



Breast Health Education for Working Women in Appalachia: Insights From Focus Group Research

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Background: *This study seeks to understand rural working women, their knowledge of health systems, and how breast health issues fit into their lives. A key aim of this study was to identify regionally and culturally specific factors that influence how these women approach breast health and to identify ways that more positive breast health behaviors can be achieved.*

Methods: *Five focus groups (N = 42) were conducted among women at sites where the Breast Health Outreach Program (BHOP) had been conducted. Focus groups were composed of 7 to 10 women who were in about the same age cohort.*

Results: *Women provided multiple insights about their attitudes and behaviors related to breast health concerns. Analysis of the data revealed that many of the comments clustered around two types of “systems” in these women’s lives: the professional health care system and personal community systems. The BHOP provides a bridge between these two systems and seems to facilitate positive actions. Workplace health professionals also provide a bridge between professional and personal systems.*

Conclusions: *Women exhibited the general distrust of the medical system that the literature indicates is often associated with Appalachian culture. However, this study found that distrust can be overcome with education programs that meet women where they live and work. Such programs are most likely to be successful when the materials and methods are sensitive to Appalachian culture and when medical services are brought into the community.*

Introduction

Studies have shown that early detection through screening mammograms and clinical breast examinations can reduce breast cancer mortality.¹ Breast self-examination (BSE) is more effective among women trained in the procedure.² Rural women typically are less educated than the general population about the importance of early detection, but several studies have found positive effects of educational programs targeted to women in these underserved areas.^{3,4}

Factors that seem to have a positive influence on breast health behaviors include perceived benefits of BSE, an understanding that mammography is a cancer screening tool, residence in an

area with easy access to mammography facilities, participation in the decision about screening, access to regular health care, health motivation, feelings of susceptibility to the disease, discussions with friends, strong social networks and social support, self-efficacy, higher income and education, marital status (married women reported more positive behaviors than single women), smaller families, Caucasian race rather than a member of a racial minority, and increased age.³⁻¹² Taken together, these factors tend to suggest that women living in rural areas may be at higher risk because of their overall lower access to health care and generally lower socioeconomic status.

Women in rural Appalachia are the primary focus of this study. In general,

Appalachian people have been found to have inadequate knowledge about cancer and the importance of screening tests.¹³ Some patients in this region have also been found to regard illness fatalistically and use religious faith to emotionally sustain themselves.¹⁴

Appalachia, a region federally defined by the Appalachian Regional Act of 1965, contains 399 counties in portions of 13 states within the United States. Appalachia has a history of economic instability, most commonly associated with outsider exploitation of its resources.¹⁵

While Appalachia is an underserved and understudied area, some studies have examined cancer education in this area. Sortet and Banks¹⁶ examined the relationship between health beliefs of rural Appalachian women and the practice of BSE. Women who reported more confidence in doing BSE and perceived more benefits from doing BSE were more likely to perform BSE regularly. Amonkar and Madhavan¹⁷ found that Appalachian women most likely to be in compliance with cancer screening recommendations are those who have health insurance, reside in urban areas, have better health (as self-reported), and are more educated.

The health beliefs of Appalachians are often different from those of mainstream Americans. By contrast, most health professionals share values of the academic cultures that shape their professions.¹⁸ This difference in value systems can lead to misunderstandings, stereotyping, and even indifference.¹⁶ A basic mistrust of the health care system among many Appalachian residents often leads to delay in seeking health care.¹⁹

Our study focused on a specific group of Appalachian women — those who live and work in rural eastern Tennessee. A key goal was to gain a better understanding of these women, their attitudes toward the health care system, and their responses to a breast health education program targeted to rural working women in this region. In particular, a key aim of this study was to identify regionally and culturally specific

factors that influence how these women approach breast health and to identify ways that more positive breast health behaviors can be achieved. This is an important group to study because Tennessee ranks fifth highest among the 50 states and Washington, DC, in breast cancer mortality, with a mortality rate for breast cancer deaths per 100,000 persons of 27.7 compared with 25.02 nationally.²⁰

Most study participants work in industrial jobs in the Appalachian region of Tennessee. Recent census data reveal that in East Tennessee, 24% to 41% of residents work in industrial jobs (manufacturing of durable and nondurable goods), and approximately half of the labor force is female. According to the Department of Labor and Workforce Development, the median salary for production occupations in this area is \$10.99 US per hour or \$21,100 gross annual income for full-time workers. Low-wage workers such as these are medically underserved because of concern about expense, lack of insurance (many of these women are part-time employees), difficulty accessing clinical services, and poor education.

