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### Publication Date

2020

### DOI

10.1177/1745506520949419

Peer reviewed

# Health system experiences of breast cancer survivors in urban South Africa

Women's Health  
Volume 16: 1–10  
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DOI: 10.1177/1745506520949419  
journals.sagepub.com/home/whe



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## Abstract

**Background:** Breast cancer is the most common cancer globally and among South African women. Women from socioeconomically disadvantaged South African communities more often present later and receive total mastectomy compared to those from more affluent communities who have more breast conserving surgery (which is less invasive but requires mandatory radiation treatment post-operatively). Standard chemotherapy and total mastectomy treatments are known to cause traumatizing side effects and emotional suffering among South African women; moreover, many women face limited communication with physicians and psychological support.

**Objective:** This article investigates the experiences of women seeking breast cancer treatment at the largest public hospital in South Africa.

**Methods:** We interviewed 50 Black women enrolled in the South African Breast Cancer Study to learn more about their health system experiences with detection, diagnosis, treatment, and follow-up care for breast cancer. Each interview was between 2–3 hours, addressing perceptions, experiences, and concerns associated with breast cancer and comorbidities such as HIV and hypertension.

**Results:** We found most women feared diagnosis, in part, because of the experience of chemotherapy and physical mutilation related to mastectomy. The importance of social support from family, religion, and clinical staff was fundamental for women coping with their condition and adhering to treatment and medication.

**Conclusions:** These findings exemplify how interventions might promote early detection of breast cancer and better adherence to treatment. Addressing community perceptions of breast cancer, patient needs and desires for treatment, structural barriers to intensive therapies, and the burden of invasive treatments are imperative next steps for delivering better breast cancer care in Soweto and other resource-constrained settings.

## Keywords

breast cancer, chemotherapy, comorbidity, mastectomy, South Africa

Date received: 5 December 2019; revised: 30 June 2020; accepted: 21 July 2020

## Introduction

More women die from breast cancer than any other cancer, with 1.5 million newly diagnosed women per year.<sup>1–5</sup> When diagnosed early, women generally survive and have good prognosis. For example, 80% of North American women have a 5-year relative survival rate due to early detection.<sup>6</sup> In South Africa, around half of women diagnosed with breast cancer are estimated to survive 5 years.<sup>7</sup> Lower survival rates can be partially attributed to later stage at diagnosis, which is significantly higher in Black women than

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others.<sup>8–10</sup> Despite better detection and treatment for breast cancer in South Africa compared to other sub-Saharan African countries, in part due to better health services in public and private sectors,<sup>11,12</sup> access to well-resourced private health care for the wealthier minority is inequitable.<sup>13</sup> Studies among Black women in Soweto,<sup>12</sup> and western South Africa<sup>12,14</sup> show delays of 8.5 months between discovery of breast lumps and the development of other symptoms that led them to seek care. This reflects lower awareness of signs and symptoms for breast cancer.<sup>15</sup> But detection at later stages among Black women reflects stunted health education, income, and health services availability,<sup>12,13</sup> as well as patient–provider barriers within the clinical encounter. One study found only 1 in 50 Black South African women with breast cancer reported that their provider had talked to them about their prognosis.<sup>16</sup>

Living with breast cancer often causes women varied physical, emotional, and psychological challenges due to enduring treatment, with some describing treatment as highly traumatizing and a period of severe emotional suffering.<sup>3,17</sup> Total mastectomy remains the most common surgical treatment today in South African public health services, despite breast conserving surgery being the surgical treatment of choice in high-resource settings.<sup>18</sup> Education around breast cancer prognosis and treatment and the fear of mastectomy and chemotherapy impede women from care-seeking,<sup>10</sup> in part, because these treatments frequently cause significant side effects and are associated with emotional distress and trauma.<sup>18,19</sup> Many women experience stress associated with physical mutilation of the body, emotional distress associated with a cancer diagnosis and treatments, and lingering depressive symptoms, particularly when women depend on an underfunded public sector where psychological support services are limited or non-existent.<sup>17</sup> Moreover, chemotherapy may pose exceptional emotional, logistic, and financial challenges for women concurrently living with HIV who are required to have initiated antiretroviral therapy at least a month prior to initiating chemotherapy treatments.<sup>20</sup>

