

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Since there is often a disconnect between provider suggestions and recommendations and what the community expresses that they want and need, we sought to gain input from the community members themselves. This section of the Community Profile aimed to assess barriers to care that may not be captured by quantitative data.

Focus groups and key informant interviews were conducted to determine the breast health knowledge, screening behaviors, identified barriers and awareness of women living within the five target counties. Women in the target communities who had sought access to breast screenings in the last two years (whether or not the screening was completed) and breast cancer survivors were primarily involved in the focus groups while breast health care providers participated in key informant interviews.

Focus groups were conducted by Louise Palmer, a consultant for Southern Research and Evaluation Institute. The Consultant attempted to recruit participants for two focus groups in each target community through leveraging existing Komen Atlanta partnerships and conducting new outreach in each community. She then moderated each focus group with the assistance of a volunteer note taker and prepared a report summarizing the findings. Key informant interview questions were asked at regular site visits to current grantees serving the target communities, and additional key informant interviews with breast health care providers were conducted by the Komen Atlanta Community Outreach and Grants Manager. Ten focus groups and forty key informant interviews were attempted; seven focus groups and 28 interviews were completed. The interviews and focus groups were designed to investigate three primary questions:

- To what extent are there barriers to accessing breast health services* in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
 - To what extent are there gaps in breast health continuum of care in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
 - To what extent are women satisfied with the breast health services they have received in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
- *Breast health services include breast cancer screening, diagnosis, and treatment services

A variety of non-random sampling techniques were used to recruit focus group and key informant interviewees. Community partners were identified that had the ability to identify women that met the sampling criteria. These partners were then able to invite women to participate in the focus groups. Recruitment flyers were also posted in community service agencies in the target groups. Key informants were chosen by beginning with Komen Atlanta grantees and using a snowball sampling technique, asking interviewees and community contacts for other providers in the target communities. It is important to note that there are some limitations to data collected using convenience sampling, particularly in that it may decrease generalizability. This means that these results may not be fully generalizable to the larger public, as respondents were not chosen at random, and thus, the sample may not be fully representative of the target population.

Qualitative Data Findings

- A. Focus group participant numbers and demographics

A total of 49 women participated in the focus groups and interviews. Of these, 15 were breast cancer survivors. In terms of socioeconomic demographics, the majority of participants identified as Black (73 percent). Of the remainder, 13 percent of women identified as white, 9 percent as Hispanic, and 2 percent as Native American.

The education status of participants varied. Eleven percent of participants did not graduate high school. For 18 percent of participants, the highest level of educational attainment was high school graduation. Nine percent of participants graduated college with a bachelor's degree and 11 percent with a graduate degree. Almost half of participants (49 percent) had between a vocational certificate and some college education. While the education status of participants varied somewhat, the majority of participants can be described as low-income. Although 27 percent of women declined to provide their annual household income, of those who did, fully 61 percent reported a household annual income less than \$20,000. In terms of age, 33 percent of participants were between the ages 40-49 years, 31 percent 50-59, and 33 percent 60-69.

B. Barriers to accessing breast health care

The focus groups explored what, if any, challenges prevent women from accessing breast cancer screening, diagnosis, and treatment services. Across counties, several common barriers emerged that prevent women from accessing breast health care services across the breast cancer care spectrum, from prevention to treatment including:

- Finances and the inability to pay for services
- Attitudes towards breast cancer, such as fear and stigma
- Factors related to culture and race/ethnicity, such as a lack of culturally appropriate information and providers
- Challenges navigating the health care system for services and resources
- Lack of prioritization of breast cancer as an urgent health issue affecting their community
- Lack of free or low cost transportation to health care facilities
- Lack of knowledge about breast cancer in the community at large

Below are details on each of these topics.

