

Low-Socioeconomic Status and Breast Cancer: Needs and Resource Gaps

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## **Abstract**

### Low-Socioeconomic Status and Breast Cancer: Unmet Needs

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Breast cancer is a threat to a large percentage of the U.S. population, affecting nearly 12% of women within their lifetime. While many studies have studied the needs of breast cancer patients, few have focused on the needs of low-socioeconomic status (SES) breast cancer patients. Qualitative interviews performed among low-SES breast cancer patients and providers from Boston, MA and Knoxville, TN were analyzed for common themes. Both regions had common themes related to low-SES patient needs that were both met, such as social support and relaxation methods, and unmet, such as transportation and attention to medical care. Both regions also had common themes among providers and professionals who interact with lowSES breast cancer patients, such as transportation and financial difficulties that affect the quality of life for low-SES breast cancer patients. Each region also had unique needs that were discussed by both low-SES breast cancer patients and providers. These findings highlight resources and programs that currently benefit low-SES breast cancer patients, as well as gaps in services that do not meet this population's needs. Future direction includes utilizing this information for development of resources to better meet the needs of low-SES breast cancer patients.

## Introduction

Breast cancer remains a threat to many individuals despite continued research and development within the scientific field. Of all female cancers that occur worldwide, breast cancer accounts for nearly 18% of this burden which makes this disease one of the most common among women (McPherson, Steel, & Dixon, 2000). An estimated 12% of women in the United States will develop invasive breast cancer over their lifetime with an expected 246,660 new cases appearing throughout 2016 (“U.S. Breast Cancer Statistics | Breastcancer.org,” 2017). Several decades of research have discovered risk factors for breast cancer, both hereditary and non-hereditary, which has allowed women to better prepare for and combat this disease (“Breast Cancer Risk Factors You Cannot Change,” 2016; Ford et al., 1998). Despite these efforts, a large percentage of women remain at risk. A comprehensive list of risk factors, both avoidable and unavoidable, gives breast cancer the potential to impact a large population of women across various degrees of education, class, and financial status. Thus, regardless of an individual’s socioeconomic status (SES), breast cancer is a threat for many women.

Breast cancer negatively impacts an individual’s quality of life. Several commonly cited consequences of breast cancer include financial, emotional, and psychological distress. For example, patients may develop anxiety about how treatment may affect their appearance or how the disease will impact their duration of life (Baqutayan, 2012; The American Cancer Society medical and editorial content team, 2016; Zimmermann, 2015). Breast cancer can also expend financial burden on affected women with some individuals accruing years of medical debt even after completing treatment (Jagsi et al., 2014; Simon, 2016). While everyone will be affected differently, it is important to comprehensively understand how breast cancer impacts women to better create resources that will improve the quality of life for this population. Resources for individuals affected by breast cancer have grown in response to the various ways

that breast cancer impacts quality of life. Organizations, both locally and nationally, have attempted to meet the needs of breast cancer patients. For example, the Susan G. Komen foundation recently released an application for smart phones that allows affected individuals to share their experiences with breast cancer (“Susan G. Komen® Statement on Mobile App Announced Today to Help Breast Cancer Patients | Susan G. Komen®,” 2015). Funds and manpower are limited, however, and the needs of breast cancer patients are important to delineate to efficiently and effectively address those that are most pressing.

A gap in the literature exists in determining the unmet needs of low-SES women affected by breast cancer. Research has thoroughly demonstrated the unmet needs of the breast cancer population, but the data has not focused on how this disease impacts low-SES women (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; Park & Hwang, 2012; Todd, Feuerstein, Gehrke, Hydeman, & Beaupin, 2015). The needs of low-SES women affected by breast cancer may differ considerably from the needs of other women also affected by this disease as SES increases; correlates of low-SES include lower education, poverty and poor health which can impact how breast cancer patients in this setting respond to their diagnosis (“Education and Socioeconomic Status Factsheet,” n.d.). With many low-SES women at risk for breast cancer, it is important to both understand how this disease affects their quality of life and determine the unmet needs that are not currently addressed by offered resources. Therefore, the aim of this study is to assess the needs of low-SES breast cancer patients and whether current resources are meeting these needs. Qualitative interview methods will be used to assess resource needs among low-SES breast cancer patients. We will also interview providers that have experience working with low-SES breast cancer patients. This will allow for deeper exploration of the needs among this population and help narrow the current gap that exists within the literature.

## Methods

This project was funded by Living Beyond Breast Cancer to assess the needs of SES individuals affected by breast cancer. Patients and providers were recruited from Boston Medical Center Cancer Care Center (BMC Cancer Care Center), Boston Public Housing Developments and the University of Tennessee Cancer Institute. Interviews were conducted by students and researchers. These locations represent safety net organizations that provide medical care and resources for our population of interest.

### *Sampling*

#### a. Participants, Recruitment, and Eligibility: Breast Cancer Patients

We recruited breast cancer patients from Boston, MA and Knoxville, TN. In Boston, Resident Health Advocates from the Boston Public Housing Developments and Survivorship Staff from Boston Medical Center recruited participants from both institutions via fliers, in-person or through medical records. Interested participants were told the purpose of the study and screened for eligibility. Eligibility requirements included a diagnosis of breast cancer, received or receiving treatment from Boston Medical Center, self-identify as low-income, and having completed no more than a high school education. If eligible, interviews were scheduled with participants. 26 cancer patients overall, including 15 breast cancer patients, were recruited from Boston, MA. In Knoxville, we recruited participants by contacting local not-for-profit organizations, including support groups, that provide resources to low income women with breast cancer and healthcare providers at the University of Tennessee Cancer Institute. These organizations distributed fliers and invitations to low-SES breast cancer patients. Interested women contacted the organization by phone or e-mail and were screened for eligibility. Eligibility requirements included a diagnosis of breast cancer, received or receiving treatment from University of Tennessee Cancer Institute, self-identify as low-income, and having completed no more than a high school education. If eligible, interviews were scheduled with

participants. A total of 6 breast cancer patients were recruited from Knoxville, TN. Overall, 21 breast cancer patients were included in the study.

#### b. Interview Methods and Analysis: Breast Cancer Patients

We interviewed breast cancer patients about their needs in association with their breast cancer diagnosis. We screened participants via telephone to ensure that they met the inclusion criteria. . Once participants were deemed to be eligible, interviews were scheduled to occur either in person or by telephone. Interviews consisted of qualitatively asking participants about how breast cancer has affected their quality of living. We also invited participants to share the met and unmet resource needs that existed during or because of breast cancer. The interview was semi-structured and included topics such as finances, worries, support programs and groups, medical treatment and communication strategies. However, we also encouraged participants to discuss topics that were not prompted by the interviewer.

