Perspectives of African American, Amish, Appalachian and Latina Women on Breast and Cervical Cancer Screening: Implications for Cultural Competence

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Perspectives of African American, Amish, Appalachian and Latina Women on Breast and Cervical Cancer Screening: Implications for Cultural Competence

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Abstract: Low-income and minority women are less likely to be screened for breast and cervical cancer and less likely than others to be diagnosed at an early stage in the cancer's growth. We consulted women and providers to understand how social, economic, and health care environments affect screening among African American, Amish, Appalachian, and Latina women, and to outline possible solutions. Women participated in 31 focus groups. Providers completed a mail survey (n=168) and follow-up interviews (n=12). We identified barriers women face: not always following recommendations; feeling intimidated during appointments; having incorrect information about risks, screening guidelines, and programs; and receiving information in ways they cannot understand or accept. Women indicated a strong desire for accurate information and, like the providers, identified strategies for reducing barriers to screening. In the terms of a social ecological model, our results point to three avenues along which to approach cultural competence: 1) policy, 2) health care provision, and 3) clinical care.

Key words: Cancer screening, race, ethnicity, cultural competence, cervical cancer, breast cancer.

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Early detection of breast and cervical cancer has a high probability of preventing death, yet researchers consistently report that women in low-income and minority populations—including African American, Latina, and Appalachian women—are less likely than other women to obtain cancer screening and more likely to be diagnosed at a later stage.[1–4] Amish women may also be less likely than others to obtain cancer screening, although data are not available. This study, funded by the Pennsylvania Department of Health, focused on these ethnic/cultural groups in an effort to provide guidance for improving their health care.

Researchers have shown that certain factors act as barriers to early screening for all women (e.g., lack of a regular care provider, lack of a doctor's recommendation, cost of health care/insurance, inconvenience, lack of English proficiency, and lack of social support).[4–7] Although low-income and minority women are more likely to have breast and cervical cancer screening when their health care providers recommend it, physicians recommend screening less often to women who are poor, are less educated, or lack health insurance.[2] Survey and qualitative data indicate differences in the screening practices of women from diverse ethnic backgrounds.[4,8–11]

Community and cultural perspectives about barriers may be best explored using qualitative methods, particularly focus groups, which can allow group members to voice their concerns, thoughts, and feelings in their own words and language of origin. However, little has been published about the influence of cultural values and attitudes on screening among minority and rural women from their own perspectives. Facione and Giancarlo,[12] using focus group research, demonstrated the power of cancer narratives as a way for African American and Latina breast cancer survivors to give meaning to their experiences. Kenney et al.,[11] also using focus groups, found that participants had incomplete knowledge of a free screening program and their eligibility. Borrayo and Jenkins[10] used focus groups in Texas, finding that the Mexican American women participants did not recognize a need for screening when they felt healthy. Baldwin[9] clarified, using focus group data, the fundamental importance of an Afrocentric worldview in framing messages to African American women concerning breast and cervical cancer screening.[9] In Canada, Van Til, MacQuarrie, and Herbert[13] established through focus groups with women ages 45 to 70 that personal experiences, including fears and lifestyle, contribute to low screening rates. However, these studies are among very few that express the views of the women themselves about how to improve screening among low-income and minority women.

As the U.S. population becomes more diverse and minority populations grow, delays in cancer detection impose an increasing burden, not only on individuals and their families, but also on the nation's economy. To succeed, early detection programs must be culturally competent, meaning that their design includes deliberate modification of health care environments to serve patients of various cultural backgrounds more effectively.[14–16] Theory-based strategies for change require specific data from particular groups.

The objectives of this study are 1) to understand how the social, economic, and health care environments affect breast and cervical cancer screening among African American, Amish, Appalachian, and Latina women and 2) to outline possible solutions that reflect the views of women and health care providers.

This study was conducted in terms of *social ecology*,[17] which posits that individuals are affected by multiple dimensions of their environment, including the interpersonal, organizational, community, and public policy dimensions. The conceptual framework is the PRECEDE model, because it includes several of these dimensions, provides a ready-made tool for devising health promotion activities,[17] and has been used before to study cervical cancer screening.[7] In this model, quality of life and health are affected by two interdependent factors: (1) environment, including the social and cultural context, and (2) behavior and lifestyle, as influenced by predisposing, enabling, and reinforcing factors.[17] One or more of these factors must be affected if health promotion activities are to bring about change.

Methods

Population. For this study, which was approved by the Institutional Review Board (IRB) of the University of Pittsburgh, we relied on focus groups with African American, Amish, Appalachian, and Latina women living in eight western Pennsylvania counties, as well as surveys and interviews with health care providers in those counties. We obtained signed informed consent from women in focus groups and included an informational script in the provider survey, in accord with the requirements of the IRB.