Financial barriers: A uniform finding across all focus groups is the lack of affordable health care options for low income women in Georgia, which directly affected participants' ability to access breast health care services. Most participants in the mammogram focus group series were ineligible for Medicaid because they did not meet the income thresholds. However, participants stated that health insurance options provided through the Federal Health Insurance Exchange were too expensive to purchase. For example, participants cited health insurance plans costing \$70/month for a single policy and \$160/week for a family policy as too expensive for their budgets. Many of these participants thought that they would have been eligible for Medicaid had Georgia opted into the expansion. Fully 40 percent of women in the focus groups were uninsured. Of the remaining 60 percent, 40 percent received government-funded health insurance, and 20 percent had private health insurance plans. Of those participants receiving government-funded health insurance, 47 percent were breast cancer survivors.

Uninsured participants described a situation in which they cannot access health care and preventive services during the critical years for early detection of breast cancer. Participants reported finding it stressful to find affordable health care and cited finances as a reason for not having mammograms or clinical breast exams. Instead of paying for preventive health services,

participants instead opt to pay bills, buy gas for their cars to get to work, or purchase other family members' prescriptions.

“Health and finance go hand-in-hand....” “The class divide in Georgia is huge....”

“The working poor are ignored....”

“Without health insurance you don't go to the doctor....”

- Focus group participants from the mammogram screening series

Participants also cited finances as a reason they might delay seeing a doctor if they noticed a change in their breasts. Unmet need is a critical measure of access to health care, which is defined as a time in the past 12 months when a person needed to see a doctor but did not. Fully 58 percent of focus group participants reported one or more unmet health care needs in the last 12 months. Excluding women with Medicaid or Medicare, this percentage increases to 88 percent. Thus, Medicaid may provide some buffer against unmet needs and increase access to health care.

Many participants in the mammogram focus group series received their mammograms for free either through the state-funded Breast and Cervical Cancer Program (BCCP) or through the Komen-funded mammogram program. Several women reported years in which they did not receive mammograms when these programs had met their annual quota. Furthermore, several women who had recently learned about the free mammogram programs had gone many years—over ten in some instances—without a mammogram.

The exception to these findings is Cherokee County in which all the women had health insurance and stated that finances were not a barrier to accessing breast health services. Indeed, these women stated that Cherokee County is affluent compared to other Metro Atlanta counties. However, Cherokee County participants also stated that there are pockets where low-income families live, such as around Teasley Middle School and further north in the county.

For breast cancer survivors, “breast cancer is very, very, very expensive.”

- Breast Cancer Survivor

Sixty-seven percent of the breast cancer survivors in the study had Medicaid or Medicare during treatment. Several participants reported they were uninsured at the time of diagnosis and subsequently received Medicaid. Despite health care coverage, breast cancer survivors described the difficulties of paying out-of-pocket expenses, such as \$2000 deductibles, 15 percent coinsurance amounts, and \$45 copays. Making these payments was especially hard for breast cancer survivors during the many months they were out of work and receiving only 60% of their salary through disability payments. Even with insurance, survivors report scrambling for sparse grants from local nonprofits to pay for daily expenses such as household bills and gas for their cars. One participant depleted her 401K account to pay for treatment. Further, participants report knowing women who turn down treatment because they cannot afford the copay amount.

“I don't know what I would have done without insurance. I shudder [at] the thought. It (cancer) probably would have gone unattended....”

- Breast cancer survivor

Attitudinal barriers: Among all focus groups, participants identified societal attitudes towards breast cancer as a reason why either they, or women in their communities, might not seek breast screening services. Chief among these attitudes, fear of a breast cancer diagnosis

remains prevalent. Participants stated that women in their communities adopt an “out of sight, out of mind” approach, whereby avoiding mammograms also avoids a potential cancer diagnosis. A breast cancer survivor who delayed seeing a doctor even though she had health insurance and experienced symptoms explained: “People who don’t go, it’s got to be fear, fear of the unknown. The big C word. If I don’t know about it, I don’t have to worry about it. I was busy but it wouldn’t have taken long to get it checked out. It had to be an element of fear. “What you don’t know don’t [sic] hurt you”—it’s a lie, but that’s the mentality...”

There may also remain an element of stigma and taboo in discussing female health issues. One participant felt that women in her community (Henry County) do not have the information they need about breast health screenings because “women are still ashamed to talk about women’s health.” Indeed, breast cancer survivors agreed that a diagnosis of breast cancer remains stigmatizing to the extent that they avoided telling people about their diagnosis.