We used qualitative interview methods to assess the needs of low SES breast cancer survivors and patients. The audio from the completed interviews was transcribed. Two coders analyzed the transcripts to assess the responses for main themes using a coding guide. Using multiple coders serves to discover all possible themes through multiple perspectives, and ensures reliability of discovered themes. The two coders discussed their differences in coding and resolved the conflicts until 80% agreement was reached. The interview guide for breast cancer patients in included in the appendix.

The coding guide that was utilized for low-SES breast cancer patients included various themes discussed among the interviews, such as financial burden, social support groups and resources, perception of medical care, and unmet needs among others. Several of the codes were deductive as we anticipated that low-SES breast cancer patients may have financial hardships and perspectives about resources and medical treatment. However, there were codes that were also discovered as transcripts were coded. Some examples of inductive codes

included insurance not covering genetic testing, unmet needs in terms of child support, and fear of recurrence.

#### c. Participants, Recruitment, and Eligibility: Breast Cancer Providers

We also recruited providers and professionals from both Boston, MA and Knoxville, TN that had experience working with low-SES breast cancer patients. We recruited providers from both locations using snowball sampling. We contacted potential interested providers that were associated with either Boston Medical Center or University of Tennessee Cancer Institute. If interested, we invited these individuals to share their experiences via a telephone interview. We also asked providers to refer us to other providers or professionals who might be interested in participating in our study. All providers and professionals were screened via telephone at the beginning of the interview. Providers were eligible to be in the study if they had at least 5 hours of interaction with low-SES breast cancer patients per week, and were employed at either Boston Medical Center or University of Tennessee Cancer Institute. From Boston, we recruited 4 providers. We also recruited 4 providers from Knoxville, resulting in a total of 8 providers included in the study.

#### d. Interview Methods and Analysis: Breast Cancer Providers

We interviewed providers to assess their perspectives of the met and unmet resource needs that exist among the low-SES patients that they interact with. We screened participants via telephone to ensure they were eligible for our study. Once determined to be eligible, interviews were scheduled with participants to occur via telephone. Interviews consisted of qualitatively asking participants about their perspectives of how breast cancer has affected the quality of life of for their low-SES patients. We also invited participants to share their views on the met and unmet resource needs for low-SES breast cancer patients. The interview was semistructured and included topics such as social support groups and programs, medical

resources, finances, worries, causes of resource needs, and collaboration strategies. We also invited participants to discuss topics not prompted by the interviewer.

We used qualitative interview methods to assess provider perspective of the needs of low SES breast cancer survivors and patients. The audio from the completed interviews was transcribed. Two coders analyzed the transcripts to assess the responses for main themes using a coding guide. Using multiple coders serves to discover all possible themes through multiple perspectives, and ensures reliability of discovered themes. The two coders discussed their differences in coding and resolved the conflicts until 80% agreement was reached. One Boston provider interview was damaged due to machine error, and notes from this interview were coded rather than a transcript. This involved writing as many detailed notes about the interview as possible and assessing the written notes for major themes. The interview guide for breast cancer providers is included in the appendix.

The coding guide that was utilized for providers also included various themes discussed among the interviews, such as patient financial burden, health and medical resources for patients, and reasons for differences in access to resources between low-SES and high-SES breast cancer patients. Several of the codes were deductive as we anticipated that providers would express patient financial burden, health differing between low-SES and high-SES, and the effect of social support groups for patients, among others. Several codes were inductive as providers discussed themes that included cultural sensitivity, language barriers, and patients not wanting help, among others.

## Results

A total of 21 low-SES breast cancer patients and 7 providers or professionals were recruited to our study from both Boston, MA and Knoxville, TN. From Boston, a total of 26 patients were recruited that included multiple cancers, but 15 of these individuals identified their cancer as breast and were thus included in the study. We recruited 6 patients from Knoxville,

TN. We recruited 4 providers and professionals from Boston, MA and 4 providers and professionals from Knoxville, TN.

The breast cancer patients all had or were currently diagnosed with breast cancer and met the criteria for being classified as low-SES. The medical providers or personnel all had experience working with low-SES breast cancer patients. All participants in this study were recruited from Boston Medical Center, Boston Public Housing Developments and University of Tennessee Cancer Institute.

### **Common Themes among Patients**

#### **I. Financial Difficulties**

Many breast cancer patients expressed difficulties or concerns about their financial wellbeing. Many participants from both locations mentioned that medical costs presented a huge burden. Several participants described having to choose between medications and living expenses.

“If it gets too bad, where I can’t pay for the medicine, then I weigh my option as [to] what I can get away with and what I can’t. Then I pay for what helps me more... My finances have drastically changed a lot. That kinda weighs on me a lot.” -Boston BC Patient

Several times, participants stated that a breast cancer diagnosis negatively impacted their job or created difficulties in securing employment. Many participants mentioned that their daily living expenses became difficult to meet.

“Financially, it was just hard, no real money coming in, so it was just a struggle for everything, food, utilities, everything that normal people would worry about.” -Knoxville BC Patient

Many participants also expressed how their treatment costs affected their ability to afford adequate housing or provide for their family. Commonly affected living expenses that were mentioned included rent, utilities, gas, and food

“Just the other day, I had to ask for gas money and some grocery money because we came up short this week or this two-week period for gas and groceries. It's hard on my pride because I don't like asking for help, so I'm grateful that it's there when I need it.” -

Knoxville BC Patient

## II. Effects of breast cancer

Several themes emerged among participants about various consequences of breast cancer. Some participants discussed how their diagnosis prompted them to become their own advocate both in terms of breast cancer treatment and improving their overall health. Several of these participants learned that it was appropriate to ask their doctors for advice and question the treatment options that were offered.

“Nobody else explained anything. I just went with the flow. Whatever they told me to do that's what I did. Now I know that I have a voice and I am my own advocate. I know that if something is going on, I have a right to ask questions and not to leave the office and not allow them to just do anything they need to do because they are the doctors, but I have a right to say, "Wait a minute. What is this for? and Why are you doing this?" instead of saying, "Okay, I'll just take the treatment and then I'll go home without any questions at all." -Boston BC Patient

Some participants mentioned that breast cancer has various emotional consequences. One person stated, “I'm a very healthy person other than of course the cancer. I've been healthy my whole life, never smoked or anything. And you're just – just sad.” Others mentioned that

although they were happy once treatment was over, they felt depressed when thinking of how breast cancer impacted their life. One patient from Boston stated, "I was happy [after treatment]. I was happy but I was also depressed because of what I went through."

### III. Fears and coping mechanisms

Several participants strongly expressed their worries about not being able to afford everything in terms of treatment and meeting required living expenses.

"I mean, during that time they helped me with gas and she's a -- we didn't even know what we were, how we were going to do everything, between the gas and the medicines and the doctors."