The counties, organized here by populations studied, were: 1) African American: Allegheny, Erie, Beaver; 2) Amish: Indiana, Jefferson, Mercer; 3) Latina: Allegheny, Erie, Washington; and 4) Appalachian: Greene, Indiana, McKean. African American women are an urban minority in all study areas (range: 6.0%–12.4%).[18] The Appalachian counties we studied share characteristics of poverty and isolation. With the coal industry's decline, many residents lost their jobs or relocated, resulting in high proportions of elderly, unemployed, and underemployed people. The median household incomes of these counties (range: $30,233–$33,040) are far lower than that of the state ($40,106).[18] Latinos constitute a small percentage of the population of Allegheny, Erie, and Washington counties (range: 0.6%–2.2%).[18] Data on the number of Amish in the counties studied are scarce. However, knowledgeable clinic staff in the study areas told us that Mercer County's Amish are scattered, isolated, and poor, while most of the Amish in the Indiana/Jefferson area live in predominantly Amish towns and, in comparison, are well-off.

Data collection. *Focus groups.* Although Family Health Council has clinics in the study areas, we approached community women directly in order to reach a broad group, some of whom might not currently get screened for cancer. Two waves of focus groups were conducted. The first, with 20 groups (210 women), investigated the different factors that affect cancer screening. Women were asked about what they knew of breast and cervical cancer screening, what experience they had with these tests (if any) and whether a health care provider had talked to them about cancer screening. They were also asked for suggestions to make it easier for women to obtain screening. The second wave of focus groups, with 11 groups (102 women), explored potential solutions to screening barriers that had been previously identified. Results from the first wave of groups, as well as results of providers' surveys and interviews, were used as a basis for constructing the questions of the second wave.

We trained one female community member for each population in each county to help recruit participants. Recruiters also served as notetakers during the focus groups. Most African Americans and Latinas in the second wave had participated in the first wave; however, transportation barriers and religious observances decreased the number of repeat participants among Appalachians and Amish. All of the focus groups with African American, Appalachian, and Latina women were conducted in community venues and audio-taped. Those with Amish women were conducted in private homes and, at the request of the participants, were not audio-taped. Instead, two women took notes and debriefing sessions were conducted with the facilitator. Participants and recruiters in all groups received $20 and $125 gift certificates, respectively.

Provider survey and interviews. Data on health care providers' views were obtained through a mailed survey and interviews conducted in person or via telephone. The survey inquired about providers' perceptions of barriers to screening for the study groups; interviews concerned strategies for providers to increase screening.

A list of primary care providers in the eight counties was compiled from information collected from the Pennsylvania Bureau of Professional and Occupational Affairs, the American College of Nurse-Midwives, the Northwestern Pennsylvania Area Health Education Center, and an Internet-based listing.

The survey was mailed to a random sample of 800 providers, stratified by county and occupation (i.e., internal medicine, obstetrics and gynecology, general medicine and family practice, nurse practitioners, midwives, and clinics). A reminder was mailed two weeks later; then, phone calls were made to 155 non-respondents (follow-up was limited by budgetary constraints). Just over 20% (168) were returned. Low participation may be related partly to poor quality of the mailing list, as indicated by the many undeliverable surveys and disconnected phone numbers.

Twelve key informant interviews were conducted, involving at least one provider in each county and each professional group that had indicated on its survey a willingness to provide additional information.

Analysis. Transcriptions of focus groups and interviews were entered into N6 (NUD*IST). [19] Transcriptions of the Spanish-language focus groups were translated into English so all of the researchers could read them. To ensure inter-rater reliability, two researchers read the transcripts, developed a free-coding scheme based on discussion of emergent themes, and then coded the text. As themes emerged, the database was expanded. Periodic discussions led both to the addition or combination of themes and to their hierarchical arrangement. Prepared summaries were read and discussed by all investigators. The final results were organized according to the PRECEDE model.[17] The results presented here are the most typical responses given by each study group; due to space limitations, we cannot present the full range of variation found in each community.

Results were triangulated by: 1) comparing results for each ethnic/cultural group to identify repeated themes and build descriptions of groups' experiences; 2) comparing results from providers and women to detect areas of convergence and divergence and identify areas for health care improvement; and 3) comparing experiences of the four groups.

Results

Women's perspectives. Demographic characteristics of focus group participants are presented in Table 1. Appalachian and Amish participants tended to be older than African American and Latina participants. Over 80% of Amish participants had a partner, compared with 55–56% of Appalachian and Latina participants and less than 46% of African American participants. The Amish participants had no health insurance. Most other participants had some insurance, which was more common among Appalachian and African American participants than among Latina participants. Appalachian participants were more likely to have a regular source of care, followed by African American, then Latina, and finally Amish participants. Latina participants were Spanish monolingual or bilingual (not shown).

Awareness of cancer risks and screening. Some participants had some knowledge about cancer risks, but many participants in each group had inaccurate information about cancer risks, as well as about guidelines for age, frequency, and types of screening needed. Furthermore, many were unaware of the available free screening program.

African American participants knew that cancer is often diagnosed too late. They identified age and family history as risk factors for breast cancer and sexual activity as a risk factor for cervical cancer. While African American participants knew the Pap test finds cancer, they also believed it diagnoses sexually transmitted diseases (STDs)

Table 1.