This article investigates 50 breast cancer patients' experiences of detection, diagnosis, treatment, and follow-up care at a large public hospital in Soweto, a major township in Johannesburg, South Africa. We have argued elsewhere that fear of chemotherapy and physical mutilation due to mastectomy were the most emotionally distressing experiences among the women we interviewed, and that many found it much more troubling than other comorbidities such as HIV, an infection afflicting more than one in five people in Soweto that can significantly undermine co-existing comorbidities.<sup>21</sup> Others have argued that such an approach is imperative to understand breast cancer patients' lived experiences through all stages of their illness for designing effective interventions.<sup>13</sup> This work seeks to understand possible solutions to promote adherence to medication and follow-up,<sup>13</sup> as well as to

understand which forms of social support are needed for breast cancer patients to cope with changes to their bodies, emotions, and especially depressive symptoms.<sup>17</sup>

## Methods

### *Setting and patients*

The 50 breast cancer survivors in this study were seeking care at Chris Hani Baragwanath Academic Hospital (or “Bara”) and enrolled in the South African Breast Cancer (SABC) Study, which is located at Bara, when they were recruited for the present study. Although their initial presentation was at a community clinic, a regional hospital or directly at Bara's Breast Clinic, or at times at a non-governmental organization (NGO), all participants had received treatment at Bara and had completed some treatment, including surgery, radiology, or chemotherapy. We invited SABC participants to engage in our qualitative interviews between May to September 2017. The women's existing relationships with care-seeking at Bara, often for other preexisting conditions, and enrolment in SABC enabled an easy recruitment and follow-up as many of the interviewers worked on the SABC study as nurses. In this way, we invited all women enrolled in SABC who were coming to the clinic during our study period to participate in the study; there were no other exclusion or inclusion criteria. We invited women to participate in the study, arranged for them to come to the research center at Bara, consented on-site, and conducted 2–3 hours of extensive open-ended interviews about women's lives before, during, and after their cancer diagnosis, often breaking for sandwiches and tea. All interviews were audio-recorded, and study participants were compensated 150 ZAR (around 12 US\$) for transportation costs, and the research project was approved by the University of the Witwatersrand Human Research Ethics Committee (Clearance number M170414).

Following consent, 29 interviews (56%) were conducted in English, while 13 were conducted in Zulu, 4 in Sesotho, 2 in Xhosa, and 2 in Setswana. Two primary interviewers completed these interviews, with one English-only speaker and a multilingual research assistant (RA) from the SABC study conducted all of the interviews in Zulu, Sesotho, Xhosa, and Setswana. The open-ended interview guide was designed to capture study participants' life histories, with focus on early childhood, family, community, education, social dynamics, marriage, religion, stress, support, chronic illness, cancer, care-seeking, and cancer treatment. Interviewers wrote extensive field notes to describe major themes that emerged in the interviews and to communicate any behaviors or dialogue that occurred off record. Each transcript was then transcribed by an external translation company that has expertise in multilingual and English

**Table 1.** Demographics.

|  | Participants<br>(n = 50) |
|--|--------------------------|
| Age (mean $\pm$ SD)                    | 49 $\pm$ 11              |
| Preferred interview language           |                          |
| English                                | 29 (58%)                 |
| Non-English                            | 21 (42%)                 |
| Education (n, %)                       |                          |
| Completed primary school or less       | 6 (12%)                  |
| Completed or attended secondary school | 40 (80%)                 |
| Completed technical or graduate school | 3 (6%)                   |
| Income (mean $\pm$ SD)                 | 2971 $\pm$ 2102          |
| Pension (R1,600) or less               | 13 (26%)                 |
| More than pension                      | 23 (46%)                 |
| Comorbidities diagnosed (n, %)         |                          |
| None                                   | 15 (30%)                 |
| One                                    | 18 (36%)                 |
| Two                                    | 17 (32%)                 |
| Three                                  | 1 (2%)                   |

transcription; most interviews included more than one language, be it English and isiZulu, or isiZulu and Xhosa, or another combination of linguistic exchange. Soweto is a context of cultural and linguistic fusion so this transcription expertise was crucial.

## Analysis

Data from all interviews were transcribed verbatim; audios from vernacular languages were transcribed first in vernacular then translated to English, while maintaining consistencies with their original meaning. We used an inductive methodology that involved reading and rereading transcripts and field notes while comparing the two to ensure no data were misinterpreted and this also enabled understanding of different parts within the context of the whole. We used various methodologies to analyze these data (BLIND); for this article, we used content analysis of the themes addressing engaging with the health system. These specific themes were extracted from the original 50 core themes that the study team identified, defined, and discussed as having emerged from the data. The codebook was co-developed among the study team, where we used the interview guide, field notes, select transcripts, and in-depth discussion to identify, apply, and interpret major codes within broader themes.