Health education programs supported by workplaces have been successful in reaching large populations and changing intentions to perform breast health behaviors.²¹ Workplace programs are also most effective, in terms of both outcomes and cost of delivery, when they take into consideration the cultural background of employees.²² Research has shown group education is a viable way to bring new advances in breast cancer prevention to women.²³

Background

This study focuses on a grant-funded educational program operated out of a major research hospital in the region. The Breast Health Outreach Program (BHOP) began in 1996, taking 1-hour educational classes and a mobile mammography unit to Appalachian East Tennessee. Educational classes are designed to provide comprehensive information on the importance of early detection and diagnosis of breast cancer, ways to reduce controllable risks, and instructions on how to do BSE. Reduced-cost mammography services are provided by a mobile unit. Women 40 years of age and older are offered free clinical breast examinations by volunteer professional health care providers and reduced-cost screening mammography.

In 2000, the BHOP piloted a program that targeted industries, a major place of employment for low-income, medically underserved women. The program now serves 25 counties located in rural Appalachian East Tennessee. Since inception, the BHOP has educated more than 10,000 rural Appalachian women and screened a similar number of women on the mobile unit. The BHOP has established a relationship with

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Submitted June 20, 2006; accepted October 2, 2006.

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This study was funded by the National Cancer Institute through a grant coordinated by the Appalachian Cancer Network.

No significant relationship exists between the authors and the companies/organizations whose products or services may be referenced in this article.

The editor of Cancer Control, John Horton, MB, CbB, FACP, has nothing to disclose.

Abbreviations used in this paper: BHOP = Breast Health Outreach Program, BSE = breast self-examination.

more than 50 industries throughout remote and rural counties to provide breast health education and screening mammography.

Beyond learning about women's evaluation of the BHOP, this study also aimed to understand rural working women, their knowledge of the rural health system, and their perceptions of breast health, as well as to learn how breast health issues fit into the broad scope of their lives. This is important for cancer education programs that focus on underserved populations. The study attempted to let women speak in their own words to provide depth of insight into these issues.

Materials and Methods

Design

Because the study sought depth of understanding of an underserved population, a qualitative perspective was identified as the best approach. This study not only utilized qualitative methodology, but also approached the research phenomenon from a qualitative paradigmatic perspective.

The basic assumptions of a qualitative paradigmatic perspective drive the methodology and evaluative standards of the study. Ontologically, the qualitative paradigm assumes that realities are multiple and socially constructed. People are active meaning makers, and the realities of any phenomenon are created by those who live the experience (such as breast health).²⁴ As such, the research method should allow participants to freely express their "realities" of breast health. For this study, the qualitative method of focus groups was employed.

Focus groups are an ideal method for several reasons. First, focus groups have been successfully used in previous studies to learn more about attitudes and beliefs related to cancer.²⁵⁻²⁷ Second, focus group interviews are a culturally appropriate method for learning about the beliefs and health behaviors of those who are not part of the mainstream culture. A study that compared focus groups with survey research found that the focus groups were more suited to reproducing community attitudes and patterns of practice and explaining the reasons behind survey findings.²⁸ Focus groups allow participants to set their own agenda for discussion and are user-centered, thus aligning with the ontological paradigmatic assumption identified above.²⁶

Recruitment

Participants were recruited from areas in which the BHOP had conducted training sessions in the recent past. Women were recruited based on past attendance at the BHOP sessions. Women at those locations were simply invited to attend a research session related to the BHOP. Without exception, sessions filled with volunteers who came at the time requested. The close relationship

between the BHOP and the organizations where it has done presentations was reflected in this high level of willingness to participate in the focus groups. Five focus groups were conducted; three among women who had attended BHOP education sessions and two among those who had not attended a session, even though it was available at their workplace. In total, 42 women participated in these focus groups (27 who had attended a BHOP program and 15 who had not). Focus group participants ranged in age from 31 to 74 years (mean age 50.4). Location was a factor that brought women of similar age groups together. For example, one session was held in a location that attracted primarily retired women, while another was in an industry that had a high number of younger female employees.

All participants received an incentive of \$20 US for being part of the group. Participants were given a clear statement of the research purpose, and they provided their informed consent to take part in the focus group and to have the entire session tape-recorded.

Procedures

Two researchers conducted focus groups using a semi-structured guide to ensure that both facilitators explored similar topics. Key topics were personal history and the health care environment, personal behaviors related to breast health, personal responses to breast health issues such as risks and reinforcements, attitudes and responses toward breast health education programs, and support systems. In addition to leading discussions, facilitators also collected some written responses from participants. These included personal responses to word associations, drawings that allowed participants to express their feelings, and demographic data. Copies of the focus group discussion guide are available on request from the first author.

Following each focus group, the full session was transcribed. Researchers reviewed each transcription prior to conducting additional focus groups. Researchers also examined written material and drawings made by focus group participants. Before conducting the next focus group, the semi-structured guide was slightly modified as needed to probe for additional insights into rural Appalachian women and their attitudes and responses toward breast health issues.