SELECTED DEMOGRAPHIC CHARACTERITICS OF FOCUS GROUP PARTICIPANTS

	African American	Amish	Latina	Appalachian
First wave				
Number of focus groups	6	2	6	6
Number of participants	72	24	57	57
Median age	33.5	42.0	29.0	47.0
Have a partner	40.3%	83.3%	64.9%	61.4%
Have a regular health care provider	81.9%	78.3%	71.4%	94.7%
Have health insurance	79.2%	0.0%	50.9%	87.7%
Second wave				
Number of focus groups	3	2	3	3
Number of participants	31	18	30	23
Took part in the first wave	61.3%	0.0%	76.7%	8.7%
Median age	33.0	36.0	34.5	51.0
Have a partner	45.2%	94.4%	56.7%	65.2%
Have a regular health care provider	80.6%	50.0%	66.7%	100.0%
Have health insurance	90.3%	0.0%	55.2%	78.3%

and involves cutting the cervix. A woman said, “You get a Pap smear. You’re going in . . . they cut that thing, take that tissue out and, you know, they analyze it” (Allegheny County, Wave 1).

Appalachian participants believed themselves to be at higher risk for cancer than the general population, believed cancer was treatable, knew what tests were necessary, and wanted to be tested. They also perceived cancer to be one disease and believed that families who had any type (e.g., bladder, lymphoma) were at increased risk for breast and cervical cancer. Because of their heightened sense of risk, Appalachian participants often wanted mammograms before the recommended age and complained that insurance would not cover them. Several told stories of women who were diagnosed with breast cancer at very young ages after arduous battles to get screened; outcomes in these stories were typically poor.

Latina participants had little understanding of particular risks for either breast or cervical cancer, although they knew that breastfeeding conferred some protection from breast cancer. Similarly, Amish participants had little information about risks and screening guidelines. While Amish participants did limit their use of technology, they did not have cultural objections to cancer screening. However, the participants tended to view all women’s health issues in relation to childbearing. Many thought that if they were having babies and being checked by their Amish midwife, they were in good health. They assumed Pap tests were performed during these check-ups. In reality, this might not happen, since many Amish midwives receive no formal medical training. As one woman explained, “When I was having babies about one a year I got [Pap tests] regularly, but not now” (Indiana/Jefferson County, Wave 2).

Desire for information. Participants in all groups expressed a strong desire for accurate information about risks and screening. However, health care providers often do not offer such information or do not offer it in acceptable or understandable ways.

Participants in all groups wanted tailored health education. They favored first-person narratives from women they knew and/or who lived in their communities. However, the desired format varied. African American participants wanted printed materials, written in plain language and supplemented with pictures. They also preferred oral presentations, followed by television, radio, and billboards. They recommended churches and shopping centers as venues for dissemination. They identified cash and gift certificates as reasonable incentives for both educational programs and screening services.

Appalachian participants wanted information and early screening. They recommended teaching women at a young age and sending messages home with schoolchildren to reach parents, as exemplified by this quotation: “I think if my child comes home and told me, ‘Mommy, would you please go to the doctor. I don’t want you to get sick and die,’ I would go to the doctor” (Greene County, Wave 1). They suggested distributing information through local papers, popular magazines, phone chains, and radio, and at the unemployment office, stores, fire halls, and churches. They did not mention incentives for screening.

Latina participants placed a high value on health education. They wanted plain-language pamphlets with English and Spanish text side-by-side and pictures.

> Well, because in Spanish, at least only those who do not know English very well it

> is perfect, but the majority of people get information in English. [Bueno porque en español solamente por lo menos los que no dominamos bien el inglés es perfecto, pero en inglés se informaría la mayoría de las personas.]
>
> And also because, obviously, if you speak Spanish and you don't know the words or the technical terms, they put them there. You then know what to tell the person that is speaking to you. [Y también porque obviamente si tú hablas español y no conoces las palabras o los términos técnicos allí te lo ponen. Tú ya sabes que decirle a la persona que te está hablando en inglés y quiero hablar con la persona bilingüe, pero sobre todo me interesa " x" cosa.] (Allegheny County, Wave 2)

Latina participants favored narratives, which they said should include signatures and the name of a reputable source (e.g., hospital, cancer center) for credibility. Any materials should include details about where to go and if "papers" (immigration documents) are required. They recommended information be disseminated on Spanish-language television, as well as at churches, stores, and restaurants.

Amish participants were receptive to information distributed by state health nurses, who have formed close relationships in their communities, and midwives, who were felt to be trustworthy and knowledgeable. Amish participants said they would not contradict their husbands if cancer screening were opposed; however, they did not seem to have this problem. Rather, their husbands tended to defer to the midwives about women's health. Other methods of dissemination Amish participants suggested include mailings, talking to women's groups or women at church, advertising in the newspapers, and posting flyers in public places (e.g., herb store, cheese house). Amish participants did not express a need for incentives to attend screening. For educational sessions, they did not require, but appreciated, light snacks.

Fears. Participants of all groups feared diagnosis, pain, death, and not knowing what happens after diagnosis. Although many did mention fear of pain from mammograms, most who had had mammograms said they were not painful.

Amish participants did not express embarrassment, but all other groups did. African American participants voiced self-consciousness about their bodies, particularly during Pap tests. Appalachian participants also mentioned embarrassment about Pap tests, although not as an insurmountable barrier. For Latina participants, embarrassment was a major barrier with sexual connotations, closely related to loss of virginity. In fact, embarrassment was the primary barrier they said they needed to overcome, even though nearly half were uninsured and many feared being turned in to the Immigration and Naturalization Services (INS), were unaware of free services, and/or lacked transportation.

