizes survey data collected during wave one with 297 participants in four ethnic groups. Using a stratified

purposive sample, we conducted surveys with African American, Latino, Vietnamese, and white patients. Bilingual/bicultural interviewers orally administered quantitative surveys in patients' preferred language (English, Spanish, or Vietnamese). Participants were diabetic or hypertensive patients at Caring Health Center who were identified and recruited from the patient database and through referrals from clinic staff. Seventy-one of these participants also completed at least one qualitative data collection activity, described further below.

Our sample reflects the federally qualified clinic's general population, which tends to be publicly insured and to have relatively low income and education levels. A third of our study participants had less than or equal to an 8th grade education and 74% estimated their household income to be less than $1,200 a month. Participants' median age was 56 years old. The youngest participant was 25 and the oldest was 85 years of age. Our sample was nearly evenly divided between men and women (men=148, women=143). Across ethnic groups, we made every effort to have equal numbers of each ethnicity but were limited by the enrollment guidelines, which required that individuals have a chronic disease, such as hypertension or diabetes. Our final sample make-up is roughly proportional to the clinic's Latino, African American, White, and Vietnamese patient populations. Thirty-four percent (n=100) of the sample was Latino, 22% (n=64) was African American, 30% (n=93) was Vietnamese, and 14% (n=40) was English-speaking White.

We chose a multi-method approach because quantitative methods provide numerical data with which we were able to seek statistically explanatory associations between health literacy, chronic disease management, and ethnicity, language, immigration status, and other cultural factors, while a qualitative approach allowed us to pursue hypotheses derived from the quantitative data and to discover new issues, factors and contextual influences.[23] This mixed methodology provided a more comprehensive understanding of behavior than can be achieved through a single method design, and it enabled us to explore the complexities within ethnic groups, which are quite heterogeneous.

Surveys included questions about self-management practices, health-seeking behavior, access to care, knowledge and attitudes toward cancer, and assessments commonly used to measure health literacy. We qualitatively explored the quantitative survey items with formative focus groups that explored health beliefs and practices, in an effort to ensure that the instrument was grounded in an awareness of a wide range of socio-cultural factors and "emic"—or "cultural insider"—understandings of health.[24] We adapted the Centers for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) to measure self-reported cancer screening utilization [25]. Participants were asked whether their physician recommended BSE or mammogram and whether they had the test. Questions regarding knowledge, beliefs, and attitudes about breast self-examination and mammography were adapted from Champion's work which employs the Health Belief Model (HBM).[26] To the extent possible, equivalent questions were asked about the two breast cancer screening tests and were intended to reflect either favorable (e.g. having the test will reduce my chances of dying from cancer) or unfavorable (e.g. the test will be painful, embarrassing) attitudes toward the test in question. We created a total of eight questions reflecting positive and negative attitudes toward these screenings. For mammography, there were a total of 3

positive and 5 negative statements; for BSE, there were 3 positive and 4 negative statements.*

In order to measure health literacy—which we define as the ability to understand and act on health information--we adapted the short form of the Test of Functional Health Literacy Assessment (s-TOFHLA) [27], the Rapid Estimate of Adult Literacy in Medicine (REALM) [28], and the Short Assessment of Health Literacy for Spanish Adults (SAHLSA).[29] We used the TOFHLA numeracy and REALM for all English speakers, the TOFHLA numeracy and SAHLSA for Spanish speakers, and TOFHLA numeracy only for Vietnamese speakers, due to a lack of health literacy instruments available for this group. For certain analyses, the REALM and TOFHLA scores were dichotomized to reflect "adequate" and "inadequate" performance. Cut-off scores for the TOFHLA numeracy, REALM, and SAHLSA tests were 13, 45, and 37, respectively.

All quantitative data were entered, cleaned and analyzed using SPSS.