All data were analyzed by a process of analytic induction. Analytic induction consists of scanning the transcriptions and other materials for themes and categories, developing a working schema from examination of initial cases, and then modifying and refining it on the basis of subsequent cases.²⁹ Negative instances that do not fit the initial constructs are sought to expand, adapt, or restrict the original construction. The emphasis is on category construction rather than enumeration. As such, results of the study focus on description of the themes and variations within the emergent categories

instead of on documentation of the number of instances of each idea as might be the case in a content analysis. Since the purpose of a paradigmatically qualitative study is to bring forth the various realities of participants, the role of theory in a paradigmatically qualitative study is to enlighten the emergent findings of the study rather than provide an a priori theoretical explanation through which to frame the analysis.

To answer the question of how many interviews are enough, the redundancy criterion was applied.³⁰ That is, the number of interviews conducted was expanded until clear patterns in the participants' construction of the Appalachian breast health experience had emerged and been confirmed. By the end of the fifth focus group, significant redundancy in responses was noted, thus indicating that no additional focus groups were needed.³¹

Finally, in reporting the findings, passages of respondents' words and descriptions are used. Such low-inference descriptors constitute the principal evidence for assessing the validity of the report and give the reader a basis for accepting, rejecting, or modifying an investigator's conclusions.³²

Results

A key theme that emerged from these focus groups was that women see two distinct and separate "systems" related to their health. The first is the "professional health system" as embodied in doctors, hospitals, clinics, and most health professionals. Various diseases and conditions also fit in this system. The second is the "personal community system" that includes family, friends, coworkers, and others who have a strong influence on health. As further discussed below, the professional health system is seen as largely suspect, while the personal community system is held in relatively high esteem. The BHOP seems to be a kind of "bridge" that, often in conjunction with workplace health programs, is seen as having personal value despite the professional orientation of the BHOP.

The Figure provides a brief overview of the relationships among professional, personal, and bridge systems. In this Results section, representative quotes are provided. Verbatim quotes are used to allow these women's voices to be heard. In the Discussion section, the Figure is explained in more detail based on insights that emerged from the focus groups.

The Professional Health System

Three key themes were related to the professional health system as revealed by women in this study: perceptions of women's health care issues in general, perceptions of local health care services, and perceptions of breast cancer.

Perceptions of Women's Health Care Issues

Overall, women who participated in this study felt that women's health issues were not taken as seriously by doctors as were those of men. Women reported their doctors telling them that symptoms were "in their heads." In explaining why this might be, participants often cited that their doctors could not understand women's problems because most of their doctors were men.

"Let me ask you this, would a man know exactly how you feel if you had cramps?"

"See, I'm paranoid on a man [doctor] because I had one [male doctor] that gave me the heebie geebies like anything."

"I think women are more compassionate and take more time. I have a female gynecologist and she'll stay there as long as you have any questions."

Yet, many women said that they prefer to hear about health issues from men.

"I'm okay with a doctor touching my breasts. I just stare at the holes in the ceiling while he is doing it. I'd rather have a male doctor. I just don't like a woman."

Perceptions of Local Health Care Services

Most of the rural women in this study did not hold their local health care services in high esteem. Many felt that they must travel to a larger city to receive quality health care.

"Rural counties have a difficult time getting good doctors. The poorer counties do not attract the better doctors, and the hospitals are not staffed."

"My doctor is always in a hurry."

"I think regardless if you have to go to the hospital you better have a family member that's going to be there and concerned with your care, or you will be lost in the cracks or they will have you on medicine you don't need to be on."

"If you're dealing with a complicated medical case and you send it to a local facility, you could be taking your life into your own hands."

For many women, health care is viewed as a confrontational rather than a cooperative experience. Some women expressed the belief that as women age, the issues are confounded. One woman summarized the sentiment, "The older you are, the worse they treat you."

The presence of medical staff at workplaces helps to offset the problems reported above:

"The doctor that saw me [at a local hospital] treated me like a speck of dirt. He told me I was having muscle spasms and to go home and rest. They didn't take X-rays, they didn't do any tests. He touched me like I was diseased, and I know why — because he found out I was on antidepressant medication. And from that point on, I was nothing. I got hold of [the plant nurse] and she sent me to the plant doctor. My rib was dislocated from my spine."

Perceptions of Breast Cancer

Perceptions of breast cancer were revealed through drawings the participants made of women with and without breast cancer. Those women with breast cancer were drawn as sad, scared, and flat-chested. Women without breast cancer were drawn as happy, secure, and buxom. When explaining their drawings, women said that breast cancer is scary but not necessarily a death sentence. For example, one woman described her drawing: "She's smiling, but she ain't got no hair because she's been to chemo, but she's smiling 'cause she knows she's going to live." Despite knowledge of treatment options short of mastectomy, women perceived those with breast cancer as having lost their breasts. Women also reported feeling a lack of control.