Several participants also expressed how they feared they would have to choose between living expenses and meeting treatment recommendations. Some participants mentioned that they had limited money for transportation which induced anxiety about returning to the clinic for needed appointments. One breast cancer patient from Knoxville expressed anxiety about, "...how we were going to do everything, between the gas and the medicines and the doctors."

Several fears were expressed by participants when told their diagnosis. Some of the participants felt that they did not know, at first, where to go, who to turn to for help, or what to expect after being told their diagnosis. Several of the participants expressed fear of the unknown or experienced anxiety during appointments. Many participants were fearful of breast cancer recurrence. One participant stated that their fear of recurrence was, "something black that you have there. It's fear that just shows up". Other participants mentioned that they were worried the cancer would spread.

Several themes of alleviating fear were expressed by participants. Many participants mentioned relying on their faith to help alleviate fears of the unknown.

“But then I have a real strong faith and so I just gave it to God. And I just went through it with having faith that He was going to take care of me and that whatever happens it was going to be okay. And so I still lean on that faith that if in four or five years my cancer returns then I'm just going to let the Lord take care of me. I'm just going to let him have it.” -Knoxville BC patient

Several participants also mentioned that they eventually had to gather strength to accept their diagnosis and move forward with treatment. In particular, one participant expressed, “I just took it as I need to just move forward with my life.” Other participants mentioned that focusing on other health problems or the needs of their family prompted them to gather strength.

#### IV. Support groups, met needs, and coordination of resources

Participants highlighted multiple ways that support groups and programs, both within the clinic and in the community, were resourceful in meeting their needs. Many participants mentioned how support groups provided a social aspect during their treatment, and several participants mentioned how strongly this need was met.

“They have a website or a Facebook page where you can go and talk about your latest problem and they give you support from other cancer survivors and from nurses and things like that. It's very supportive.” - Knoxville BC Patient

Another patient from Knoxville stated how support groups and programs tended to offer many resources.

“All of those services are free, the yoga, the exercise, the meeting with other survivors and just talk about that. I utilize that. And then I am a member of a support group just for African-American breast cancer survivors which is now through the University of Tennessee.”

Many participants also mentioned that the support groups and programs assisted with financial need. One participant mentioned how support groups and programs assisted with her living expenses by saying, "...we got some financial help through some of the organizations to help with the gas and the food." Many participants also mentioned that the support groups and programs were beneficial in providing exercise and healthy living opportunities, such as camping or white water rafting, and personal development activities, such as painting or pottery. Some participants expressed that social support groups and programs provided opportunities for relaxation, such as yoga or massage, and opportunities to learn more information about breast cancer and treatment opportunities. A few participants mentioned how support groups and programs were beneficial in providing emotional support. Overall, many participants expressed that nationally recognized cancer organizations were beneficial in supporting their needs, although some women felt that these organizations were not helpful during their treatment.

#### V. Unmet needs outside of medical care

Several unmet needs were expressed among participants. Some participants expressed that they lacked a support system within their families and daily life. One participant mentioned that their family made their quality of life worse rather than better.

"And as much as I feel like we've got a lot of family folks around. I don't mean to disrespect the family people, but sometimes I think they make you more sick than what you are. They make you feel bad about this and that and you know. Sometimes I don't think people heal properly because of all the heavy stuff that they got on them." -Boson BC Patient

Participants from both regions also expressed how support groups and programs did not meet several of their needs. Several participants mentioned that resources did not provide

emotional support. One participant stated that support groups needed to provide, "...emotional support like a psychiatrist that's available just for cancer patients." Some participants also expressed that support groups and programs did not prepare them for what to do beyond treatment; participants mentioned confusion on how to obtain prosthetics after treatment or how to develop a healthy lifestyle upon remission. Some participants also mentioned that transportation was inadequate which resulted in treatment recommendations being difficult to achieve without private transportation.

#### VI. Perspective of medical treatment and unmet medical needs

Many participants expressed both negative and positive perspectives of the medical team during treatment. Many participants expressed how helpful their oncologist was in ensuring their needs were met, and some participants also felt that their primary care doctor was attentive and supportive during their care. Several participants also felt that the hospital provided a supportive environment during treatment, and some participants felt that the medical team became like family. Several participants mentioned that they relied on their doctors for information as they were trustworthy sources.

Despite participants mentioning positive aspects of their medical treatment, many participants had negative experiences with their primary care doctors or surrounding medical team. Several participants mentioned that their doctor did not refer them to resources beyond medical treatment. Several participants mentioned that they felt uninformed about their health and how to navigate medical resources; for example, one participant stated, "And sometimes I felt like I was not really informed enough about my health and insurance..." In addition, some participants felt that the medical team was disconnected, or that medical teams in various specialties did not collaborate for the integrated health of the individual. Several participants felt very strongly that the doctors they interacted with did not provide adequate explanations of treatment and were emotionally unavailable and unsupportive.

“But that’s one of the I guess worst things. I think also the breast surgeons can probably be a little more - I remember that when my breast surgeon called me at work to tell me that I needed a mastectomy he was so blunt about it. There was no like not feeling or anything.” -Knoxville BC Patient

Many participants also felt strongly that doctors did not inform them about post-treatment expectations. One participant mentioned that their doctor did not provide adequate medical support beyond treatment.

“My insurance company is saying, “Well, you need to see your doctor every six months,” and I’m like, “He’s not giving me those types of appointments.” -Knoxville BC Patient

Some participants stated that their doctor assumed what they needed or wanted, such as prosthetics. One participant questioned her doctor’s assumptions by saying, “I was like did I say anything about wanting bigger breasts?” Several participants also noted that follow-up appointments were burdensome for them, either financially or as a time commitment.

“I was tired. I hate going to the hospitals..., especially when I have to drive down there. I don’t like driving that much. It kinda bothersome to me. Then, too, you have to pay that money to get outta there. Every time I go down there, every three months... I’m on a fixed income. I don’t have the money to be spending that for doctor visits and stuff like that.” -Boston BC Patient

## **Patient Themes Specific to Each Region**

### **I. Knoxville, Tennessee**

## A. Financial

Several financial themes were expressed among participants from Knoxville, TN. Some participants mentioned that they experienced difficulties in obtaining or affording prosthetics after treatment. While some patients had adequate insurance, several participants did not have adequate insurance to cover their medications or prosthetics. Only one participant mentioned not having insurance prior to receiving their breast cancer diagnosis. One participant mentioned that their insurance would not cover a genetic test that they deemed to be important.

“One thing that really bothered me, too, was I had that test to see if -- that genetic test for that BRCA gene. I had that done, but when I had it done, insurance was not paying for that. And so, I ended up having to pay for that.” -Knoxville BC Patient

Some participants mentioned that the hospital or medical team were accommodating of their financial needs and allowed extra time for patients to make payments or reduced the amount that was owed. One person mentioned that they were still paying off medical debt despite their treatment having been completed several years prior.