We used content analysis to interpret the data analyzed for this project. Each transcript was coded using Dedoose Qualitative Software according to these 50 codes with one primary coder and two secondary coders reviewing each code. We selected codes that conveyed health systems challenges for care-seeking with breast cancer for an in-depth analysis within and between these major themes,

including: (1) detection; (2) perceptions of is and what it does to the body; (3) treatment (including fear, care-seeking, care provided); and (4) follow-up care and perceptions of treatment on the body. We used content analysis to write up each theme category broadly; then, we used axial coding to describe more nuanced analysis of sub-codes, which are delineated in the “Results” section by subheadings. Axial analysis of these major themes provided a deeper understanding of the complexities around detection, perception, treatment, and follow-up as cancer patients engaged with and moved through treatment and care.

## Results

Table 1 shows that most women were between 28 and 76 years of age, with an average age of 49. Most participants had completed secondary school, employed in either formal or informal sectors, and resided with four to five family members, including children, siblings, or parents. Fifteen women reported co-morbid hypertension, 15 reported co-morbid HIV, and 20 reported conditions such as diabetes, depression, anxiety, and arthritic pains.

### *Detection: finding abnormalities in the breast*

Fifteen percent of participants described a family history of breast cancer. Few connected this family history to their own diagnosis, as they did not express suspicions that they were at higher risk of developing breast cancer. Yet, one 47-year-old woman said she pushed her doctors to test for breast cancer “because my aunt was having breast cancer and I know the signs.” But most women believed prior exposure to breast cancer influenced a fatalistic view of cancer as something that would inevitably kill them. One 61-year-old woman whose mother and her grandmother died of cancer stated that she saw cancer “is not curable.” This was in part why another 64-year-old participant shared that her mother had refused to undergo an operation to remove her tumor and subsequently passed away. In one 49-year-old woman’s case, her mother’s breast cancer diagnosis directly affected her own self-care; she did not initiate chemotherapy earlier because she “didn’t want to worry [her mother]” who had a late-stage breast cancer diagnosis and was unable to undergo an operation or chemotherapy.

Women reported finding a lump in their breast or armpit or intense pain in their breast as the main reasons to seek clinical care. Most had no prior experience with cancer and went to have their lumps assessed because they were unusual or painful (as opposed to self-identifying them as cancer). One 62-year-old woman reported having a lump in 2000 that was purportedly benign. In 2005, she sought care for a bleeding nipple, and received a cancer diagnosis and later underwent a mastectomy. At 30, one woman’s family pressured her to seek care from a traditional healer instead

of the hospital; a progressively growing lump in her breast made her return to the hospital for medical care.

But women described diverse reasons for care-seeking. Some women associated a lump in their breast with a milk clot caused by breastfeeding and sought care for this reason. Others credited television and radio for increasing their awareness of breast cancer and detecting a lump. Some women described teaching others about breast cancer detection. For instance, a 60-year-old woman said that she enjoys telling other women at faraway clinics about cancer: "I am healing myself to tell people what cancer is." Another similarly aged woman with HIV "encourages other people with HIV to go to the clinic and get tested" and tells them not to be scared, because she is "alive and well because of [the pills]." Similarly, a 40-year-old woman said that the reason she talks about cancer is that others "can't go to the hospital if they don't know [what cancer is]." Another woman was encouraged by her friends to go to the clinic because they suspected breast cancer based on her symptoms.

A few women described initial misdiagnosis of breast cancer as something that could be treated with painkillers or antibiotics. One 41-year-old woman connected this initial misdiagnosis with "cheaper doctors" that can only give people antibiotics. Another 59-year-old woman "went to the clinic twice" because she detected "a seed" in her breast while bathing. She was given painkillers, which were not effective in stopping the pain in her nipple. After her third visit to the clinic, she was referred to Bara, where she received her diagnosis. An older woman was given antibiotics for her problems with breast feeding, thinking that her lump was a milk clot, before eventually being referred to Bara and receiving a breast cancer diagnosis.

### *Breast cancer perceptions*

Most women felt that they were going to die once they were diagnosed with cancer regardless of a prior cancer diagnosis. This strong association of cancer with inevitable death was one of the clearest and overarching themes in this section, in part, because women were diagnosed with late-stage cancer. Here, the association of cancer with other chronic diseases such as HIV was evident, as many said that they thought cancer cannot be cured. One 36-year-old woman described her reaction to being diagnosed with Stage III cancer: "I thought when you have cancer, you die." Another 61-year-old woman talked about her daughter's support after her diagnosis since she was "doing things out of fear now. . .preparing yourself for a burial." One 40-year-old woman explained the fear and stigma around cancer: death is "the only thing [people] know about people [with] cancer. There is nothing else they know. They know that we are going to die."