"It's just like a curse on the world that was set forth from Adam and Eve, that's just one of them. We're living here, we're susceptible. You don't have to drink or smoke."

"Knowing you're at risk doesn't give you a lot of control. I guess that's why you should do the self-breast exams, you do the mammograms, you know your family history and at least you can have a little control in it by doing those few things."

"I just don't want to deal with the ramifications. If I'm gonna pass, I'm gonna pass and when the time comes I'm ready to drop and don't want to stress out between now and then. How many stories have we heard where early detection didn't do anything, and I just don't want to stress over it."

However, fatalistic views seemed to be contrary to what most women in the study believed. Those women who seemed more motivated to actively participate in breast health activities used phrases such as, "I like being around," and "I think about my kids," which focus on reasons to live. Several respondents focused on the

need to take a positive approach to breast health. These responses often seemed to be embedded in a deeply held religious faith.

"Cancer is a very scary word, but it's treatable. I feel like it's treatable, and I think that with a positive attitude and you know having faith. Believing that you're going to get well is really important and it would scare me to death if I had it, but I would feel like I could get through it."

"You know what kills a lot of people with cancer, they're scared. They lay down and give up. You fight it, you got to fight it, and you've got to have faith in the good Lord."

The Personal Community System

Women in the study identified several different themes related to their personal communities that influenced their attitudes and behaviors concerning breast health. In particular, they discussed interpersonal influences, gender issues, and generational differences.

Interpersonal Influences

Many women reported that interpersonal communication channels (friends, family, and coworkers) were important sources of information and motivation related to health issues. Frequently, those who reported positive breast health behaviors indicated that the experiences of family members were a strong motivating factor.

"My sister had to have lumps taken out of her breast so I think about that usually right before I take a shower and do my exam."

"Well, my grandmother had breast cancer ... and had a breast removed, and my mother's had a cyst, which I've had, I've got cysts ... and uh, you know it's scary. I was young when my grandmother went through it and it's just something I wanted to keep an eye on. It is scary."

"Yeab, but if you're ever faced with it and someone in your family has it, the fear will knock you back to it [doing self exams]."

For other women who did not have family histories of breast cancer, the experiences of friends and acquaintances were important.

"Well, to me finding out a friend has it because that stays on my mind all the time. That reminds me to do my self exam."

"Cause it just seems like that if there was somebody close to me like my sister or best friend or something, that would make me think, 'You know, I need to do this.'"

Participants also talked frequently about the need for support systems to help them better understand and cope with women's health issues. At several of the focus group sites, one or two women had become either formal or informal leaders on health topics. In some cases an occupational nurse encouraged women to sign up for classes and mobile mammography. However, perhaps some of the more interesting stories were of women who were breast cancer survivors who became informal sources of information for their colleagues.

"I go to Karen [a coworker who is a breast cancer survivor], and I ask Karen a lot of questions ... because I feel like I can depend on her because she's there."

"I have good friends who would stand by me and even like my supervisors and people here at work. We've had three or four people here at work who've had situations with cancer and so I know if anything like that were to happen, I'd have people here to support me."

Gender Issues

In discussing sources of support, these women's conversations frequently turned to men in their lives. Women in this study generally felt men want to be supportive but do not have necessary information to cope with women's breast health problems.

"I think some men are more scared than their wives are, and they won't accept it. There's a lot of them like that. And they'll say, 'Well, you've got to have it [mammogram] done' but they just don't understand what you're going through. It's not their fault really, 'cause you don't know what you're going to go through."

"They just don't know, they're not ignorant, but they were raised, you know, women take care of theirselves, men take care of theirselves, I mean they just don't understand the times that it's not like it was way back when ..."

Not all women saw men as uninformed. In fact, several pointed out that men are more understanding today than they once were. Others noted that men can actually be partners in helping to screen for breast cancer.

"The men that I'm around are very open to discussing pretty much anything, and seems like society has opened up a whole lot more than what it was 15 or 20 years ago."

"I had three friends who died, and each one of them, their husbands were the ones who found the lumps."

Several of the women suggested that education programs should focus not only on women but also on men.

"I wish they'd bring more men into the awareness of it, and trying to get it out because I think a lot of people listen to men better than they do women."

"I mean just like always in the past, men have always been the leaders. So sometimes we still revert to that, you know, if a woman is telling you one thing and the man is standing up there, you may have a tendency to listen to the man because a lot of times, he's supposed to be the leader."

"I think if more men did talk about it publicly, the other men would listen, and then they're going to be more concerned with their spouse's health, their friends, their sisters, their mothers. You know, I think it would just help the whole issue a lot."