> For me, the Pap smear is something exasperating because they put different things in you. Even though one relaxes, if the gynecologist is a man, forget it, I'm going to be much more tense and I tell him: "Don't look at me please." [All laugh.] Then, [words incomprehensible; all participants laughing] . . . And this time that it was a woman I told her: "Doctor, please, don't look at me!" "Don't worry," she told me, "I'm going to do it with my eyes closed." [All laugh.] . . . With that, I relaxed . . . , but it always hurts. It's something that I do not, do not like very much. [El Papanicolau

> para mí es algo desesperante porque te meten distintas cosas, a pesar de que uno se relaja si el ginecólogo es hombre, olvídate voy a estar mucho más tensa porque yo le digo: "no me mires por favor" [All laugh.]. Entonces, [words incomprehensible; all participants laughing] . . . Y esta vez que fue una mujer, le dije: "Doctora por favor, no me mire," "No te preocupes, me dijo, que voy a hacer con los ojos cerrados." [All laugh.] . . . Pero así me relajé por mí mismo . . . pero siempre duele. Es algo que no, no me agrada mucho.] (Allegheny County, Wave 1)

Responsibility. Participants in different groups conceptualized their screening responsibilities differently. Feeling responsible for their own lives, African American participants generally judged themselves harshly for delaying their needs in favor of their family members'. This is exemplified in the following exchange from one focus group:

> —Um, the hustle and bustle of life, and not taking enough time to take care of myself. I'm taking care of my kids, my mother, my job, everybody else but not [me].
> —Typical.
> —Just trying to schedule . . . .
> —That's us altogether. We're always last. (Allegheny County, Wave 1)

At the same time, the African American participants felt they had a responsibility to urge their female peers to take care of themselves, even saying they should take other women to screening appointments.

Appalachian participants felt responsible for verifying what providers had told them through research using trusted sources like the Internet and the popular media (e.g., *The Oprah Winfrey Show*). Most seemed anxious to be screened, both because it is "the right thing to do" and due to a heightened sense of risk.

Latina participants also felt they must do research, but for many of them this primarily involved talking with family and friends, whose opinions greatly influenced health care decisions: "You have to investigate. Ask your mother, your sister, your aunt" ["Tienes que investigar. Preguntarle a la mamá, a la hermana, a la tía"] (Erie County, Wave 1).

Obtaining care. Cost and/or insurance were problems for participants in all groups. Many participants were unaware of free services, even though all participants qualified. For African American and Appalachian participants, who were frequently insured, costs often tended to include co-payments, transportation, and childcare. Many African American participants had public health insurance, and several said they were treated as second-class patients as a result.

Appalachian participants often did not receive health insurance from their jobs, which tended to be part-time positions; still, many were ineligible for medical assistance. For some, the closest health care services were across state lines, which their insurance would not cross.

Latina participants also tended to receive limited or no health insurance coverage from their jobs. Further, they said they receive little or no paid sick time from their jobs: "I suppose that the hard part is not necessarily being able to leave work. The hard part is when you get your check and you are missing all those hours that you were out" ["Yo supongo que la parte difícil no es necesariamente el poderte ir del trabajo, la parte difícil es cuando te llega tu cheque que te faltaron todas las horas que estuviste afuera"] (Erie County, Wave 1).

All Amish participants were uninsured, even those who qualified for medical assistance, because the Amish oppose government programs, especially those they perceive to be handouts. These women said they wanted to pay a nominal or in-kind fee for services.

> Who pays for this? We would feel dumb to get something for nothing. If we know the tax moneys that we pay help to pay for the program, it would be better. We do not feel comfortable taking charity or taking money from someone else . . . we pay school, real estate, and tobacco taxes and things like that. Does it come from there? (Mercer County, Wave 2)

Scheduling appointments was complicated for all participants. Amish participants did not have home telephones and, as their children's primary caregivers, were often unable to get to outside phones during office hours. They would like to be able to use cell phones outside of their homes or make appointments by mail. Latina participants felt the process of obtaining appointments was overwhelming.

> You have to go to the doctor, you have to call, you have to ask for an appointment. It's not easy. It's not like one shows up at the door and they do it, no, rather it's like it requires a lot of planning and then the price and that it is not pleasant. [Hay que ir al médico, hay que llamar, hay que pedir cita. No es fácil, no. No es que uno se presenta a la puerta y ya lo hagan no, sino que como que requiere mucho planeamiento y entonces el precio y que no es agradable y dices bueno.] (Allegheny County, Wave 1)

Transportation was a paramount issue for African American, Appalachian, and Amish participants. African American participants reported the necessity of leaving their neighborhoods for care and suggested that bus passes would help. Some voiced the view that bringing a mobile unit to the neighborhood might help some people, but that others would not use it, due to concerns about cleanliness. These participants wanted brick-and-mortar health care services in their communities.