“People’s reaction to breast cancer is stigmatizing; it’s (telling people) a coming out process....”
– Breast cancer survivor

Culture and race/ethnicity: The findings indicate that current education and outreach efforts to Latino and African American communities need improvement to better reach and resonate with these groups of women. Latina participants stated that breast cancer is not a topic of conversation at all in the Latino community because of fear, stigma, and a general knowledge deficit about the disease, its cause, and prognosis. Participants explained that many Latinos still regard breast cancer as a death sentence, and subsequently there is a belief that early detection through screenings provides no benefit. Similarly, one participant explained that in the Latino culture, “the focus is on healing, not sickness,” and as such there is rarely dialogue about disease prevention. In addition to possible language barriers, participants also suggested that it is especially hard for undocumented immigrants to receive screening services because they are ineligible for government-funded programs.

Some African American participants indicated that breast cancer is not generally perceived as a topic of concern for their community. Rather, other diseases such as HIV, diabetes, and heart disease are considered more pressing health issues for African Americans. Indeed, one participant stated that even doctors do not emphasize breast cancer as a high priority for African Americans, but instead screen for other diseases with high prevalence rates in the Black community. Another participant said that, until she knew of a Black friend with breast cancer, she considered it “not a black issue. It’s a white disease.” Other participants explained that women think breast cancer is “an old woman’s disease.” Therefore, education and outreach initiatives in both Latino and African American communities should emphasize that breast cancer is a disease that can and does affect women of all ages in their communities.

“ Make it known that it (breast cancer) is an issue that affects the black and Latino communities....”
– Latino participant from the mammogram focus group series

Other African American participants discussed how there is a historical and cultural unspoken rule not to discuss health issues, and that this creates a culture of secrecy around illnesses like breast cancer.

“We were taught as children what goes on in the home, stays in the home. We were taught that health and illness is a secret... you don’t want to be ostracized (by talking about it). It’s still that way. It’s part of our culture. We don’t talk about it....”
– African American breast cancer survivor

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African American participants strongly urged Susan G. Komen to work with their communities to develop health education messaging and outreach campaigns that are culturally appropriate. Participants stated current breast cancer education materials are missing their mark among African American women because “they do not use our language.”

*“Talk our language. Be direct. Speak to us the way we talk to each other.
Don’t make it too medical.”*

– African American breast cancer survivor

To resonate culturally with African Americans, participants suggested placing messaging on beauty products used by African American women. Also, to overcome the “this won’t happen to me” mentality, participants recommended identifying local role models of all ages from the Black community who have had breast cancer to talk to other women.

In addition to comments about health promotion messaging missing its mark, several African American participants expressed the importance of finding an African American breast health provider who they could relate to and with whom they could feel comfortable.

Health care system navigation: In most focus groups, participants expressed frustration navigating the health care system for services and resources, a concern especially heightened for women lacking health insurance and most breast cancer survivors. Low-income women in the mammogram screening groups expressed difficulty navigating the health care system to find free health care services. Across groups, women did not know free breast screening services were available until they discovered about either BCCP or the Komen mammogram program by happenstance. For example, several women stated that they went to the Health Department for another reason and while there, the nurse asked if they had had a mammogram recently. Indeed, participants explained that the Health Department is widely known as the community location for WIC services and not as a place to get preventive screenings. Therefore, better advertising of available services at the Health Departments may increase the number of women who receive breast screening services. However, participants who use the Health Department applauded the staff there for making the appointment at the mammography imaging center on their behalf and giving women the paperwork they need for the mammogram.

Low-income, African American participants explained that what services are available in their communities tend to be disjointed from other health care services. For example, while there may be occasional mobile health screening trucks in their neighborhoods, they are disconnected from primary care providers or breast health specialists if a woman needs to be referred. Breast cancer survivors expressed frustration in finding resources to help them pay for treatment.

Several African American breast cancer survivors noted the need to train Black women from their communities as patient navigators to assist women in their neighborhoods with accessing the breast health services they need, especially after a diagnosis. Survivors also suggested a “virtual” navigator program, with simple step-wise advice on what women needed to do after a diagnosis.