Many women described cancer as recurring. One 42-year-old woman called cancer "unpredictable," saying

that "you cannot just remove [cancer] quickly. . .[in] two years, ten years, it'll come back." The idea that cancer can spread was a point of distress, as one 74-year-old woman doubted that her cancer would ever completely go away: "I don't think [this cancer] will end. Because it emerges from here and then from there. When you think it is here, they then tell you that it is there." In part, this perception was associated with age: women with a cancer diagnosis late in their lives may die of something else after treatment. Most women also stated that breast cancer can recur even 20 years after diagnosis.

*Acceptance.* One in five women accepted their condition soon after diagnosis. This does not include women who were able to find acceptance later on, during or after treatment, so this category mostly encompasses women who were able to see their cancer as something treatable or even curable rather than an immediate death sentence. Those who accepted their cancer diagnosis and saw their cancer as temporary (akin to an acute illnesses) often perceived their disease surmountable. One 47-year-old woman analogized her breast cancer to "a flu," because "it's just a phase." She explained, "some people, when they say cancer, they start seeing death;" she felt that she was able to "go through this, but then [move] on." Interestingly, another 43-year-old woman used the same comparison, and said that "if you go for your treatment and you stick to it, then it's just another disease that's fine. It's just like flu, you can live." One 51-year-old woman credited the role of the clinic, saying, "as they explain to us in the clinic, it's not a death sentence. It goes with your mentality." Many expressed that particularly when diagnosed in the early stages, cancer will not kill you.

### *Treatment: fear and its repercussions*

Chemotherapy fueled the most fear, distress, and pain among participants. Many women expressed that it was not cancer that made them sick; rather, it was the chemotherapy that made them feel sick. Some women even referred to chemotherapy as a separate disease from breast cancer altogether. This is likely due to the association of conditions with their side-effect symptoms. Thus, because people connected chemotherapy with vomiting, nausea, diarrhea, hair loss, loss of appetite, and so on, it seemed to them that chemotherapy was an illness itself rather than a cure. One 62-year-old woman described chemotherapy as "a poison that attacks the cancer." A woman in her mid-40s characterized chemotherapy as a deadly condition separate from cancer by saying, "If you are weak, [you are] saying cancer killed you. Only to find out it is the treatment that killed you." As another 54-year-old woman explained, "the hardest thing about cancer treatment is the chemo. Chemo is hard because you think it will make you better but it makes you sick and makes you sick in ways you weren't."



Due to the intense physical symptoms associated with chemotherapy, several women preferred mastectomy over chemotherapy. One 43-year-old woman said that she knew someone with breast cancer that chose to “have her breast amputated so she didn’t have to go through chemo,” and said that she prayed to God that she herself could avoid chemotherapy. Another woman said that after chemotherapy, “operation is nothing.” One 42-year-old woman who had undergone a double mastectomy said, “even the surgery is better for me. . .the pain, it was much better [than chemo].”

Chemotherapy effects on one’s physical appearance was deeply felt among women. Intense bodily symptoms such as nausea and vomiting were reported to last for a few days after receiving a drip. More distressing were the longer lasting effects on women’s appearance, notably hair loss, skin discoloration, and weight loss. One 42-year-old woman with co-occurring conditions said that cancer was worse than her other conditions, as cancer was her “first time to experience the hair loss. . .that is the worst part, the chemo part.” Another 62-year-old woman directly associated the pain she felt from the “red devil” (a colloquial term for anthracycline-based chemotherapy) with the changes to her appearance: “my hair fell, and it was painful. . .the pain you will feel, like [when] your body weight drops, and you change color, you become dark.” One 41-year-old woman simply said, “I was so ugly,” of the physical effects of her chemotherapy.

**Barriers to care.** Participants identified a number of barriers to receiving adequate care. These included the distance to local clinics and hospitals, cost of transportation, long wait times, and overcrowding. When asked why she did not go to the clinic, one 52-year-old woman said, “I don’t have money to go to the clinic, because the clinic is too far [and] I must take a taxi.” Similarly, another 30-year-old woman said that she was, at times, unable to attend check-ups or pick up her medication “because I did not have money for transport.” Other women were able to come to the clinic on time, but expressed stress because they had to “spend a lot of money” to use public transport or wake up too early to do so.