## B. Consequences of Breast Cancer

Fear was a common theme among many participants in Knoxville, TN. Many participants expressed concerns of their breast cancer diagnosis being a burden to their family. Some participants developed anxiety about dying with one participant mentioning that she feared, “Death and also you know, how to pay for it.”

Participants mentioned that their breast cancer diagnosis resulted in several consequences that related to their mental health and financial well-being. Some participants expressed that they became insecure of their appearance after treatment. While less common among participants, sexual insecurity and lack of self-esteem were also expressed themes.

## C. Support systems and resources

Participants expressed a multitude of met and unmet needs in terms of support systems and resources. Some participants lacked spousal support and one participant mentioned a lack of resources within the home, such as internet or a computer. One participant mentioned that they were unaware of support programs and resources that could help meet their needs. However, many participants were aware of at least several support programs and resources within the community. One participant only knew of 1-2 resources they could utilize, but most of the participants expressed knowledge of 3-5 support programs and groups.

Participants expressed that support groups and programs met some of their needs during treatment. Many participants expressed strongly that support groups and programs provided needed financial assistance. One participant mentioned that funds given by the Susan G. Komen program in Knoxville, "...has helped a lot with the gas and the grocery." One participant also mentioned that they were able to obtain adequate transportation from the offered resources.

Although some participant needs were met through support groups and programs, many expressed needs that were not met. Some participants mentioned that support programs and groups did not assist with associated medical expenses, such as lymphedema sleeves. One participant expressed that they felt more like a number in the system rather than an individual with actual needs. One participant also mentioned that current resources do not address self-esteem issues that can occur after treatment. Several participants strongly expressed wanting support groups and resources for family members. Other participants mentioned that transportation services were inadequate and not addressed by current resources.

There were few unmet needs specific to Knoxville participants that pertained to their medical care. However, a few participants mentioned negative experiences with their medical care during treatment. One participant lacked confidence in her primary care doctor's decisions and instead relied upon their own understanding when making medical decisions; they stated,

"I'm pretty in tune with my body so I'll go back when I feel it's necessary." One participant also felt that the medical team was not supportive or encouraging of them during their care.

#### D. Communication and information

All the participants expressed that they preferred to be communicated with in person regarding medical information. Many participants also mentioned that communicating by telephone would be acceptable. Few participants mentioned that they preferred to be communicated with by e-mail or mail.

Improving communication from support groups and organizations was a prevalent theme among participants. Many participants felt that organizations and support groups or programs needed improved collaboration with the clinic, hospital, and doctors.

"Yes. So I guess maybe a strong emphasis needs to be stretched with that surgeon or maybe before they're dismissed from the hospital somebody come by and say, "Here's the information." I don't know. Just something like that to try to help people because I think that's one of the weakest areas right now probably of any health field is just not knowing what's out there, what's available to you." -Knoxville BC Patient

Some participants felt strongly that social media could be a useful tool in disseminating information from organizations and resources. One participant mentioned that tailored messages would be beneficial, or, "...to maybe individualize it if they could." Others mentioned that telephone calls, approaching church groups, and utilizing media may also improve communication between resources and breast cancer patients.

Participants relied on various sources when gathering information about breast cancer or resources. Many participants expressed using a trusted source for finding information while one participant specifically mentioned using peer reviewed materials. Several participants also felt that stories from breast cancer survivors were beneficial. A few participants expressed

reliance on either breast cancer organizations or their nurses for information relating to breast cancer.

Participants mentioned several methods of how they received information about resources. Most participants expressed receiving information from their social support network that included family and friends. Several participants mentioned how a nurse at the UT Cancer Institute offered information about available support groups and programs. Several participants also mentioned seeing posted information at the clinic. A few participants stated that a social worker or medical personnel at the clinic provided information about resources. One participant mentioned that another breast cancer patient shared information about support groups and programs. One participant stated how they independently discovered support groups and programs by visiting an organization; they said, "I just happened to go there to see if I was eligible for food stamps and stuff."

## II. Boston, MA

### A. Family

Family was a prevalent theme among participants from Boston, MA. Some participants did not feel comfortable telling their family about their breast cancer diagnosis and expressed that their diagnosis was their burden to carry. Several participants also mentioned that cancer was seen as taboo within their culture, and they did not want to speak about it with their families. Some participants preferred to discuss their cancer diagnosis as a way of demystifying the disease within their family and community. Many participants noted that family support was critical to their care, especially with maintaining the household or assisting with medical treatment.

“Oh, they were such a great help! Everybody in my family was reaching out to me... they were saying positive words, kind words, to encourage me... I had my father that at that point was dying from colon cancer was giving me strength... I felt that I had my sister. She's a nurse... I also have my next colonoscopy scheduled for next Thursday. I told my mom in advance I have a test on that day you need to go with me. She said okay. Every time I have a test I need to have somebody and I need to call my sister in Cape Verde.”

Boston BC Patient

Many participants also expressed that they did not lack family support during treatment, but some participants felt that their family support subsided after treatment was completed. In several instances, participants mentioned that their family was a burden rather than a support system, and one participant stated, “Now here I am trying to take care of a sister, my older sister with Alzheimer’s, and my brother that’s blind...[and] I’m in the middle doing what I have to for myself”.

#### B. Resources and Needs

Participants expressed several needs that were both met and unmet by resources outside of medical care. Boston participants mentioned that support groups were helpful in providing techniques and methods to improve self-esteem. Participants also mentioned various needs that were not met by current resources. Many participants strongly felt that available resources did not offer financial support.

“I go to the food pantries and two dollar bag trucks. I have to work it like that, being on a fixed income. I don’t get much. I get like 54 dollars’ worth of food stamps. This isn’t how I like to live my life, but right now, I am in recovery of not only cancer but also schizophrenia.” -Boston BC Patient

Several participants also mentioned that support groups and programs did not aid breast cancer patients about post-treatment expectations. Some participants felt that support groups and programs should help members transition to healthier lifestyles or provide guidance in how to cope with emotional distress. Many participants felt that programs lacked legal support, such as providing guidance in obtaining housing or applying for government resources. For some participants, support groups and programs were not beneficial. These participants perceived current support groups and programs as negative reminders of their diagnosis. Some participants expressed that they would like more culturally and ethnically focused support groups beyond the resources that were offered.