Participants also suggested an online clearing house listing free health services for women that they could search and find health resources to meet their needs.

Breast cancer as priority for women: In most focus groups, participants described women as caregivers who put their health needs last, and that this mentality is a barrier to accessing

breast health services in a timely manner. As one participant stated, “women are advocates for others first” and themselves last. Most women worked or had families to take care of, and stated that they were too busy with each day’s challenges to prioritize their health needs, let alone breast health. Participants strongly agreed that the message to women should be to put their health needs first so that they can be healthy to effectively look after their families. Several participants cited that they decided to get a mammogram when they made the determination to live a long life for their significant others.

“I don’t know what it’s going to take to have people say “I see about me.” Commercials are great but it’s just an individual thing. Had it not been for the pain, I would never have gone to see about it (a lump she felt). I don’t know what it would take. Just be persistent “let’s take care of you. Check yourself.”

—Breast cancer survivor

With age, women’s feelings towards both prioritizing their health needs and breast cancer appeared to change. As one participant said, “as you get older, you take it (breast cancer) more seriously.” With the exception of Cherokee County, participants generally perceived breast cancer messages to be visible in their communities, especially in October. However, unanimously across groups, participants stated that breast cancer does not become a high health priority until you either know someone affected by breast cancer, you have a scare or symptoms yourself, or you have made the mental shift to put your health before others whom you care for. Participants therefore emphasized that breast cancer messaging should focus on the fact that this really could happen to you.

“Until breast cancer happens in your community, you don’t think about it...”

“You don’t hear about it unless someone’s sick with it...”

– Participants from the mammogram focus group series

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Transportation: The availability of public transportation and the extent to which it contributes as a barrier to accessing breast health services varies by county. In Henry and Clayton counties, participants expressed that transportation could be a barrier to seeking breast health services for women who do not own cars. Clayton County currently has no public transportation, although a recent transit referendum voted to fund reinstatement of a County bus service and future rail service. Therefore, to access health providers, residents must pay for taxis (generally at \$2 per mile), get a ride from a friend, or own a car. However, breast cancer survivors pointed out that many women must sell their cars to pay for treatment.

The situation in Henry County is only marginally better. The County transit service is a by reservation only service whereby residents must call ahead to make an appointment and pay \$4.00 per stop. Participants complained that sometimes when you call to make an appointment, there are no drivers available to run the service. Further, one breast cancer survivor was unable to take the County transit service to her appointments because her breast health specialist was located over the county line and out of the jurisdiction of the transit service.

In North Fulton, participants felt the transportation difficulty would affect seniors the most because of potential mobility limitations. Otherwise, participants reported no difficulties in traveling to breast health providers, other than distance to providers. In Dekalb County, participants felt there were many transportation options available and they also reported no problems getting to appointments. Participants in Cherokee County felt that most people had

cars and would not move to the County otherwise. However, they did acknowledge transportation to health services may be a challenge for some people.

Knowledge: Participants across all focus groups were well informed about breast cancer screening recommendations. Indeed, 74 percent of participants who answered the question “at what age should women have annual mammograms” answered correctly. Further, the majority of participants had had a mammogram in the last 12 months. Therefore, at least among our sample, lack of knowledge about screening advice is not a major barrier to accessing care. However, participants suggested that other women in their communities might not seek routine breast health screening services if they were asymptomatic, but rather only if they experienced breast pain or identified a lump. As one participant explained, “they feel well and so are not going to get a mammogram.” A few participants also said that people in their communities believe there’s a breast cancer cure and that survival rates are good, therefore there is no need for early detection. This belief is in direct contradiction to the perception among Latinos that breast cancer is a death sentence.

Several participants across focus groups expressed a desire to know the cause of breast cancer and how they could prevent it. For breast cancer survivors, this knowledge gap extended to a wish to participate in long-term research studies collecting data from survivors. Further, when asked what they would do if they noticed a change in their breasts, several women said they would go to the emergency room, rather than to their primary care provider.