Many women found the long lines and overcrowded clinic to be stressful. One 61-year-old woman explained, “the queues are very long. . .and not to say [the staff] are doing it quickly because they want to attend someone else. They spend time with you,” demonstrating a positive attitude of breast cancer patients toward the staff. When asked what she didn’t like about the clinic, one 36-year-old participant complained that, “it’s always full. . .you stay maybe more than 4 hours there before you see a doctor.” An older woman (74 years of age) said going to the clinic takes up her entire day. Despite these concerns, participants rarely mentioned their experience with clinical staff as barriers to receiving effective medical care.

**Support from health providers.** Participants consistently felt supported by the doctors, nurses, and other staff at the Bara Breast Clinic during their treatment. One 43-year-old woman summarized this feeling, saying, “the doctor helps me feel relaxed and comfortable,” and that she felt open asking questions about her illness and talking about her problems and well-being with her doctor. One 48-year-old woman spoke openly about her mastectomy and said that she was alive and healthy because of the doctors, and said that they did not let her die during surgery “because of love of the doctors. . .that’s why I am always happy.” In an especially powerful account, one 42-year-old woman who said she had experienced no support from her family during her treatment reported that the sisters and doctors at the clinic were the ones taking care of her and her fellow breast cancer patients. She credited them for giving “that hope, that this thing is going to pass one day. . . follow your treatment, [and] you’re going to be fine. You’re going to be a survivor.”

Many reported a connection between prayer and their doctors, regarding faith in both God and following their doctors’ treatment as essential factors in their survival. Several women even said they prayed with their doctors, or that their church prayed for their doctors to cure them. One 44-year-old woman expressed the feeling that “everything will be okay” because she trusts her doctors, who pray with her and ask God to make her medication be effective in her body. Another 65-year-old woman said that while other people’s prayers could not directly heal her cancer, “they pray for the doctors who are going to handle me, for God to bless them so that they can have strength to help me when I go for a check-up, to help them when I go for chemo.”

## **Follow-up: conceptions of self and illness**

### *Disfigurement*

The physical impacts of a single or double mastectomy were deeply felt and at times internalized by women with breast cancer. For many women, the loss of one or both of their breasts was a significant source of distress or internal tension, affecting how they felt about their bodies and their femininity. Some women expressed that without their breast they felt the loss of normality. One 40-year-old woman described this viscerally in talking about her experiences with her neighbors, who were at first unable to believe that she had undergone a mastectomy because she looked so normal to them. The woman responded, “Can’t I act normal? I just don’t have a breast.” Another 44-year-old woman was waiting for a grant to be able to buy a new breast, and said that in the meantime, “it doesn’t look nice, [so] I put a sock here” to disguise that she had lost a breast.

Another 52-year-old woman associated the loss of her breast with a loss of her femininity or sexuality, saying

that, "a woman's pride is her breast. So now I do not feel a woman." Furthermore, a younger woman (33 years of age) described the discomfort she felt in her own skin following her mastectomy. She said that after her breast was removed, she felt, "Like I'm uncomfortable with myself. . .like with my body."

### *Loss of independence*

For many women, one of the largest impacts of breast cancer on their lives was a decrease in their independence and self-sufficiency. This was especially true for women who used to work and were now unable to make money for themselves, or had lost business due to the time spent in treatment. One such 44-year-old woman said she "lost all my clients because of the sickness. . .because I went in for chemotherapy." She further explained that even once she recovered from chemotherapy, she was unable to regain clients because she took more time off to come back to the hospital for further treatment, and "by that time they transferred to another lady." One woman said she was treated poorly at work because her coworkers were annoyed with her for missing work to go to the clinic for treatment and another described the cycle of sickness and unemployment. She said she had been unable to continue going to work after her treatment, which led to what she called "a double stress: you are sick, you are not eating healthy food, you don't have money to pay rent, you don't have money to go to the hospital. What are you going to do in that pitiful time?"

Many women described being sick as "to have hindrances in life." These involved mostly the loss of being able to take care of themselves independently, and having to rely on others for basic functions such as bathing. One 39-year-old woman described sickness as making her feel like she wasn't the same person anymore, unable or too fatigued to "do the things I like." For instance, one 30-year-old woman described the difference between her co-occurring HIV and cancer in terms of their impact on her life: after her cancer diagnosis, "it meant that I had to change my lifestyle completely. [When] I was diagnosed with HIV, I had to remove a certain part and add a certain part to my lifestyle, but with cancer I had to change completely."