Transportation added to the cost of care in Appalachia, especially for participants without cars, because public transportation was nearly absent. Husbands sometimes provided rides, but usually remained uninvolved in their wives' health. These participants welcomed and would use mobile units, especially if announced in advance and brought to central, well-known places (e.g., fire halls, churches) or places they must go anyway (e.g., grocery stores).

In some areas, Amish participants had volunteer drivers, but these drivers might require small payments. Otherwise, they had no motorized transportation available and would have to travel by buggy or foot. A mobile unit would help, especially if available when seasonal work does not impede them from taking time for health care.

Participants of all groups said waiting times for appointments and at the doctors' offices were important barriers to screening.

The community and social support. Social support was limited for all groups of participants, except the Amish. Even though they had little contact outside their communities, within them their social network was highly active. Social support was crucial to Amish participants, who gathered frequently for quilting and completing other domestic tasks. They had developed the habit of making appointments in groups, both to share rides and to avoid going alone.

Many African American participants, who perceived their communities as lacking health care services, spoke of low incomes, relatively low literacy, and limited social support. Since fewer than half had husbands or partners, many African American participants were the main supporters of their households. They had a network of family and friends, but were often unable to extend extensive support to their female peers, who were similarly overwhelmed. However, they favored going to screening with family members or friends; a member of one group suggested that “group testing” would make the experience “more fun” and would provide social support. African American participants in the second wave of focus groups embraced this idea.

Appalachian participants tended to live in isolated homes or small communities; the most geographically isolated tended to be the least educated and the most disconnected. This, in addition to their many obligations, impedes the development of strong social support. Appalachian participants said that men have opportunities for connecting with each other (e.g., hunting, fishing) that women don’t have. Rather, Appalachian participants explained that women primarily connect through “phone chains,” which can be especially important to the most isolated among them. They said, “There are some pockets of the county that are very country . . . some women don’t drive . . . they depend on their husbands to take them. . . . And, these men are not educated to women’s health issues, certainly” (Greene County, Wave 1).

Latina participants felt they are often “invisible” to the larger community. In Allegheny and Washington counties, the Latino community is loosely-knit and relatively unorganized. Most Latinos settling in the U.S. have left their extended families behind, which makes it difficult to obtain social support and leads to social isolation. Husbands are usually uninvolved in health care, but sometimes support women with rides or interpretation. Most Latina participants said they wanted to connect with other Latinas. When they hear Spanish spoken by strangers in public places, they often seek to exchange phone numbers and form connections. Like African American participants, Latina participants were enthusiastic about group testing, seeing it as a chance to have fun with friends and speak Spanish, as shown in this exchange from one focus group:

> Well, I think that it would be good because just knowing that you are going with your friends, that we are going to the same thing, you are motivated a little because you don’t feel so alone in this, right? So then you say, “Well, okay, let’s go.”
>
> When one comes out and says, “Listen, I forgot to ask this . . . he did not explain it very well, maybe you can ask,” . . . also, [you can share] the ride if you sometimes go together . . . . Or [childcare], a friend [says] “I will stay with the children this time, I will go with another two the next time.”
>
> [Pues pienso que sería bien porque simplemente el pensar que vas con tus amigas, que vamos a lo mismo. Ya te animas un poquito porque no te sientes tan sola en esto, ¿no? Entonces, dices, “Bueno, okay, pues vamos.”

> No todo porque lo que una sale y le dice, "Oye, que yo me olvidé de preguntar esto . . . oye no me explicó muy bien a ver si tú le preguntas" . . . también [puedes compartir] los aventones si van juntas a veces. o [el cuidado de los niños] una amiga [dice] "Yo me quedo con los niños esta vez, yo voy a ir con otras dos el otro próximo."] (Allegheny County, Wave 2)

Communication with providers: Issues of information, trust and discrimination. Participants in all groups faced issues related to communication with providers. Often, providers neglected to recommend screening. Limited literacy made it difficult for many to understand any technical medical pamphlets they might receive. They also said that they did not always follow their providers' recommendations and often felt too intimidated to ask questions during visits.

African American participants talked about discriminatory experiences in health care, saying they had become accustomed to providers patronizing them or providing insufficient explanations. They also believed the free services they receive are substandard, and some felt they were treated as experimental subjects, as illustrated by this comment: "Or they try to treat you like a science project. 'Well, let's try this,' and 'let's do that.' And I said, 'No, you're not gonna try that on me.' We're doggoned guinea pigs" (Erie County, Wave 1).

Negative perceptions reinforce Appalachian participants' reluctance to get screened, although most were willing to do so if their providers recommended it. Unfortunately, doctors tend to leave Appalachia for urban settings after short periods of time. These "temporary" providers are not natives of the area, and Appalachian participants said they sometimes have difficulty understanding them, increasing the likelihood of cultural miscommunications. Yet it is these transient providers who work in the clinics that accept medical assistance and offer low-cost services, which most participants could access.