Therefore, the findings regarding knowledge gaps in the sample are conflicting. Participants expressed good levels of understanding about annual screening requirements, but their knowledge on causes and prevention strategies was mostly absent. Additionally, participants described misunderstandings in the community at large about breast cancer and what they should do were they to experience breast changes.

Provider attitude: It is possible that some women are discouraged from accessing breast health services because of real or perceived negative provider attitudes. Women expressed that they have experienced negativity from health care providers in general because of their uninsured health status and feel that compared to insured women, they receive “the bare minimum treatment.” Participants also stated that they often feel rushed at breast health appointments and expressed a desire for doctors to slow down, be more attentive, and provide more details about the screening test and any findings. However, many women also reported they felt satisfied with the care they received from their breast health provider.

D. Breast health providers

Participants in North Fulton, Henry, and Clayton Counties feel strongly that their communities lack general health care options for low-income people – both in terms of health care providers and resource centers that can advise them on available free or low-cost services.

In Henry and Clayton Counties, the Health Departments are critical safety net service providers to the un/underinsured. However, some participants were unable to get free wellness visits at the Health Departments unless they had symptoms or could not afford the sliding scale fee offered. Even a sliding scale of \$30 for annual tests was cited as too much by one participant, who as a consequence is past due a checkup for several chronic conditions. This participant was able to get her mammogram through the Komen program. Therefore, while a critical health care resource in low-income communities, Health Departments are limited in the services they provide and offer only a “Band-Aid solution” to the un/underinsured.

For participants undergoing treatment for breast cancer in Clayton and Henry Counties, there were limited options for imaging, treatment centers, and support groups. However, there is a new breast health center in Henry County and as a result, participants expect to see improvement in the services at the hospital.

Breast cancer survivors in Dekalb and Fulton Counties did not have any problems finding a breast health specialist, but some participants felt their doctor choice was limited by the insurance they had. Participants in Cherokee County felt there are plenty of convenient breast health options for women seeking screening and treatment services and that providers in the area are well respected.

E. Outreach gaps and suggestions

Participants felt that more outreach and education in their communities is necessary across all age groups. Participants in Cherokee County in particular said they see very little in the county in terms of breast cancer messaging. Participants in all groups emphasized that outreach and education on breast cancer should be yearlong and not just in October. Participants felt that breast cancer awareness organizations were not engaging certain communities – in particular, poor neighborhoods, Latina and immigrant communities, seniors, and women under the age of 40.

“In October you see the pink ribbons everywhere, but the outreach people don’t go in the poor neighborhoods....”

“Make yourself visible....” “You can’t start too young....”

- Participants from the mammogram focus group series

F. The role of church in health

The role of religion and faith in women’s health were dominant themes in all the focus groups. For some women, the lack of a safety net is compensated for by faith. Indeed, participants shared a deeply held belief that their faith in God would assist their health care struggles. Many breast cancer survivors discussed their diagnosis in terms of their symptoms being a sign from God. In one instance, a participant ignored her symptoms until she received this “signal.”

“For a couple of months I just ignored it. I’m a woman of extreme faith and that is what got me through it. At the end of June, I started to have pain and it was God’s way of saying it’s time to make a decision (about her course of treatment). God allows everything to happen for a reason.”

- Breast cancer survivor discussing her two month delay in getting breast cancer treated after diagnosis

“The information was overwhelming. I had to pray . . . I didn’t want to deal with it for awhile....”
– Breast cancer survivor

“We (the African American community) put a lot into our faith....”
– Breast cancer survivor

G. The experience of breast cancer survivors

Breast cancer diagnosis: Breast cancer survivor group participants discovered that they had breast cancer either because they experienced symptoms or through a routine mammogram. A

few women delayed seeking medical advice after experiencing symptoms. One survivor experienced symptoms on and off for eight years before she went to her primary care provider. After visiting a health care provider, most participants experienced a swift diagnosis, and their providers helped them with the next steps – from referring them to an imaging center, discussing the mammogram findings, referring them to a biopsy surgeon, discussing the results, and referring them to an oncologist and treatment facility.