However, even though they thought men should be more educated and become more involved in breast health issues, they did not want men to be in the same training sessions as women.

"Maybe if they had a class just for men, which could educate them, without it being in a co-ed setting, you know where a woman wouldn't feel as open to discuss certain things."

Generational Differences

Some women in the study felt that breast health was a topic that their mothers were uncomfortable or unwilling to discuss with them. However, these women felt that they owed it to their daughters to have conversations about breast health. The women attributed this to overall changes in attitudes toward women's health issues; that is, women's health issues are not taboo as they were in the past.

"Growing up, me and my mother we got along really good and we always have, but as it comes to stuff like that [breast health], it's just

something that was never brought up or nothing was ever said. I don't know if it was embarrassing to her because most of my stuff that I found out was always at school, you know, from my friends. I have three girls, and I decided that I'd always be open with them and they could ask me anything. That's something I feel is important to do is make their daughters really know."

Good mother-daughter communications about breast health can also be of aid to the mother. As one participant stated, "My daughter calls me once or twice a month, 'Mother, it's time to check your breasts.'"

Breast Health Outreach Program

Women were asked to discuss specific aspects of cancer education training programs that were particularly useful to them. This section summarizes women's responses to training materials and methods, reminders, mobile mammography, and general responses to a rural workplace cancer education program

Training Materials and Methods

Participants reviewed materials that are used in the BHOP training program. They were asked to comment on what they found to be particularly useful and helpful.

"Most of those papers like that, you know, I would probably flip through it, but with the one that shows how to do the breast examinations, I would probably pay more attention to it because I hate to read."

The video used by the BHOP in the educational sessions was rated as very important.

"That video was a real good informing class. It shows you how to lay down and check it. And I thought, I was laying in bed one night watching TV, and I said, 'I'm just going to start doing that...'"

BHOP attendees also reported learning from the model used in training sessions:

"I liked the breasts where you were trying to find the lump 'cause I didn't realize how hard they were to find. I didn't know how deep you had to push to find the lump until I had that class the first time, 'cause I thought it would just be real easy to find one, and when I had that education, I realized that you've really got to mash to find them."

Women who have attended the BHOP sessions reported that personal stories told by the women who experienced breast cancer were powerful and motivating. Hearing stories of other people's personal experience with breast health problems was cited throughout the focus groups as being highly motivating in getting women to take breast health seriously. As one woman stated, "Seems like that sticks with me, you know, when I hear of other people."

Many women talked about how important it was to learn to do BSEs correctly. Some saw that as an activity that should begin early in a girl's life and saw medical professionals as core to the process of learning to perform BSEs correctly.

"My daughter's pediatrician told her how to do a breast exam when she was 13. He said just about the time they start their monthly cycles, start teaching them about getting a normal routine. That way they know early what's right and what's not."

Not all women had positive experiences with medical professionals.

"I don't reckon the doctor tells you how to do it."

"I go to a doctor, every year, and it's like, they do, you know, a breast exam, but that they like poke at you everywhere but you didn't understand why. He never explained a lot of things, about, you know that we learned from reading your packet, you know from the class."

Many women reported that prior to attending a BHOP class, they were uncertain about how to properly conduct a BSE.

"I always wonder if I'm doing something wrong. Whenever I'm feeling this breast, am I supposed to have this arm up when I feel, you know, when I'm examining this side?"

Reminders

Women also reported the need for reminder systems. Many pointed to a local television public service program that reminded women to do a BSE each month. Others praised the shower hanger reminders distributed by the BHOP.

"This [the shower hanger reminder] is the handiest little thing I've ever got a hold of. I hang it on the things behind my showerhead in the bathroom in the shower and it's hanging there. And it helps me to think of it [breast self-exams]. That little thing that hangs

around the showerhead has done me more good than anything.”

However, many women reported that it was difficult to remember to perform BSEs.

“I think it’s just getting tied up with children and not giving myself the time to do things that I need to do. I just forget to do it.”

Reminders were also important for annual clinical examinations and mammograms. Women reported that receiving a notice from a hospital or clinic or having the mobile mammography unit come to their workplace was the best way to remember those annual checkups.

Mobile Mammography

For women in the study without health insurance or who do not qualify for TennCare [Tennessee’s program for serving the Medicare-eligible population], mobile mammography is often the only opportunity to have a breast checkup.

“In all honesty, had the mammogram vehicle not come over there and [a staff member] put my name down and said to do it, I probably still wouldn’t have had one.”

The above quote also shows the importance of prompting by friends or opinion leaders within the community. While many participants associated discomfort, fear, and dread with mammograms, some participants suggested looking at mammograms in a more motivating light:

“I try to make the good out of it [mammograms]. They might find something I miss. I don’t look at it as much as something that I dread — it’s something that may find something I need to know. It’s a help to me, really.”