Quantitative findings were triangulated with qualitative data from a sub-sample of 71 participants. We conducted 35 in-depth interviews, thirteen focus groups with 47 participants, 15 chronic disease diaries, and 12 home visits. The qualitative data reported here come from in-depth interviews and focus groups. These qualitative activities elicited participants' self-care practices and explanatory models for chronic disease, experiences with cancer screening, and their ability to adhere to lifestyle changes recommended by their health care providers. With participants' permission, interviews—including focus groups, chronic disease diary discussions, and home visits—were audio-recorded, transcribed verbatim and translated into English if conducted in another language. English transcripts were coded following an open-coding method [30] and analyzed using Atlas.ti, a qualitative data management software. Intercoder agreement was achieved through regular meetings among the PI, the research coordinator, and research assistants, who periodically coded the same transcripts and discussed their coding decisions to ensure that all raters understood how to apply particular codes to the data.

RESULTS

Many women told us they have performed breast self-examination (85.2%) and that their providers recommended it (78.3%) and/or taught them how to do the exam (69.9%). Historically, health educators targeted young women for BSE because they had not begun mammography yet and because they felt training while young will generate life-long breast health practices.[31] Some women in our study described learning BSE during their teenage years or in young adulthood and it is knowledge they retain into middle age and use regularly. When we asked about BSE in focus groups, many women raised their arms and demonstrated the procedure for us. In an African American focus group, women discussed their first opportunity to learn about BSE:

*The negative statement, "Having a mammogram or x-ray of the breast would cost too much money," was not applicable to BSE and therefore was not included in the BSE statements.

> Q: …And has one of your doctors told you about a self-breast exam or where did you learn about doing that?
>
> P3: I was young.
>
> P2: Yeah well they say you know…
>
> P3: You know, teenager years.
>
> P2: Yeah. Long time ago the doctor was saying oh you can, you know, check it yourself before…you start going to the mammogram 'cause … well, when you get forty they want you to start.
>
> P3: I was in high school when they taught me. When I first started seeing the doctor.

Later, in the same focus group, women told us that their doctors had not discussed BSE with them in quite some time. One participant mused that mammography might replace BSE as one ages. Explaining her providers' lack of BSE instruction, she said, "I guess they figured you'd probably know already know how to do it. But you're doing something, like going to have your mammograms and stuff, very regular." Importantly, women in our study learned BSE from their doctors, but they also told us they learned from public service announcements on television.

We found a marginally significant association between BSE use and ethnicity [$\chi^2(3)=6.23$; $p<.10$], indicating that Vietnamese participants were somewhat less likely than African American and White participants, in particular, to report that they had ever done a self-exam (Table 1). This pattern notwithstanding, the percentage of Vietnamese participants in our study who have done BSE is much greater than in studies of BSE in other low-income Vietnamese communities.[32]

When we asked participants how often they do BSE, the sample was nearly equally divided between those who have a routine of doing it at least every two months (45.5%) and those who perform BSE "when I think of it" (46.3%)☒. However, the picture becomes more complicated when we look at these same data by ethnic group, where we see ethnic variation in BSE practice (Table 2). White and Latino participants were more likely to say they do BSE at least every two months, while Vietnamese were least likely to do it every two months, replying instead that it is done "when I think of it."

Women who have a regular practice of BSE (rather than "when I think of it") describe doing it as part of daily and monthly routines of self-care, something they do while watching television or while in the shower. A Latina participant shared her BSE routine with us, telling us *when* she times her exam. She explained she does it, "like when I go to the bathroom, like when [I take] a shower, but since it is a monthly thing, [I do it] after I pass my period." We documented several instances of women describing BSE practice as part of their self-care regimen, an opportunity to "check themselves out." An African American

☒"At least every two months" includes the answers "every month," "every two months," and "weekly." Furthermore, 8.1% told us they never perform BSE or do not know how often they do it.

woman told us she does it, “Like when I’m showering, I make sure I give myself a breast test or if there’s anything on my skin, I immediately take care of it. Or unusual growths or something…anything. I really do check myself out as best I can.”

In examining the interaction of health literacy and BSE use, we found that while those with adequate TOFHLA and REALM scores are more likely to have done BSE, a large percentage of those with inadequate health literacy have done it as well (Table 3). While women with low health literacy *do* perform BSE, we must also consider the statistically significant difference in use between women with adequate and inadequate health literacy. We found that women with adequate health literacy appear more likely to rely on BSE than those with inadequate health literacy.