### *Faith related to religion and/or medical care*

Faith emerged as fundamental to women's healing processes. Women cited their faith and their communities around faith as giving them hope and will to live. They often said that their faith combined with good medical care at the hospital was essential to their survival.

For many, faith was perceived to prolong life and gave people hope. Women frequently said that their faith in God prolonged their life, and was in many cases necessary to

getting through their illness. This belief was often in direct opposition to people's fears of inevitable death associated with cancer. Their faith gave them hope that they would survive cancer. One 43-year-old participant said that her faith "give me hope to continue with treatments and coming to the hospital" and that "faith helps me believe that I will indeed heal." Another 57-year-old woman had an apt metaphor for her faith: "it fuels me. When I put it in the literal sense, I'd liken it to a car, when there's no petrol, the car won't move you have to add petrol. It's the same with us human beings." Similarly, one 36-year-old woman felt empowered by her faith as giving her some control over her own fate, saying, "if I pray, everything can be possible. I can be a survivor, it is up to me."

Another woman explained the physical de-stressing she finds by going to her church and praying: "I become healthy there. . .if you pray hard to God, [even if you go to church with an empty stomach] you feel that you have filled your stomach." Another 74-year-old woman said that praying was all she could do to address her cancer and found joy and peace in prayer, saying "I feel happy, I just love [praising] God's name. That is all, and then I am well, in my soul."

Several women expressed that the impact of their own personal faith on their health was separate from the impact of other people's prayers, including their pastor. One 36-year-old woman, when asked if it is the church or their own faith that healed them, responded that it was definitely her faith. Another 44-year-old woman said that it was her own faith that healed her, and questioned how her pastor could possibly heal her when the real healing takes place when you "take the heavy load and give it to God." Another 62-year-old woman dismissed the role of medical care and doctors in ultimately deciding her death, saying that "it is only God that makes decisions. . .the doctor cannot make decisions about my life."

Several women said that their faith, while important, worked in conjunction with the medical care they received at the clinic. One 34-year-old woman said, "there's things that can be healed in church and things that cannot be healed in church." Another 43-year-old woman agreed with sentiment, elaborating that although smaller things like headaches might be healed, and although faith was important to her healing process, faith alone was not enough to heal cancer: "God is amazing but I don't think my cancer will go away because I have been prayed for by a pastor. I think having faith in God can also help heal you but only after having gone through treatment."

### *Mistrust of traditional healers*

Several women felt traditional healers were either fraudulent or were unable to cure breast cancer; most agreed medical doctors were more helpful. One 44-year-old woman said that despite receiving advice from people to

go to a specific *sangoma* (a traditional healer), after her symptoms failed to resolve, she “left the *sangoma* and continued with the hospital. My mind told me that only the hospital will help me.” A 74-year-old woman agreed with this statement. This woman and another 48-year-old participant also claimed that the traditional healers “are not real these days, they are fake.”

Three women said that the *sangomas* were not necessarily fake, but were unequipped to deal with breast cancer. One 62-year-old woman said that although her *sangoma* told her not to undergo a mastectomy, she ultimately decided to go through with it because she thought to herself, “if I don’t do the operation and the cancer spreads, how will [the *sangoma*] stop it from spreading?” Another 41-year-old woman called the traditional healers ignorant, as evidenced by the fact that they tell people with HIV that they are “bewitched” and do not treat them. Another 65-year-old woman said simply that “traditional healers can no longer help with that.”

### Support and coping

The most prevalent theme throughout the follow-up care process was support from family and loved ones, as well as from people’s churches and counseling groups with peers who were also faced with breast cancer. Social support enabled women to speak openly about their problems, and served to renew or reinforce their wills to live.

The most common source of social support came from family members and close friends. One 44-year-old woman said the best type of support available was the family, as she was able to just sit with her children in the evenings and “talk and laugh together.” Another 43-year-old woman said that talking to people helped her believe that she would be fine and that “many have healed from cancer. People tell me that it is not a death sentence and I shouldn’t just put my life in corner and stop living and urge me to continue working.” She further spoke about the importance of her younger sister in her life, saying that they speak on the phone and she “constantly reassures me that everything will be okay. Her words and talking to her make me feel better.” For another 42-year-old woman, her daughter was the main driving force in her life: “I said I will be strong for her, each and every day. No matter how difficult it is, I will.”