Response to Rural Workplace Education

Both those who had attended a BHOP session and those who had not were asked to give their impressions about the BHOP. One nonparticipant summarized the rural workplace education program as follows:

“Somebody cares enough to go out there and tell you what to do. So that’s how I see them. They care about women.”

Women who had attended a BHOP class thought the experience was useful.

“They [the BHOP presenters] are both so optimistic and enthusiastic about it, you know, just to watch them you think, man, I really need to make sure I’m doing this [BSE] every month, you know.”

“I found a lump under my arm that I found from doing the video. I didn’t know to check the back, and I checked under the back of my arm and I thought there’s a knot under there.”

The BHOP is a welcomed resource for the women who have attended a BHOP session. Compared to doctors and hospitals, which women spoke about as confrontational experiences, the BHOP was described as a cooperative and educational experience by women in the study. Clearly, women perceive the need for BHOP and view it as a useful, friendly, and caring information and health care resource.

Discussion

The Figure illustrates the basic relationship among the professional health system, the personal community system, and the BHOP as defined by the women in this study. At the top of the Figure are the two “systems” identified by the women. Clearly, they do not overlap. In fact, in the eyes of these women, the professional system does not seem to have direct relevance to their personal lives. At the bottom of the Figure are two circles indicating two basic types of behaviors — those that require a professional and those that are a woman’s personal responsibility. The BHOP sits in the middle of the Figure as a type of “bridge” system. The two-way arrow between the BHOP and the Personal Community System shows the strong two-way communication that links the BHOP to the women it serves.

The +/- markings represent insights that women provided about professional, personal, and bridge systems and behaviors. For example, women who have family members with cancer are more likely to engage in positive breast health behaviors. By contrast, most women reported that their mothers had little influence over their own breast health behaviors. Also, women were mixed in their response to how important the men in their lives were in influencing breast health behaviors. Most of the indicators in the professional health care system are negative. However, participants in the study saw the BHOP as bringing credible information from the professional system into the realm of women’s daily lives. They perceived strong two-way communication between the BHOP and the women whom the program serves.

One explanation for this finding is that incorporating culture into health information may significantly

enhance adherence to the pro-health messages advanced therein, a contention widely accepted by both practitioners and health communication researchers.^{33,34} Health intervention researchers often adapt two strategies to tapping into the underlying assumptions and traits of a culture: “constituent-involving” and “sociocultural.”³⁵ According to Kreuter and Haughton,³³ constituent-involving approaches draw on the experience of group members “indigenous to the culture [who] can help provide insight into values, norms, and meanings that are not always observable to an outsider.”

Given that the BHOP serves 25 rural Appalachian East Tennessee counties, has educated more than 10,000 rural Appalachians, and is present in 50 industries in Appalachia, the culture of these areas is inevitably and increasingly interwoven in its practice and relationships with its target public. Because the BHOP is considered to facilitate a strong form of two-way communication, establishing a sender-receiver dialogue that results in mutual adaptation and change, it is a constituent-involving approach to breast health campaigns. With its incorporation of values and norms specific to this region into its communication, the BHOP might create a critical bridge between professional and personal systems by intertwining elements of personal culture into information traditionally, and perhaps ineffectively, delivered by health professionals.

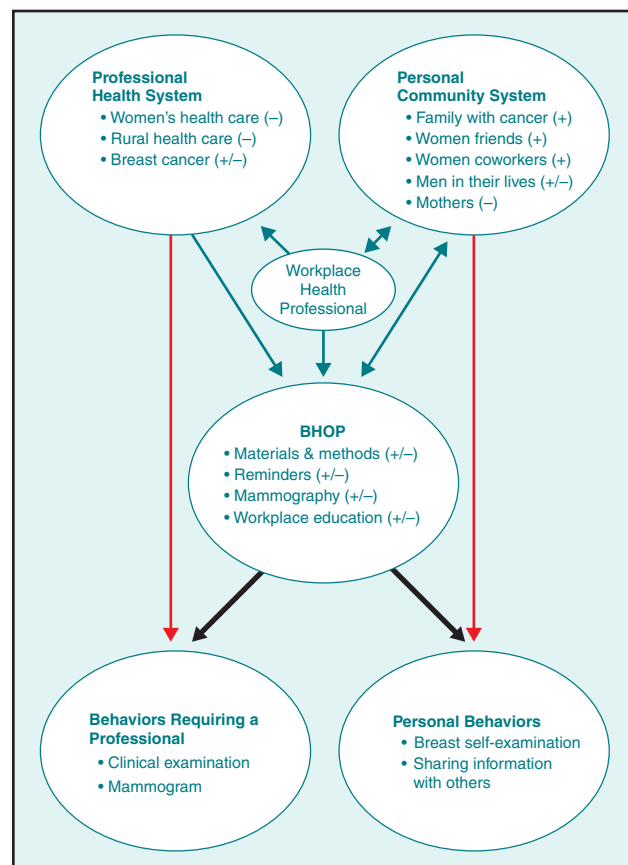


Figure. — A summary of systems and behaviors among study participants.