> Because this is literally a medically underserved area . . . . This is Appalachia. Doctors looking for, you know, internships and so forth come and use the clinics as a way to get experience through their funding. That type of thing. But they seldom stay. (Greene County, Wave 1)

Latina participants reported valuing their providers' recommendations. Their main communication barrier stems from language differences. Most medical offices lack any Spanish-speaking staff; many do not offer phone interpretation lines. Therefore, Latina participants often relied on husbands or other family members, who lack a bilingual medical vocabulary, for interpretation. Latina participants also reported discrimination, often in the form of rude treatment and anti-immigrant attitudes. The following two examples illustrate this point. "But people here if you don't speak the language they think 'This [person] . . . is not here legally; [she] is an illegal'" ["Pero, aquí la gente si uno no habla el idioma ya piensan: 'Este no tiene, no está aquí legal; es ilegal'"] (Washington County, Wave 1). "Also . . . a receptionist . . . there are cases that the person [says], 'I don't understand what you said. Well, I'll talk to you later,' and they hang up on you . . . it is only your accent" ["También . . . porque si una recepcionista . . . y hay casos que la persona, 'I don't understand what you said, Well, I talk to you later,' and [they hang up on you]. Porque solamente es tu acento"] (Washington County, Wave 2).

Latina participants said they believe that Spanish-speaking providers are both easier to understand and more able to foster trust than providers who do not speak Spanish. Even participants who are reasonably proficient in English can have difficulty expressing themselves about health issues, and it helps to be able to fill in the gaps with Spanish words.

> Because no matter how long you have been speaking English, you are never going to express yourself the same way in your second language as you do in your own language. Because there are a lot of things that are not the same, that can't be said. [Porque aunque mucho tiempo tendrás de hablar inglés nunca te vas a expresar igual en tu segundo idioma que en tu propio idioma. Porque hay cosas que no son iguales, que no se pueden decir.] (Washington County, Wave 1)

Latina participants said they are more eager to follow recommendations if they feel an effort has been made to take time and communicate with them. While they welcome Spanish-speaking providers or interpreters, they also feel positively about phone interpretation lines. Still, instead of obtaining care locally, some participants wait for months or even years to return to their country of origin for care. "When I go to my country with more trust . . . I have a checkup . . . for everything because it is much cheaper than here" ["Claro, cuando voy a mi país con mayor confianza y me hago un chequeo, pero de todo porque me sale mucho más cómodo que aquí"] (Allegheny County, Wave 1).

Although it has not been a regular part of their health care practices, Amish participants said they could accept that there might be a need for cancer services beyond their childbearing years. They explained that they valued their providers' recommendations, but felt intimidated by doctors. Some reported that providers had not told them when to get screened or why it is important.

In all groups except the Amish, some participants voiced a preference for women providers. However, in all groups, there were several participants who said that male providers were equally acceptable to them.

Health care providers' perspectives. A total of 164 health care providers responded to the survey. The majority were physicians, reported seeing fewer than 100 patients per week, had been practicing in their geographical area for more than 10 years, and self-identified as White. Twelve participated in follow-up interviews.

Responses to the mail survey showed that the vast majority of providers agreed that routine mammograms and Pap tests could significantly reduce breast and cervical cancer mortality (97–99%). Survey respondents ranked the following factors as most influential for cancer screening: health insurance (87.2%), family history of cancer (72.7%), cost (69.5%), and having a regular health care provider (68.8%). They reported that the greatest difficulty for uninsured women is finding a way to pay for treatment if a problem is detected, particularly for cervical cancer. Providers ranked waiting time to get an appointment (34.6%) and waiting time in the office (33.8%) as considerably less important (Table 2).

Most survey respondents reported that their ethnically and culturally diverse patients understand their recommendations, but that less than half follow them. They indicated that community-based health education programs are the best way to increase screening rates and that improving patient-provider communication will help. They saw a need for creating overall confidence and allocating more time to counseling, especially for Appalachian (37.3%) and African American (30.2%) women, but also for Latinas (20.8%) and Amish (17.9%) women. However, most believed cultural competence training to be unnecessary for improving patient-provider communication (Table 3).

To increase cancer screening, providers suggested explaining why it is important, asking patients before leaving if they have more questions, and encouraging patients to bring written questions to their visits. To disseminate information, providers suggested distributing pamphlets or other printed materials in community venues, incorporating information in school curricula, displaying posters, and having staff talk to community groups. To help with scheduling, most providers recommended making appointments before patients leave and using a system that prompts providers to follow up with reminders. Several providers noted that problems with scheduling are primarily related to patients' transportation, rather than providers' availability. However, to decrease waiting times, they suggested having flexible hours, not overbooking, and having nurse practitioners handle routine screenings.

Table 2.

PROVIDERS' PERCEPTIONS OF FACTORS THAT INFLUENCE WOMEN HAVING MAMMOGRAMS AND PAP TESTS

	Influences/Influences to a great extent	
Factors	**Count**	**Percentage**
Health insurance	143	87.2%
Family history of cancer	117	72.7%
Cost	114	69.5%
Having a regular health care provider	110	68.8%
Talking with family members	105	65.2%
Transportation	101	62.7%
Level of education	95	60.1%
Cost of lost work	90	56.3%
Belief that screening is painful	83	51.9%
Childcare	69	43.4%
Long waiting time to get an appointment	56	34.6%
English proficiency	55	34.0%
Long waiting time in the office	54	33.8%
Cultural beliefs	39	25.2%
Religious beliefs	25	16.3%

Table 3.