Maintaining Breast Health: BSE and Mammography

Our findings support other research that reports patients at community health centers are likely to have had a mammogram within the past two years.[33] Approximately 93% of our sample reported having had a mammogram, with about 78% of these women reporting it was within the past year. We found that across ethnicities, women were generally positively inclined toward both BSE and mammography. Furthermore, they had fewer negative feelings about BSE in general (Table 4). Vietnamese participants were the most positively inclined toward BSE and mammography, and showed a positive orientation toward all cancer screenings.

Based on answers to attitude scales about mammography and BSE, we found that participants believed in the efficacy of mammography and most did not believe that BSE is a screening that replaces it (only 11.9% believed mammography was not necessary if you do BSE). For example, 68.5% of women told us that mammography decreases one’s chances of dying from breast cancer (Table 5); on the other hand, fewer women, 60.1%, told us that BSE decreases one’s chances of dying. However, pain seems to be a major barrier for mammography that doesn’t exist for BSE: a significant percentage of women (51%) told us that mammography is painful, whereas only 7.7% told us that BSE is painful.

In in-depth interviews and focus groups, women in our study expressed an awareness of and desire for breast health, acknowledging that mammography may not be a pleasant experience and facing a cancer diagnosis is scary, but it is best to do whatever you can to address a potential health problem. Moreover, in an effort to maintain good health, some women expressed a desire to examine their breasts. A Vietnamese participant told us she only recently learned how to do BSE from the radiation tech who took her mammogram, but, she says, “Besides that, I would just feel [my breast] myself, before I [knew] about [how to do it]. Just to check.”

In general, participants in our study did not seem to feel that BSE replaces mammography or a clinical exam; instead, they view BSE as their contribution to the care and well-being of their bodies. One of our Latina participants described feeling as if she does a better job of examining her breasts than her doctor. She says, “Because sometimes the professional isn’t willing to rub well like one would on oneself.” However, she acknowledged that a

professional clinician or a mammogram would have a better chance of finding a lump than she would.

DISCUSSION

We found a significant number of participants in our study have done BSE and many of these women told us their provider recommended it and taught them how to do it. However, many of the mostly middle-aged women in our study also conceded that their providers have not reminded them to do BSE in many years. It is commonly accepted that women are more likely to do breast cancer screenings when their physicians recommend them, yet research has found that physicians may not recommend screenings to all patients equally.[34]

African American and White women were the most likely to have ever done BSE, although Latinas were more likely, along with White women, to have done BSE within the past two months. Medical recommendations state that BSE should be done at least once a month.[35] Despite the fact that Vietnamese women in our study reported more BSE use than those in other studies and they were also positively disposed toward performing BSE, many did not perform it consistently. Since many White women and Latinas reported that they performed it regularly, we see value in further research that investigates how health care providers and community educators approach BSE education in these groups.

Across ethnicities, women were positively inclined toward BSE. While the women in our study were positively disposed toward both mammography and BSE, they also acknowledged pain to be a barrier to mammography. Perhaps introducing women to BSE, as a low-barrier screening exam for breast health, can encourage regular mammography and other cancer screening use as well. We have previously reported that a positive attitude toward one type of cancer screening is associated with positive attitudes toward others as well.[36]

Despite being positively inclined toward BSE, Vietnamese women, who also had the lowest health literacy scores in our sample,[37] were less likely to perform BSE regularly. This finding is in line with other research that reveals low BSE utilization among Vietnamese immigrants to the US.[38] While we report here that those with adequate health literacy were more likely to perform BSE than women with inadequate literacy, we noted the high percentage of women with low health literacy scores who *have* done BSE. We hypothesize that BSE may resonate with many women, including those with low health literacy and we suggest educators and providers seize upon the positive feelings women feel about the self-exam to encourage proper BSE practice.

BSE appears to be an appealing self-care routine that resonates with many women, including those with low health literacy. BSE is often taught through verbal and touch instruction, which seemed to stick with many of the women in our study. By analyzing the reasons why BSE is so effective, health educators may be able to employ a similar approach for other preventive care practices, as well as reconsider BSE's utility for breast health programs. In considering BSE's resonance, we must also consider the multiple and varied sources from which women receive information about breast health and cancer, including the media, [39]

and the relative influences of these sources in forming their opinions about BSE. Moreover, our qualitative data lead us to understand that women retain the details and form of BSE instruction over time.