The survivors advocated for this seamless system, which is not always the experience. Indeed, one survivor in Henry County had a very different and difficult diagnosis experience. After the lump was discovered, the imaging center gave the survivor two biopsy provider options, and only one of these options was local (the other being in Cobb County). The local biopsy option was a thoracic surgeon who was unable to answer the survivor's questions when the cancer diagnosis was returned. The surgeon was also unable to provide the survivor with referrals to a breast specialist. A friend referred the participant to a local breast health specialist, but she was unable to get an appointment for several weeks.

The participants strongly agreed that standalone imaging centers require training on how to give diagnoses to women and provide the information they need for the next steps. The participants suggested that all imaging centers should be integrated into a system of breast health care with clear protocols on the steps to take upon a diagnosis. Survivors complained that imaging centers feel "like a cattle chute" and "like a business."

Breast cancer treatment: After diagnosis, women had to wait up to one month for treatment, which they said was too long. During the waiting period, the women did not sleep and worried greatly about if the cancer was growing during this time. One survivor discussed how she had a difficult time deciding on her course of treatment after being given two different options to consider: "I didn't like either option (total mastectomy, or partial with radiation). I couldn't wrap my head around losing my breast."

Most of the survivors were prescribed Tamoxifen for five years post radiation. The women expressed feelings of frustration that they had to take more drugs after finishing radiation, especially one that causes side effects, including the chance for uterine cancer. Consequently, several survivors commented that they inconsistently take Tamoxifen. Survivors also discussed how they now have other co-morbidities as a result of breast cancer treatment. Participants expressed the difficulty of working through treatment and suggested legislation changes so that women do not have to do so.

Breast cancer support: All the survivors stated that they received the most amount of support from their church and their breast cancer survivor support group. However, survivors agreed that there should be more support groups and that they should be highly visible, as "you only hear about them by word of mouth." Not all survivors went to a survivor group because they preferred to handle it by themselves. Furthermore, participants said some women do not like to go to survivor groups because they are depressing.

The general consensus was that breast cancer continues to be stigmatizing in the community at large, and even if they had a great support group of friends and family, only at a survivor group could they access the level of empathy and support that made them no longer feel alone. However, participants pointed out that there are financial barriers to accessing support groups when women do not have transportation. Also, when women are really sick, they are unable to leave the house to go to a support group.

“I didn’t feel like I needed a survivor specific group because I had so much support from church. But it was the best thing in the world. I didn’t know I needed it until I went. They get it....”
– Breast cancer survivor.

Additional sources of support came from hospital-based breast cancer patient navigators. Patient navigators were breast cancer survivors and greeted women as they signed in for their treatment appointments, stayed with them if needed, provided them information, and answered their questions. Survivors who did not receive help from a navigator thought that it would have been helpful.

Women wished there was meals delivery assistance and education on the types of foods to eat to promote recovery. Finally, breast cancer survivors said that the co-survival model of support had been helpful to them and their friends or family and that there need to be more spousal support groups. In all, survivors advocated for greater levels of visible support in their communities both for women with breast cancer and their families.

Survivorship years: Despite side-effects from cancer medications and the financial burden of cancer treatment, survivors are looking for ways to stay healthy, have fun, and help other women in their communities who have breast cancer. Survivors are especially looking for low impact exercise classes that are appropriate for their physical condition, for example, chair yoga. Survivors asked that classes also have options for women working full-time.

C. Key Informant Interview Data

Key informant interviews generally supported the observations made by focus group members but elucidated a few additional themes:

- 1) Breast health care providers were generally aware of some free and low cost screening programs but feel that demand far exceeds the available resources. This perceived or actual deficit in available services may keep providers from referring asymptomatic women who may need a breast exam.
- 2) Providers noted that many of their patients with insurance had difficulty with diagnostic or treatment copays and out of pocket expenses.
- 3) Providers, with the exception of nurse navigators, often had little to no resources to offer patients regarding financial assistance and transportation during diagnostics and treatment. Most providers stated that they could connect patients with language translation services, if needed.
- 4) Providers in Fulton and DeKalb stated that they knew of wellness resources for breast cancer survivors. Providers in Cherokee, Clayton, and Henry counties did not know of survivorship programs in their home counties.