SELECTED PROVIDERS' RESPONSES BY CULTURAL/ETHNIC GROUP

	African American		Amish		Latina		Appa-lachian	
	Total	**%**	**Total**	**%**	**Total**	**%**	**Total**	**%**
My "ethnic" patients face more of a challenge than my other patients in complying with their recommended screening tests.	61	60.7	50	46.0	29	72.4	51	72.5
How confident are you your patients will UNDERSTAND your recommendations?	60	88.3	51	60.8	29	65.5	46	73.9
How confident are you your patients will FOLLOW your recommendations?	61	54.1	51	39.2	29	10.3	47	38.3
Best WAYS to increase the number of women getting a mammogram or Pap test								
Health fairs	63	4.8	72	5.6	39	0.0	59	6.8
Health fairs with screening	63	28.6	72	23.6	39	48.7	59	44.1
Worksite screening events	63	34.9	72	29.2	39	10.3	59	23.7
Health education	63	54.2	72	48.6	39	38.5	59	54.2
Improve patient provider communication	63	49.2	72	48.6	39	25.6	59	37.3
Ranking of WAYS to help providers improve communication with their patients: Ranked FIRST as best way								
Health education programs in community	63	50.8	72	30.6	39	43.6	59	40.7
Cultural competence training	63	7.9	72	5.6	39	12.8	59	6.8
Interpreters available	63	1.6	72	25.0	39	2.6	59	3.4
Ability to devote more time to counseling	63	30.2	72	20.8	39	17.9	59	37.3

Providers' suggestions for reducing embarrassment included having a female provider conduct cancer screenings, explaining the procedures, making patients feel comfortable (e.g., by suggesting that embarrassment is not uncommon, providing privacy, helping them relax), and treating patients with respect.

Survey respondents indicated they consider interpretation services to be useful for Latina patients, yet providers with phone interpretation lines seldom used them. Instead, they resorted to trained or untrained interpreters, who are "more user-friendly and accurate." One provider in Appalachia reported that a language barrier exists even with some English-speaking patients, specifically those who have very low literacy.

To improve provider's knowledge about the latest guidelines and the availability of free screening programs, interviewees suggested the Department of Health provide pamphlets to providers, who can pass them on during staff meetings.

Discussion

Our results support a multilevel approach to understanding how the socioeconomic and health care environments affect breast and cervical cancer screening. To discuss them, and possible solutions, we use a social ecological model[17] and an understanding of cultural competence that encompass systems, organizations, and professionals, and behaviors and policies; in this, we follow Betancourt et al.,[14] Brach and Fraserirector,[15] and Sue and Sue.[16] We discuss solutions for environmental impediments to screening that were suggested by participants themselves and their health care providers, including involving family in health decision-making (Latina and African American participants), using interpreters (Latina participants), establishing walk-in clinics (all groups), and developing alternate methods of payment (Amish participants). While our focus group participants were unlikely to be familiar with the term "cultural competency" and did not discuss these strategies using the term "cultural competency," their concerns did relate to quality-of-care issues that would be addressed by cultural competency training.

Approaching cultural competence along multiple avenues is uncommon. Often, cultural competence is understood as a trait of health care providers, who, after some form of training, are able to work effectively in cross-cultural settings.[21–24] However, organizations without culturally-attuned processes and policies limit the problem-solving capacity of culturally-competent providers.[15] In turn, organizations themselves operate in a policy environment that may or may not favor cultural competence.

Cultural competence, in the terms of a social ecological model, manifests itself in three realms: 1) policy, 2) health care provision, and 3) clinicians. *Cultural competence in policy* includes the federal, state, and local laws and regulations that govern health care (e.g., payment schemes). *Cultural competence in health care provision* includes care delivery (e.g., appointments, transportation), hiring, and retention. *Cultural competence in clinicians* includes the training of health care providers and staff. Policies affect the way organizations act and these actions, in turn, influence providers' cultural competence (Figure 1) in the clinical setting.

Culture, lifestyle, and living experiences affect both health and health care, and understanding that is central to developing cultural competence.[14–16] Below, we present some examples of adaptations stemming from our data along the continuum of the health care system.

Health education: first-person narratives. In the focus groups, we found that women want to receive health education and prevention messages through real-life, first-person accounts of women like themselves disseminated locally via sources that they trust. This preference is consistent with providers' view about the importance of community-based health education programs for increasing screening rates. A health