CONCLUSIONS

Although it may be performed less often and with less regularity than among groups with adequate health literacy, BSE appears to be a productive educational tool in promoting breast health and illness prevention even among groups with inadequate health literacy. Our research suggests its educational impact is long-lasting and is well endorsed by women across ethnic groups. Furthermore, BSE may facilitate a positive cancer screening experience that may lead to positive feelings about other cancer screenings and generate greater use of more medically invasive procedures.

BSE has become part of a self-care routine for many women in our study, as women initiate BSE practice after learning how to do it. While knowledge, beliefs and attitudes about cancer and cancer screenings are important, women receive information about breast cancer and encouragement toward screenings from many sources and are expected to be active consumers of information and care. In fact, research suggests that “patient activation,” in which patients are oriented to the general practices of caring for their health, can reduce health disparities regardless of health literacy levels.[40] We suggest that BSE instruction may offer a productive opportunity for women to partner with their doctors in maintaining good health. Our research among low-income women in a medically underserved area of the United States suggests that they have integrated information about breast health into their lives and health practices and they look to BSE as a method for taking an active role in their health care.

Acknowledgments

The project described was supported by Award Number R01CA128455 from the National Cancer Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Cancer Institute or the National Institutes of Health.

Thanks to the providers, staff, and patients at Caring Health Center for sharing their expertise with us. We appreciate Gloria DiFulvio, PhD, taking the time to review previous drafts of this paper. We also acknowledge the thoughtful input and contributions of Phuong Do, Jeffrey Markham, Ana Vargas, Victor Reyes, and Fayana Richards.

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Table 1

Have ever done BSE by ethnicity (p<.10)

African American	27 **(90%)**
Latina	44 **(86.3%)**
Vietnamese	35 **(76.1%)**
White	15 **(100%)**

Table 2

How often do you do breast self- exam? (by ethnicity [$\chi^2(6)=36.64$; $p<.0001$])

	African American	Latino	Vietnamese	White
At least every two months	48.1%	**63.6%**	10.8%	**73.3%**
When I think of it	33.3%	31.8%	**83.8%**	20.0%
Never/Don't know	18.5%	4.5%	5.4%	6.7%

Table 3

Use of BSE and Health Literacy

Have done BSE by TOFHLA [$\chi^2(1)=10.11$; $p<.001$]	
Adequate TOFHLA	93.7%
Inadequate TOFHLA	74.6%
Have done BSE by REALM [$\chi^2(1)=4.01$; $p<.05$]	
Adequate REALM	100%
Inadequate REALM	85.7%

Table 4

Overall disposition toward breast screening, by ethnicity

	White (n=15)	African American (n=30)	Vietnamese (n=47)	Latina (n=51)	F(3,139)
Mammogram					
Positive	**2.27**	**2.17**	**2.77**	**2.06**	**6.38 (p<.0001)**
Negative	**1.53**	**0.90**	**1.28**	**1.86**	**3.60 (p<.02)**
BSE					
Positive	**2.33**	**2.10**	**3.06**	**2.12**	**8.29 (p<.0001)**
Negative	**0.67**	**0.53**	**0.47**	**1.00**	**2.87 (p<.04)**

In developing the positive/negative scale, we summed the number of positive (n= 3) and negative (n=5) items expressing beliefs about BSE. “Positive” scales can reflect values ranging from 0 to 3 for both mammography and BSE. The “negative” scale for mammography can take values from 0 to 5 and the BSE negative scale can take values from 0 to 4. The “scores” reflect the number of positive or negative statements endorsed.

Table 5

Overall disposition toward breast screening

Attitudinal Items (selected)	Mammogram	BSE
When I have a____ I don't worry as much about breast cancer	59.4%	54.5%
Decreases chances of dying from breast cancer	68.5%	60.1%
I'm afraid to find out there is something wrong	50.3%	42.7%
Is embarrassing	10.5%	7.7%
Is painful	51.7%	7.7%
Not necessary, if you do (BSE or Mammogram)	11.9%	18.3%