### C. Perception of Medical Care

Several themes were discussed by patients about their perspectives and experiences during breast cancer treatment. Several participants strongly felt that their primary care doctor was emotionally unavailable and did not fully invest in their well-being. One participant said, “My primary care doc, I would like for her... now that she knows that I had cancer, to say to me...if you have any issues...you can come and talk to me. We can sit down and talk about it”. Several participants also mentioned that they felt like a “number” instead of a patient to their primary care doctor. Some participants expressed that they did not follow treatment recommendations due to negative side effects.

During appointments, several participants strongly mentioned that language was a barrier in communicating. Even with an interpreter, some participants felt uncomfortable with this form of communication during appointments. One participant stated, “We have lots of translators, there are a lot. But I don’t really like the translators because you lose that communication with the doctor or nurse. You lose that”. Some participants also felt that the interpreters did not provide all the full information being communicated by the doctors. For

several participants, they expressed wanting understandable and ethnic specific materials that were free of medical jargon.

Participants expressed several negative themes about their post-treatment medical experiences. Some participants expressed that they were confused about the differing roles between their primary care doctor and oncologist. Some participants felt that there was a disconnect between the oncologist and the primary care provider when providing post-treatment care.

“To be honest with you, I don't think they talked. They probably sent e-mails... But in my gut feeling, I don't feel that they ever really talked... I don't think they actually...said well, "X is finished now and this is what you need to look for. And if she comes in with this type of sign, they need to get back in contact with me or you need to tell her boom, boom, boom, boom, boom." I don't think they did.” -Boston BC Patient

Several participants recognized that reducing cancer risk after treatment was important but confusing. Some participants mentioned that they lacked knowledge of what constitutes a healthy diet, or they needed guidance with making healthier life choices. Many participants expressed that fear was common after treatment. Several participants felt that follow-up appointments were necessary but also intimidating. Some participants felt that their doctor was not honest about their cancer being in remission, and several participants intentionally skipped appointments due to fear of recurrence. Several participants mentioned that follow-up appointments were still burdensome in terms of time and finances, and they wanted less frequent medical visits. In terms of support, some participants developed and maintained strong post-treatment relationships, but other participants mentioned that they perceived a lack of support after treatment was finished.

## **Common Themes among Providers**

### **I. Patient Financial Burden**

Financial burden for patients was a prominent theme discussed among providers. All the providers expressed patients having access to or utilizing state sponsored insurance, but whether this health coverage was sufficient for the needs of the patients varied in response. Several providers mentioned that patients had adequate insurance while others felt that patients lacked adequate health coverage. Some providers stated that insurance did not cover prosthetics needed by patients, such as lymphedema sleeves or cold caps.

Most providers mentioned that breast cancer negatively affected living expenses among low-SES breast cancer patients. In particular, several providers felt that breast cancer affected an individual's means of transportation. On top of the cost of treatment, one provider highlighted how difficult it was for low-SES breast cancer patients to afford transportation by stating, "...they can't afford to either—can't afford the gas or they can't pay someone to bring them." Many providers also mentioned how affording rent or mortgage payments became difficult for low-SES patients after receiving their diagnosis.

"If you're talking about comparing them to people who have higher...if you're really putting your lens on SES level, those are some of the main challenges I'm seeing. Like really tangibly difficulties in both finances and in housing." -Boston BC Provider

### **II. Patient Fear**

Providers expressed several similar perspectives of patient fear and methods of coping. Almost all providers strongly expressed that low-SES patients typically experience more anxiety and fear when thinking about how to financially afford treatment in addition to current living expenses.

“I will tell you that patients who come from disparate backgrounds tend to-, in my estimate, in my experience, tend to worry much more about “How am I gonna pay for this.” -Knoxville BC Provider

Several providers also mentioned that patients expressed concerns about how their breast cancer diagnosis would burden their family.

### III. Support Groups and Resources beyond Medical Care

All providers mentioned that social workers or other support personnel within the hospitals were integral in connecting patients to resources outside of medical treatment. Several providers felt that a majority of the patients utilized available support programs and resources, but more providers felt that offered services were highly underutilized. In terms of resource needs, many providers felt that low-SES populations had different needs than those classified as higher-SES.

Many providers expressed that current support groups and resources met many of the needs of the low-SES populations that they serve. All the providers mentioned that support programs helped breast cancer patients with living expenses, such as vouchers or money for food, utilities, and rent.

“And when those needs were identified then we provide things like ... essentially cover folks utilities or rent or support for groceries or gas cards for transportation needs.”

Knoxville BC Provider

All the providers also expressed, several of them strongly, that current resources were able to connect patients with transportation services or offer financial assistance for transportation. One provider stated that a transportation method heavily utilized among participants allowed individuals to, “...arrange to have this bus come and pick them up from their house and bring

them in to have their appointment.” Many providers also mentioned that offered resources addressed needs associated with social support, relaxation, and opportunities for exercise and healthy living. Several providers stated that patients were able to access support for medical expenses and prosthetics through current resources. A few providers also expressed that church and religious groups were useful resources for low-SES patients during treatment. Some providers felt that support programs and services worked well, but many providers felt that current resources needed improvement. Providers expressed several unmet needs among breast cancer patients not met by support programs and services. Many providers felt that current resources did not adequately provide medical support or prosthetic assistance for low-SES patients. Many providers also felt that current resources did not provide emotional support. Several providers expressed that resources did not adequately finance living expenses or assist with housing among low-SES patients. Some providers mentioned that offered resources were not always adequate in providing social support.

Providers felt that local and national organizations outside of the medical center were beneficial in helping address the needs of low-SES breast cancer patients. Many providers said that collaborating with organizations provided funds and resources that were critical in addressing patient needs. For example, several providers mentioned that the American Cancer Society sponsors a highly utilized event called ‘Look Good, Feel Better’ that helps low-SES breast cancer patients obtain wigs and improve their self-esteem. While many providers felt that patients were able to utilize resources and programs outside of the medical center, some providers felt that low-SES breast cancer patients did not or were unable to utilize outside resources.

#### IV. Medical Resources and Needs

Providers expressed that the most common method for low-SES breast cancer individuals to receive information about medical resources and programs was through a social

worker within the clinic. Several providers mentioned that the medical center they worked at was the main clinic for the surrounding community and region. While these medical centers typically serve low-SES populations, a few providers noted that they perceived medical treatment to be the same quality as the care given to higher-SES populations. Several providers felt that the health status of low-SES populations was different from those classified as higher-SES; one provider mentioned that low-SES individuals may not have access to a primary doctor, "...so they tend to come in with more advance cancers." Several providers also expressed that follow up appointments were burdensome for low-SES patients.

#### V. Addressing Resource Needs

Providers gave many reasons as to why low-SES populations may have different needs than those with higher-SES. Many providers felt that current resources were constrained due to limited funding. Almost all providers strongly felt that financial insecurity was a large contributor for the lack of access to resources experienced by low-SES breast cancer patients.