Unfortunately, audience segmentation in health campaign design has historically relatively ignored culture by substituting it with race or ethnicity.³³ Thus, programs such as BHOP might serve as exemplars to health intervention researchers and practitioners seeking to incorporate culture into health communication. Given the depth of the data provided in this study, it provides an interesting point-of-entry for future research to continue to build and evaluate models of health communication with culturally targeted approaches such as the BHOP.

Workplace health professionals are also important. Occupational nurses are often the primary contact for bringing the BHOP into the workplace. Two-way communication between these nurses and working women also seems to be strong. Nurses are able to help women make contact with plant doctors when needed to supplement the rural health care system, but the workplace health professionals have relatively little direct effect on breast health behaviors.

While the primary focus of the current study was on gaining depth of insight into the attitudes and beliefs of a particular population, the findings also provide some insights into behaviors. The red arrows connecting the professional and personal systems in the Figure with behaviors suggest relatively weak relationships. Without the BHOP, women do get minimal breast health services from the professional system, and there are some weak linkages between the personal system and personal behaviors with friends, coworkers, and others sometimes having direct influence on personal behaviors. However, as illustrated by the black arrows connecting the BHOP to positive behaviors, this bridge system strengthens the likelihood of both personal behaviors and behaviors requiring the services of a professional. The strong two-way communication between the BHOP and the women it serves helps to strengthen and channel the influence of the personal community system. The BHOP also brings professional values and services to Appalachia women. Even though the women did identify some potential negatives in the delivery of the education program, there is strong evidence that the BHOP is continually adapting its materials and methods to the culture of the people whom it serves and thus is enhancing positive behaviors.

Participants recognized the need for professionals to provide breast health services. However, because of relatively negative perceptions of and attitudes toward the professional health system, they seemed reluctant to seek out those services. Many indicated they would be more likely to get a mammogram if the BHOP brought the service to their workplace. Data provided by the women support this idea. Among the questions asked of all focus group participants was how many had been given a mammogram (among those for whom it was age-appropriate). All the women who had attended

a BHOP session reported having a mammogram at least once, compared with 73% of non-attendees. These data demonstrate that bringing messages into the home or workplace enhances results, and perhaps bringing culturally tailored health messages into the day-to-day environments or “real worlds” further enhances the perceived credibility and trust in the message, thus improving adherence.

As noted earlier, several factors in women’s personal community system might influence personal behaviors related to breast cancer. However, the linkages between the personal system and personal behaviors are often relatively weak, particularly for women who are not close to someone who has experienced breast cancer. Women were also asked to self-report on their personal behaviors. The BHOP seems to be a factor in influencing women to conduct BSE. A total of 96% of those who had attended a BHOP session reported doing regular BSEs compared with only 69% of non-attendees. There was also some evidence that those who had attended a BHOP session might take part in other personal behaviors such as sharing the information they learned with others, particularly with daughters.

The Figure shows that there is relatively little “cross-over” between the professional system and personal behaviors. While participants recognize the need for clinical examinations and mammograms, most feel that they do not learn adequately how to conduct BSE from health professionals and they do not gain information from health professionals that is valuable enough to share with others.

Implications for the Professional Health System

Findings of this study are consistent with literature on women’s health and rural health care. Recent studies have shown rural health professionals are “stretched thin” in terms of the number of people and geographic diversity of their service area, and they are also in need of continuing education about cancer-related issues.³⁶ Thus, programs that help to provide bridges between women and the health system are clearly needed in rural areas.

Several studies have explored the development of partnerships between community groups and health professionals. A key finding is the importance of communication and relationship-building that is based on mutual respect.³⁷ The current study illustrates the need for programs to bridge the gap that seems to exist between the professional health system and the women it serves. Both the BHOP and workplace health professionals fill that need.

Implications for the Personal Community System

Findings of this study are also consistent with earlier studies that examine the influence that significant others have on women’s breast health issues. In particular,

several earlier studies have shown the importance of both male and female family members.

As the women in the current study indicated, there seems to be an opening up of lines of communication between mothers and daughters. This is also supported by findings of other studies. Specifically, programs targeted at adolescent girls have been shown to help stimulate conversations about breast health with mothers and grandmothers.³⁸ Such intergenerational communication seems to be important to Appalachian women as well.