When asked why she had such a good experience during her cancer treatment, one 40-year-old woman attributed it to “the support system I had with my family, and partly my friends. Everyone was [there] for me.” Another 56-year-old woman described the help she received from her sister and her neighbor was especially important to her, “because a lot of the time when you’re sick people don’t care about you. But they were able to be beside me.”

For other women, their family and friends assisted with the practical side of managing their illness. An elderly woman (74 years of age) reported that her niece and

nephew check on her when she is sick. Another 56-year-old woman said that her children lived with and helped manage her cancer in multiple ways, including ensuring that “the phone has an alarm so I drink the pills at the same time,” pouring water for her, and helping her wash things. In another case, a 59-year-old woman said that her friends paid her transportation to the clinic when she could not.

Several women talked about the positive impact of speaking to other breast cancer patients, either from just talking to one another in the clinic or during group counseling (or a support group). One 36-year-old woman described her impact on other patients in making them less scared of chemotherapy, and said that her fellow patient in the clinic had told her, “you make me brave, I can go and I can do [chemotherapy.]” Another 62-year-old woman described how she, despite thinking that her cancer diagnosis “was the end of the world,” was encouraged by speaking to “the real people who have had the same experience, those who have survived.” She was then able to accept that cancer “is an illness and it is curable, as long as you attend your treatment well.” Speaking to peers was a powerful demonstrator that cancer was not a death sentence, and was helpful for giving people advice in managing their own condition and understanding that other people had gone through the same or worse experience they were going through.

Some identified the church as a source of social support. One 44-year-old woman said that going to church surrounded herself with people who “encouraged me and even told myself that I should accept my situation and accept it.” Two women spoke about the church simply as a place of friendship and comfort.

### Perception that cancer will get worse despite treatment

In conjunction with misunderstandings and fear around cancer, several people said that they thought cancer would inevitably come back and continue spreading. One 44-year-old woman, after experiencing three operations to remove her cancer, asked, “Why does it come for me for so many times? I think now it’s gone for good and won’t come back again. That’s a lie. . . after ten years it will come back.” Two women in their early 40s feared the long-term impact of cancer. One referred to chemotherapy as a “lifetime treatment” because the aggressive nature of cancer causes it to spread unpredictably through the body. Another said that she feared that the cancer would spread to other parts of the body, citing cancer as being stressful because when she meets fellow patients at the clinic, she finds that often their cancer has spread.

### Discussion

To the best of our knowledge, this article is the first to contextualize patient experiences with breast cancer in urban South Africa—bringing to light fears experienced around



detection, diagnosis, treatment, and recovery. Managing how people perceive and experience breast cancer treatment and recovery is a critical step for improving not only survival rates but also how people perceive and address the diagnosis. Surely this is more complicated among those whose diagnosis is too late.<sup>12</sup> This is why clinical recommendations involve not only communication—such as clinicians better informing and explaining breast cancer disease and treatments in accessible language—but also involves health care providers truly listening to acknowledge and accommodate patients' needs and desire as they experience therapeutics. Finally, it is imperative that patient-reported outcomes are collected and communicated as part of routine care to individualize and optimize this type of specialty care. This involves less-toxic options for treatment where indicated, such as currently underutilized endocrine options that patients tolerate better. In what follows, we discuss these points in turn.

First, understanding the complexity of immediate effect of cancer diagnosis is imperative. On one hand, there are merits to have a dedicated breast center where specialist and allied support is available immediately after diagnosis and throughout their treatment. On the other hand, fear and worry around treatment, as well as death cripples many after diagnosis.<sup>21</sup> This powerful point underscores the need for more psychosocial support both at clinics—which at Bara may involve clinical nurses or patient support groups—and home environments. Moreover, among the most severe cases, palliative care teams, social workers, nurses, and family members must be included in supportive care and information sharing.

Importantly, we found that the patients in our study had all detected the abnormality in their breasts themselves and had come to the clinic after the fact. Many women waited months after discovering the lump to seek care because no or minimal threat to their health was initially perceived.<sup>22,23</sup> This situation is in opposition to countries where screening is routine and detection earlier is common and thus leading to better prognosis.<sup>6,23,24</sup> Despite ongoing awareness programs designed to promote preventive measures, our findings suggest patients are not aware of the urgency of early detection and treatment.<sup>25</sup>

Second, taking account of the fear and worry around chemotherapy and physical mutilation of the breast is an imperative clinical need. Community narratives around mutilation cultivate some of the most powerful fears around breast cancer treatment.<sup>21</sup> Non-mutilating options of breast conserving therapy, have historically played a minor role in poorly resourced settings.<sup>18</sup> In part, choosing mastectomy may reflect the delays and transport problems that emerge in a 6-week course of daily radiation that is currently mandatory for SABC study—which often is a difficult decision for surgeons and their patients. Recognizing the structural and social complexities through which people navigate illness and treatment is imperative

when thinking about the social and cultural ramification around intervention.