"Well I mean I think when you have a higher income, you don't have any of the financial challenges that I just sort of outlined for you with regard to paying for your bills and having a home. Pay for your medicines, getting private health insurance, having access to care and usually having a financial buffer in your ability to take off work and go get your cancer treated." -Boston BC Provider

Many providers also felt that differences in health status or resource utilization between lowSES and high-SES breast cancer patients were due to social determinants of health, such as education and wealth. Several providers expressed that a lack of resources in the community, such as public transit or affordable primary care clinics, also contributes to differences in need between low-SES and high-SES populations. Some providers mentioned that low-SES populations tend to have fewer resources available in the home, such as computers or private

transportation options. Stress was also mentioned as a contributing factor as to why low-SES populations may have more difficulty in accessing resources. Several providers felt strongly that low-SES breast cancer patients have less support systems within their social network which creates more difficulty in obtaining needed resources. A few providers also mentioned that an individual's location of residence may prove burdensome in accessing resources.

Currently, Boston Medical Center and UT Cancer Institute have several methods of addressing gaps in resource needs for low-SES breast cancer patients. Many providers mentioned that free or low-cost programs and services are offered to low-SES breast cancer patients to help meet their needs. Many providers also mentioned that the clinics offer guidance for low-SES breast cancer patients, as seen by the social workers, chaplains and financial counsellors that are available. Several providers expressed that financial help was given to low-SES breast cancer patients for needs associated with rent or living expenses.

Providers in both Boston, MA and Knoxville, TN are attempting to address the gaps in resource needs for low-SES breast cancer patients, but many felt that increased funding could help improve resources or create services for needs that are not currently being addressed. Almost all the providers expressed that they would improve support groups and programs given more funding. One provider mentioned that increased funding would help with, "...rent, and groceries, and all those types of things, and then we could help even more than we already do." Many providers also mentioned that increased funding would be beneficial in helping low-SES breast cancer patients attain affordable lodging or housing. Some providers felt that increased funding would be best served in improving public transportation or creating more accessible transportation methods.

## **Provider Themes Specific to Each Region**

### **I. Knoxville, TN**

#### **A. Patient Financial Burden**

Several themes surrounding financial burden were discussed among providers from Knoxville, TN. Some providers mentioned that medication costs were burdensome to low-SES breast cancer patients, and insurance did not provide adequate coverage for needed medicine. Conversely, some providers expressed that they or the clinic were financially accommodating towards low-SES breast cancer patients and allowed patients to make delayed or reduced payments for services.

#### B. Patient Fear

Fear was a common theme discussed by providers from Knoxville, TN. In terms of breast cancer, several providers mentioned that low-SES breast cancer patients expressed fear of death or recurrence. One provider discussed how the patients they interact with are burdened with fear in general after diagnosis, or fear the unknown with the course of the disease.

“I’ve had other patients who sit there and cry the whole time that I’m talking to them because they can’t even accept what’s going on and that’s fear.”

#### C. Support Groups and Needs

Providers expressed several means of connecting low-SES breast cancer patients with resources. Within the medical clinic, providers from Knoxville, TN mentioned that low-SES breast cancer patients sometimes receive information about resources from their doctor or nurse. Outside of the clinic, several providers mentioned that low-SES breast cancer patients find resources through their church, social network, or from another breast cancer patient. Several providers also expressed that low-SES breast cancer patients were sometimes their own advocates and found resources by their own means. Some providers strongly felt that low-SES breast cancer patients lack awareness of resources that may benefit their needs.

Providers discussed how current support groups and programs offered by UT Cancer Institute do or do not meet the needs of low-SES breast cancer patients. Several providers

expressed that support programs and services meet the emotional needs of their patients. However, all the providers strongly felt that current offered resources do not meet the transportation needs of low-SES breast cancer patients; one provider stated that among lowSES breast cancer patients the, "...transportation issue is also very real." Several other providers also mentioned that offered resources do not address the needs of low-SES breast cancer patients surrounding family support, child care, or psychological treatment.

#### D. Medical Resources and Health

Providers expressed several medical themes specific to Knoxville, TN. Many providers felt that Knoxville lacked accessible medical resources within the community.

"It's not necessarily a decrease in seeing the primary care physician but it's a decrease in number 1 primary care physicians and providers being available and then what areas they may serve. So if we're talking about our more rural communities and there are 10 primary care providers in these counties that cover hundreds of square miles and the patients don't necessarily have reliable or frequent transportation, how helpful is that?"

Several providers expressed that low-SES breast cancer patients have difficulty in meeting treatment recommendations due to lack of accessible treatment; several providers also expressed that lack of accessible medical treatment can cause treatment methods to differ between low-SES and high-SES breast cancer patients. One provider also mentioned that medical resources are located within the urban area of Knoxville, and available resources for rural communities are lacking; however, some providers did mention that UT Cancer Institute has satellite clinics or offers telehealth although these methods do not provide the same treatment that would be provided at the medical center.

#### E. Differences in Health and Resource Needs, and Addressing Gaps

Providers gave some reasons, specific to Knoxville, for why they believe resource needs and health differ between low-SES and high-SES breast cancer patients. One provider mentioned that low-SES breast cancer patients tend to have lower health literacy and may not utilize resources that could benefit their health. Another provider expressed that low-SES breast cancer patients may not have access to child care which prohibits them from utilizing support programs and services.

Providers at the UT Cancer Institute employ several methods of addressing resource gaps for low-SES breast cancer patients, and many providers thought of ways that increased funding could further meet the needs of their patients. Some providers expressed that outreach within the community and working with key stakeholders to create jobs for low-SES breast cancer patients can help address the resource gaps for this population. One provider stated using methods of, "...community assessment [to] find out what people actually need and how do we access that." Given more funding, providers expressed that they would expand on current methods of outreach, and one provider stated it would be beneficial, "If we could provide more community outreach." Several other providers mentioned that they would expand the medical resources available, such as E-Health, or provide support for more medical exams and screenings for low-SES breast cancer patients. A few providers expressed that more funding is needed to provide guidance to patients, such as increasing the number of social workers available or creating guidance books with listed resources.

## II. Boston, MA

### A. Patient Financial Burden

Providers from Boston, MA discussed several themes surrounding patient financial burden. Many providers expressed how breast cancer negatively impacts jobs among low-SES

patients. Several providers also mentioned strongly that low-SES breast cancer patients tend to be financially unstable even before beginning treatment.

“Some homeless women I’ve cared for...so just down to like basics of not even having a home. We have that problem. So those are the biggest things – like no money and no home.”

Some providers expressed that many of the low-SES breast cancer patients they interact with also tended to experience homelessness either during or after treatment.