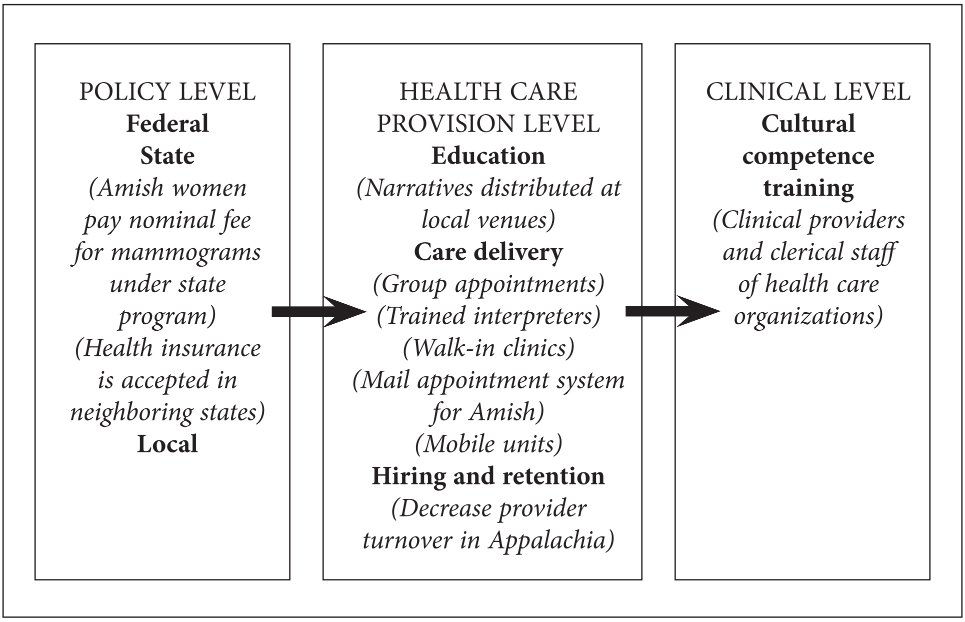

Figure 1. A social ecological framework for cultural competence, highlighting selected strategies derived from this study (specific strategies are shown in parentheses).

promotion approach using personalized narratives has successfully increased condom use among low-income, inner-city women in two Pennsylvania cities. Community women's stories were collected, adapted to a culturally-acceptable format, augmented with some factual sidebars, and distributed through community venues.[25]

First-person narratives can be good instruments for delivering accurate information about cancer risks and tests, diminishing fears about diagnosis and death, and addressing community-specific concerns. In addition, narratives may reduce the false sense of security produced by a lack of awareness of cancer risks.[26] To ensure cultural competence, narratives could draw upon women's sense of responsibility and, when appropriate, their communal orientation to health and health care.[12,27,28] For example, Appalachian women could hear in their own voices a story that clarifies their cancer risk, addresses embarrassment, and provides information about the state's free screening program. The message for Latinas could include basic information about risks and tests while addressing embarrassment and immigration-related fears. A narrative prepared for African Americans could clarify the purpose and nature of tests in an effort to increase trust.

Health care provision: group screening. Group screening may be a culturally-appropriate strategy for organizing breast and cervical screening for Amish, Latina, and African American women. Our results confirm reports that women need social support for daily activities, for their emotional and social well-being, and for screening.[6,29] Latinas and African Americans conceptualize health, including health care, as a collective affair,[28] and *sister circles*[28] have been found to be particularly important to

African American women for decision-making in a climate of mutual aid and cooperation. However, many women in our study lack strong social support because their responsibilities leave them with less time and energy for building and maintaining broad social networks, because their extended families are absent, or due to a combination of factors.[6,9,30] In addition to being culturally appropriate, group appointments would use social support as an aid to dispelling fears of diagnosis, pain, death, and even asking questions.

Clinical cultural competence. The literature shows that provider recommendation is one of the most important correlates of screening.[2,4] Although women in our study say they are willing to follow their providers' recommendations and most providers believe that breast and cervical cancer screenings are beneficial, these women do not always receive such recommendations or a clear explanation of their health risks; together, these findings strongly suggest a failure in communication.

Cultural competence training (encompassing the importance of an open attitude, specific but non-stereotyped characteristics of cultural groups, and laws and regulations prohibiting discrimination) can assist health care providers in improving communication with patients.[14,20] While such training for clinical providers (e.g., physicians, nurses) is commonly endorsed,[19,22–24] our results underscore its equal importance for clerical staff (e.g., receptionists, secretaries), as patients' first contacts in the health care system.

Policies. Some of the strategies identified for improving cultural competence in the clinical setting and, thus, cancer screening behavior among patients, may require revisions of policy as a first step. These include (among many others) the development of a system that enables Amish women to pay nominal fees for services, offers alternative appointment scheduling methods, and explores options for treatment of uninsured non-citizens diagnosed with cancer.

Conclusions

Using concrete strategies based on the suggestions of community women, rooted in their own experiences, is a promising strategy for decreasing barriers to breast and cervical screening.

This study's methodology has limitations, primarily in the lack of detailed information about participants' individual cancer screening experiences. For reasons of time and cost, as well as to preserve participants' sense of privacy, we were not able to administer questionnaires about individuals' cancer screening histories. Another limitation is lack of information about the providers' demographic characteristics; most of those who were interviewed were White and the researchers did not ask interviewees about their origins (e.g., Appalachian, Amish).

To address concerns about the generalizability of findings, we included three non-contiguous counties for each ethnic/cultural group; this approach enabled us to distinguish between cultural differences and regional differences. We ensured constituent validity by asking the women, in the second wave of focus groups, to discuss their own suggestions from the first wave. This study also enables us to make cross-cultural comparisons by using a relatively large number of focus groups and collecting data from both women and providers.

Future studies should focus on demonstrating culturally appropriate interventions in the realms of policy, health care provision, and clinician training. Adapting these strategies for other cultural groups or other geographical areas will require further exploration.

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