Several studies have shown that men play an important role in the women’s breast health issues. Many of those studies have focused on husbands of women who have been diagnosed with breast cancer.^{26,39} Generally, men were supportive of their wives and girlfriends but were perplexed about how to respond to their health needs.³⁹

Studies have found women are more frightened of cancer than men are, while men are more likely than women to hold negative opinions about cancer education programs.⁴⁰ The women in this study suggested the importance of bringing men into cancer education. They not only want the men in their lives to better understand the importance of cancer screening, but also want Appalachian men to lend their “authority” to women’s health issues.

Implications for Health Education Programs

The study revealed that women want information about breast health to be short, visual, and prescriptive. Women want to know how to conduct a BSE, how to interpret lumps, and what to do when detecting a lump. Printed material, videos, and the use of a practice model were all cited by women as effective ways of communicating information about BSE.

Findings are generally consistent with earlier studies. Visual communication techniques have proved to be valuable among younger women.^{38,41} Videos targeted to high-risk groups by age and ethnicity have conveyed desired attitudes and behaviors to targeted populations.³⁸

Personal stories of breast cancer survivors were identified as highly relevant and motivating to women. This is consistent with the theory of parasocial interaction introduced in the 1950s.⁴² The basic premise is that individuals can develop a form of relationship with “performers” who convey a message and thus find the message to be much more personal. For example, if women were to hear testimonials from breast cancer survivors and/or see videos of women demonstrating how to do BSE, the women in the audience could “personalize” the information more and be more likely to take action.

Messages that were cited by women as motivating them to care about breast health issues focused on reasons to live rather than fear of the consequences. Fear of finding out a woman had breast cancer and the negative perceptions of treatment options such as radia-

tion, chemotherapy, and mastectomy inhibited some women from engaging in breast health care procedures. In short, the reasons to live must be seen as outweighing the negative perceptions of treatments.

Once convinced to care about breast health issues, the primary reason women cited for not taking action was forgetting to do so. Reminders such as shower hangers were cited by women as being useful. The study revealed that no one type of reminder was favored by all women, so reminders should be delivered in multiple ways. However, these women do not have high access to technology so tools such as e-mail and Web sites do not have high value at this time.

Interpersonal communication channels (friends, family, coworkers) were important sources of information and motivation related to health. Education programs should extend their reach via these interpersonal channels by encouraging women who participate in education programs to become sources of information for other women. Women should be encouraged to share extra information with work colleagues, family members, and friends. Teaching women to advocate for better breast health among their friends should encourage those women advocates to “practice what they preach,” thereby developing better breast health care procedures for themselves. Other programs that have been designed to teach women to be disseminators of breast health education have been successful.⁴³

Finally, women suggested that men need to be better educated about breast health issues. As detailed in the Results section, women generally feel that men want to be supportive but do not have the necessary information to cope with a woman’s breast health problems. Women suggested men-only sessions to talk about how breast health issues affect men.

Limitations and Suggestions for Future Research

Though this study achieved its primary goal of seeking depth of information about rural working women, their knowledge of the rural health system, their perceptions of breast health, and understanding how breast health issues fit into the broader scope of their lives, some limitations should be noted. First, the sample was drawn from a relatively limited geographic region. Second, much of the discussion of program-specific issues related to one specific breast health education program. These limitations could have resulted in findings that were idiosyncratic to a specific health system or education program. However, as noted in the Discussion section, these findings seem to be fairly consistent with the literature.

Future studies might draw on more widely dispersed populations. Because of the importance of the personal community system identified by these

women, future studies might also explore in more detail the role of men, family members, coworkers, and others in the lives of rural working women. What influences do these others have on women’s breast health behaviors? How can education programs reach these significant community members most effectively? How can women be encouraged to leverage their interpersonal influence? Does the concept of parasocial interaction apply in this situation?

The current study was not designed to specifically address the relationship between cancer education and behavior. Future studies should more directly address such links. Does a workplace-based program in rural Appalachia really increase positive breast health behaviors? How long do women continue to practice those behaviors? Can a program such as the BHOP help to bridge the apparent gap between the professional health system and the actual lives of women living and working in rural Appalachia?

Conclusions

The key aims of this study were to identify regionally and culturally specific factors that influence how Appalachian women approach breast health and to identify ways that more positive breast health behaviors can be achieved. The factor that seems most likely to inhibit positive behavior is distrust of the medical system. However, that distrust does not seem to extend to the BHOP even though that program is linked to a university hospital. Because the program came to their workplaces and encouraged dialogue, it seemed to be a “bridge” that helped women connect their personal community systems to the professional health system. By adapting to the culture that it serves, the BHOP has become a strong factor in encouraging positive behaviors.

An important contribution of this study was the demonstration of the importance of cultural understanding in delivery of health information. By using focus groups that allow women to express their own needs in their own voices, important implications were discovered for both professional and personal health systems and for breast health education programs.

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