#### B. Support Groups and Needs

Providers expressed how support groups and services met several needs of low-SES breast cancer patients. All the providers mentioned that offered services were beneficial in improving patient’s self-esteem. Many providers also expressed that support groups and services were beneficial for a patient’s personal development, and activities such as pottery or painting were offered regularly. One provider stated that physicians and scientists regularly spoke to low-SES breast cancer patients who were interested in learning more about their cancer. Another provider expressed that current resources met family support needs among low-SES breast cancer patients. Other met needs that were discussed included lodging, translator services, and support groups for various ethnicities.

Although providers felt that resources at Boston Medical Center met some of the needs of low-SES breast cancer patients, other needs were not met. Many providers expressed that low-SES breast cancer patients still experienced problems with language barriers regardless of translation services being offered. As stated by one provider, “...being able to understand your providers, that’s another barrier that’s different.” One provider also felt very strongly that lowSES breast cancer patients may not want help.

“Some patients don’t want resources and I think there’s like needs to be a very good sensitivity to that too. And that’s what’s really tricky, is meeting patients where they are and that’s really different with different people.”

Several providers also mentioned that low-SES breast cancer patients have reasons for not utilizing resources that are offered by the clinic, such as shame or fatigue. One provider also expressed that low-SES breast cancer patients may have cultural reasons for not participating in support groups and programs.

#### C. Perception of Medical Treatment

Providers expressed a few themes surrounding medical treatment for low-SES breast cancer patients. One provider mentioned that low-SES breast cancer patients tend to be unaware of what steps to follow receiving their breast cancer diagnosis and may need more guidance from providers. One provider also mentioned that long-term support is lacking with medical treatment, and patients may benefit from continuous support.

#### D. Addressing Gaps

Providers from Boston, MA had several specific resource gaps that they would address if given additional funding. One provider expressed that having a building that housed support groups and programs outside of Boston Medical Center would be beneficial, as this would allow low-SES breast cancer patients to focus on resources without thinking about their illness. One provider also mentioned that Boston Medical Center tends to provide care for many immigrants, and they tend to lack legal resources for these patients to gain access to housing or employment opportunities; thus, the provider felt that increased funding could be beneficial in improving access to legal resources for low-SES breast cancer patients.

### Discussion

The aim of this study was to explore the met and unmet needs of low-SES breast cancer patients through use of qualitative methods. Low-SES breast cancer patients and providers who

interact with this population were invited to participate. By conducting interviews among these populations at UT Cancer Institute and Boston Medical Center, we aimed to discover unique needs of low-SES breast cancer patients from both an urban and a rural setting.

Low-SES breast cancer patients from both regions expressed various common themes about their met and unmet needs both within and outside of the medical center. Resources offered at both Boston Medical Center and UT Cancer Institute were beneficial in meeting some of low-SES breast cancer patient needs, such as living expenses and social support programs. These resources are critical in providing needed support for this population. However, patients from both regions also expressed many unmet needs within and outside of medical treatment. Many patients expressed financial hardship, disappointment with medical treatment, and transportation barriers among others. These unmet needs highlight a gap in current resource offerings from both locations, and increased funding in these areas could further support this vulnerable population.

Providers from both medical centers also expressed common themes about the met and unmet needs of low-SES breast cancer patients. Their views are also critical as they have a different understanding of what resources can and cannot be feasibly funded. Providers agreed that both medical centers connect low-SES breast cancer patients with many support groups to help address their needs. However, many providers also expressed that there are many unmet needs for this population, such as transportation or housing. As stakeholders in the medical community, providers can help advocate for low-SES breast cancer patients to close the resource gap that exists for this population. Beyond medical care, providers are aware that low-SES breast cancer patients face unique challenges.

Both low-SES breast cancer patients and providers from both regions expressed met and unmet needs that were specific to each region. This dichotomy in needs for low-SES breast cancer patients from each region shows that resources are not spread universally, nor are the

wants and needs of low-SES breast cancer patients equal across the country. As an example, low-SES breast cancer patients and providers agreed that transportation was a large unmet need for the women of Knoxville, TN; however, this was less of a barrier discussed among lowSES breast cancer patients and providers and professionals from Knoxville, TN. Low-SES breast cancer patients and providers from Boston, MA expressed how affording housing was a large barrier for individuals. While low-SES breast cancer patients and providers from Knoxville, TN mentioned that individuals had financial difficulties, homelessness or eviction were not expressed by participants from this region as they were by participants from Boston, MA.

There have been very few studies in the literature that focus solely on the needs of lowSES breast cancer patients; however, many studies have been conducted that assess the needs of breast cancer patients in general. Studies assessing the needs of breast cancer patients present different themes than those collected by this study. Breast cancer patients face many needs as well that include psychological care, information about their disease, and coping mechanisms (Board, Hewitt, Herdman, & Holland, 2004; Thewes, Butow, Girgis, & Pendlebury, 2004; Waring, 2000). While low-SES breast cancer patients in this study expressed similar needs as those from other studies, they had greater pressing needs that were fundamental and included transportation options, financial assistance, and post-treatment support. This may demonstrate that low-SES breast cancer patients face more basic needs than breast cancer patients that have higher-SES. This also demonstrates that resources cannot be generalized to the entire population; additionally, low-SES breast cancer patients from different regions may have similar needs, but they also have unique needs based on their surroundings.

This study had several limitations. Only two sites nationally, Boston and Knoxville, were selected in our study due to time constraints. However, these two sites represent women from both rural and urban settings which allows for a wider understanding of the unmet needs lowSES breast cancer patients experience. Interviews with low-SES breast cancer patients

were conducted by two different researchers which may result in differences among interviews due to internal preferences of interviewing styles and methods; however, both interviewers used the same interview guide to reduce potential inconsistencies. Data for one provider interview was lost due to machine error, but notes from that interview were included in the analysis. Future direction should include advocating for increased funding to reduce resource gaps for low-SES breast cancer patients and continuing to research the unmet needs for this population. As evidenced by this study, different regions may result in unique needs for low-SES breast cancer patients. Funding for programs and resources should use this study and expand on these findings to include low-SES breast cancer patients from different regions and environmental settings in order to effectively meet the needs of this population. Funding is typically finite, but this study shows that this vulnerable population has needs that are not being addressed by offered resources. Creative methods to stretch funding dollars should be a next step in efficiently using limited funds to meet the needs of more low-SES breast cancer patients. Future studies should also assess why low-SES breast cancer patients cannot access or use current support programs and services, as these reasons may elucidate how to better serve this population without spending more money. Ultimately, low-SES breast cancer patients have unique and unmet needs beyond medical treatment. Improving resources outside of medical treatment may allow low-SES breast cancer patients to better adhere to treatment or improve their health which has implications for health care expenditures.