Relatedly, our study suggests that the number of required clinic visits needs to be monitored and minimized. This may be addressed in part by having a community health worker or nurse visit patients in their homes to monitor their breast cancer recovery.<sup>26</sup> Too often, patients must attend clinics for non-essential interactions. In doing so, patients travel lengthy distances in a fragile, recovering physical state, while paying some out-of-pocket expenses through the course of diagnosis and treatment.

The powerful resilience of the existing built structures within communities in Soweto may play a role in supporting a network of cancer care and recovery apart from the tertiary hospital. This may include religious communities as much as primary health care. Many patients describe acceptance of their diagnosis through their religious beliefs to be fundamental to their breast cancer experiences.<sup>27</sup> Churches are significant communities of care not only through fostering strength people find through religion but also through a community of dialogue around cancer detection, diagnosis, and treatment. Fostering discussion of what types of treatment exist to religious communities may stymie fear after diagnosis; also promoting dynamic supportive groups for people living through treatment is possible through religious spaces. To date, such communities are underutilized partners responsible for sharing information and patients support through each stage of cancer care and recovery.

Notwithstanding the above narrative, the considerable suffering experienced by South African women with breast cancer is associated with the high incidence of late stage at diagnosis in countries that cannot afford population screening. We must find solutions that enable much earlier detection and referral of patients with cancer symptoms to eliminate the current undue delays in referral, diagnosis, and treatment of patients in the public health sector. Training of primary care nurses in oncology and mandating routine clinical breast examinations for women aged 40 years and older, implementing electronic referral and tracking tools, and eliminating undue waiting lists for appointments and treatments through better operational management of busy tertiary clinics and surgical services are interventions that need to be tested.

This study is not without limitation. First, it was exploratory so only explains the perceptions and experiences of patients enrolled in the SABC. While these findings may relate to others seeking cancer care, their experiences may actually be better than other contexts where breast cancer detection and treatment are negligible. For example, the fact that many people in Soweto can access Bara already enables their access to a higher level of care when compared to many South Africans residing in rural communities. More research is needed to understand the complexities and needs of those residing far from care, and/or who live

with and die from breast cancers that are detected even later, or not detected at all.

## Conclusion

Understanding the fears and emotions involved in delayed care-seeking, invasive treatment, and recovery among breast cancer survivors is imperative for improving clinical care in South Africa and elsewhere. Recognizing the importance of implementing breast conserving surgery—the less invasive option—as standard of care should be a priority not only to improve the lives of women living with breast cancer but also to deter the stigma and fear surrounding breast cancer diagnosis more generally. To achieve this, one has to recognize the existing economic constraints, such as an under-resourced health system for South Africans seeking care in the public sector. This is further complicated when women are unable to afford the time out of work and transport costs associated with multiple therapy sessions, which impedes their ability to attend their sessions thereby contributing to a poorer prognosis. Recognizing how important social and family roles are in people's health and recovery from chemotherapy and radiation is further a low-cost solution for health systems to improve survival rates among breast cancer patients. Thus, addressing community perceptions of breast cancer, patient needs and desires for treatment, structural barriers to intensive therapies, and the burden of invasive treatments are imperative next steps for delivering breast cancer care in Soweto and other resource-constrained settings.

## Acknowledgements

This study benefited from the mutual commitment and collaboration of nearly 10 research staff, multiple projects, and three universities. We are indebted to those who collaborated on this project, helping each other in social, emotional, and material ways that were beneficial not only to understand the project but also to make sure our interlocutors were safe and fed and provided transport back home. We are also indebted to the generosity and insight of our wonderful study participants. In particular, we thank the additional team members who conducted interviews for this project, including Phindile Mathe, Edna Bosire, Brooke Bocast, Nontlantla Mkwanzazi, Victor Shandukani, and Thandi Ma Sbhong. Finally, we thank the administrative team at the Developmental Pathways for Health Research Unit at the University of the Witwatersrand.

## Declaration of conflicting interests


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by grants awarded to EM from the School of Foreign Service Summer Academic Grant and

Provost's Pilot Research Project Grant at Georgetown University. Other funding came from the South African Medical Research Council.

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