This study found that low-SES breast cancer patients have unique needs that are different from breast cancer patients that have higher-SES. Few studies have assessed the needs of low-SES breast cancer patients, and this study helps fill the gap that exists within the literature. By gathering the perspectives of low-SES breast cancer patients and their providers from a rural and urban setting, we were able to contribute knowledge of how effective current resources are in meeting the needs of this population, as well as determine what areas could be

improved. This knowledge is valuable in helping policymakers and stakeholders determine how funding is spent on resources and programs to help breast cancer patients. Low-SES breast cancer patients face unique challenges both within and outside of the clinic in accessing resources that meet their needs, and raising awareness of these obstacles may improve the quality of life for this vulnerable population.

## Appendices

### Appendix 1: Interview Guide for Breast Cancer Patients

#### ***Interview:***

***Hello. Thank you for taking time to talk with us today. We are here today to have a conversation about your journey as a breast cancer survivor and some of the hurdles that you have faced throughout this journey. Our main goal is to learn about the services that you have utilized and/or programs that you need to make your experience with cancer a little easier. Throughout this conversation I will use the words “service” or “program” to describe anything information or service that could have been or was provided by a doctor, social worker, advocacy organization or community group to assistance with your life as a breast cancer patient. I don’t mean treatment like chemotherapy or surgery, but services or information like a brochure about where to find***

***affordable prostheses or how to talk with the health insurance company, or a program that provided financial assistance for help with paying for treatments, gas to get you to the doctor, or food. We are interested in learning all we can about all the information and services that helped you in your experience with breast cancer. I would like you to keep these things in mind throughout our conversation. Our goal is to use what we learn from you to guide future services and better meet the needs of women with breast cancer. Your honest answers are strongly encouraged, but if you do not feel comfortable answering a question, you are welcome to pass. Thank you***

#### **Concept A: Economic Deprivation**

1. What were the most difficult things about your breast cancer diagnosis/treatment?

*Probe:* What were your greatest worries or concerns before, during, or after your diagnosis/treatment?

2. Cancer diagnosis can cause financial problems for individuals and their families. What financial difficulties did you have that affected your life because of your breast cancer?

*Probes:* How did these impact your daily life? Did you see financial difficulties the most during your treatment, or after your treatment?

What would you say the most pressing financial problems that you experienced were? Bills piling up, not being able to pay for food or gas, not being able to keep a steady income due to treatment schedule?

## **Concept B: Targeted Marketing of Commodities**

1. What programs and services are available in your community for people who have been diagnosed with cancer?

Probe: Are there things in your community available like: support groups, webinars (web or phone), facebook groups, social events, conferences?

- i. Which of these types of programs would you like to see more of in your community and which would you be most likely to use? How do people connect with these programs? What is the process? How did you learn about these programs? How well do these programs work in your opinion? Who are these programs available to?

2. If you could have access to any programs, what types of programs do you think that you would find useful for helping you to live your life?

- a. Probe: Have you utilized any of these programs in the past? Why or why not?

## **Concept C: Inadequate Health Care**

1. Can you tell me about any information or programs learned about from your doctor or healthcare provider that talked about what to expect after your treatment was over?

*Probes:* Who provided the information? Doctors, nurse navigators, social workers etc

What did they provide?

What the information useful?

2. What do you need from the clinic, hospital, or breast cancer organization now that you are done with cancer treatment?
  - a. If not done with treatment: what services do you think your hospital, clinic, or breast cancer organization could provide to you that would be immediately useful to you?

Probes: Some breast cancer survivors have told us that sometimes they aren't getting what they want or need during or after treatment is completed. Is there anything you aren't getting that you need or want?

Concept D: Access and barriers to information

1. What is your preferred method of getting or receiving information about your health or breast cancer?

Probe: for example, are you more likely to respond to a phone call, an email, a letter in the mail, or a tweet/post on facebook?

2. Do you receive different types of information from other types of sources? Ex. Television, internet, social media, newspapers, emails etc etc

Probe: for example, if there was an event that you might be interested in attending, what would be the best way to communicate this information to you?

Probe: What do you look for from sources of information? Images or stories that you can relate to? Resources that are provided to you by a doctor or trusted medical provider? Materials that are medically reviewed? etc

3. What do you think could be done to improve communication between you and a local/national breast cancer organizations or you and other important people related to your cancer?
  - a. For example: what barriers do you see getting in the way of communicating with organizations that aim to help people with breast cancer? What would make connecting with these organizations more easy for you?

*If participant has not disclosed any barriers or challenges in their treatment and experiences:* It sounds like you have had a mostly positive experience with your breast cancer. Although many breast cancer survivors tell us that there are significant barriers to having needs met. Thinking back on your experiences, thinking back, can you remember any times when your needs weren't met? Can you describe that experience for me?

*Additional probe:* For example, some breast cancer survivors have told us that they have experienced financial challenges such as having enough gas money to attend treatments, or having the money to pay rent, or afford follow-up appointments. Can you recall any experiences like these, or other experiences where your needs weren't, that you have had that relate to your cancer?

Other:

4. Is there anything else about your experiences with breast cancer or the consequences of breast cancer, or your needs that you want to share with us?

Thank you for joining us here today. You have helped us by providing valuable information about the needs that women with breast cancer may have after treatment. This will help us to better meet women's needs in the future.

## Appendix 2: Interview Guide for Breast Cancer Providers

### Interview Guide for Providers:

#### Basic demographics:

Where do you work? \_\_\_\_\_

What is your job title? \_\_\_\_\_

How long have you held this position? \_\_\_\_\_

How many hours of direct interaction do you have with breast cancer survivors/patients weekly \_\_\_\_\_

Sex \_\_\_\_\_

Age \_\_\_\_\_

#### Interview Questions:

1. In your experience what are some of the resource needs that low SES people affected by breast cancer have that are different from people with higher SES?
  - a. What are some of the reasons that you believe these differences exist?

- b. How do you or your organization try and meet these needs?
    - c. What are the challenges in meeting these needs?
    - d. How do the treatment needs of low SES patients differ from those classified as higher SES?
2. Where do you see the biggest gaps in services outside of healthcare for breast cancer patients with low SES?
  - a. How do you or the organization that you work with try and address these gaps?
  - b. What role can national organizations play in addressing these gaps
    - i. Have you heard of the organization Living Beyond Breast Cancer?
3. What programs or services do you work with which actively target people of low SES?
  - a. What is the effect of these programs? Do you think they are beneficial to low income women with breast cancer? Why or why not?
  - b. In your opinion, do you think that there is anything that could be done to make these programs work better?
    - i. Communication? Finances?
4. Given unlimited funds: What sorts of programming would you think would be ideal for assisting people of low SES? What would you provide that would make these people's lives easier?
5. Is there anything else you would like to tell us about providing care and treatment for patients of low SES?

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