Women's pathways to breast cancer diagnosis and care

CANSA DETECTIVES

Toll-free 0800 22 66 22
www.cansa.org.za
CANCER DETECTIVES

Booklet 6
Background
Breast cancer is the most common form of cancer among women worldwide, with 1.7 million women newly diagnosed with the disease each year. In South Africa (SA), breast cancer is a major public health problem, accounting for 16% of all cancer deaths. One in 26 South African women are at risk of developing breast cancer in their lifetime. Of concern is the fact that the majority of women in SA present with late stage disease, which is associated with a poor prognosis.

In SA, breast cancer is diagnosed when women present to a health care practitioner with a suspicious symptom. Women are then referred for further tests and a diagnosis is made. Studies have shown that time to cancer diagnosis may be influenced by several factors including women's knowledge and awareness of cancer symptoms, whether women see themselves as being at risk for breast cancer, barriers or facilitators in the health system, knowledge and attitude of health providers, and psychological, and socio-cultural barriers to health care. Understanding the influence of these factors on the pathway women follow to breast cancer diagnosis is vital to develop interventions that support women with breast cancer symptoms to present to health practitioners earlier.

Study 1 - Women's pathways to breast cancer diagnosis and care: qualitative research

Using a framework to guide research
Little is known about the pathway that women follow in reaching a breast cancer diagnosis in South Africa. The Model of Pathways to Treatment shown in Figure 1 provides a useful research framework to explore and understand patient's journeys as it takes into account the complex and dynamic nature of help-seeking behavior. The Model identifies five key events in the pathway to care viz. detection of bodily changes; perceived reasons to discuss symptoms with a health care provider; first consultation with a health care provider; diagnosis and start of treatment, and four important intervals between these events: the appraisal, help seeking, diagnostic and the pre-treatment intervals. Importantly this framework can be used to identify targets for interventions to promote timely diagnosis. Using this Model of Pathways to Treatment framework, we explored patient's interpretation and understanding of breast cancer symptoms and factors influencing their pathway to diagnosis.
The aim of our study was to explore women's interpretation and understanding of breast cancer symptoms and factors influencing their pathway to diagnosis. As little is known about factors influencing symptom interpretation and the pathway to care, we chose to start our investigation with qualitative research methods. Qualitative research methods are particularly useful when little is known about a problem. Further it allows for a more subtle and detailed understanding of complex issues.

We interviewed 20 newly diagnosed breast cancer patients at a public sector breast cancer clinic in Cape Town, South Africa. The interviews probed women's: interpretation of breast changes; understanding of breast cancer signs and symptoms; perceived risk; social and family support; triggers to seeking care; access to health care; and commonly held community beliefs. Women were allowed to respond freely to open-ended questions and with their permission interviews were taped and transcribed. The interviews were analyzed to look for common themes, with the analysis guided by the Model of Pathways to Treatment framework.
Our findings

Profile of the participants
The average age of the women interviewed was 52 years (range 30 - 74 years) and almost all had a high school or higher education. Five participants were employed, four were pensioners and the remaining eleven were unemployed. Half of the women had late stage cancer (i.e. stage III or IV) at the time of diagnosis. The average time between discovery of breast changes and cancer diagnosis was 8.5 months, with an average of 5.5 months between women finding a breast change and visiting the first health care practitioner. However the sample size in qualitative research component is small and the intervals will be verified in a follow-up quantitative study that will include many more women.

Women's knowledge of breast cancer
Most women in this study had very little knowledge of breast cancer and many did not perceive themselves as being at risk of the disease. Some had seen breast cancer pamphlets and posters but did not understand the contents. As one women said,

“… not really, you read the pamphlets and you actually don't understand it.” (ID01)

A few women had heard of breast self-examination and some had discovered their lump whilst examining their breasts.

“They also teach us when we sit there and waiting for the family planning clinic: how to examine your breast clockwise and that and how to keep your hands on your breast and when is the best time to do it and so on. Because of the knowledge that’s why I examined myself I felt inconsistency on this one (pointing at right breast) that was not here and so I went to the private doctor.” (ID 12)

However, a few women found the discussion on breast self-examination awkward, and reported feeling uncomfortable palpating their own breasts.

Interpreting breast changes
For all the women interviewed, the first change noticed was a breast lump. Lack of accompanying symptoms such as pain or skin changes led some women to believe that the lump was not serious and led to a delay in seeking medical care. One participant explained,

“I stood in the mirror and looked and I was like it's okay for one of your breasts to be bigger than the other and that's normal and I didn't see the redness or any signs that one looks for and then I thought it was not breast cancer because there weren't any of those signs of breast cancer” (ID10).

Prior experience of breast conditions caused some women to interpret their symptoms as being benign.
“It is 6cm at the moment, so I didn`t take note of it because… reason being when I was in high school I also found lumps in my breast and it was breast mice [fibroadenoma], so automatically I thought it`s that again, so it`s nothing to worry about.” (ID10)

Many women thought that the initial symptom would disappear and only became concerned when the lump increased in size or there were additional symptoms. Others reported being afraid when discovering an initial breast change, causing them to deny or rationalize the seriousness of the symptoms.

“I felt like you know what, whatever… I am not going still bother about going. I think I was a little bit scared because I would rather not know, than know what it is. So if it's just painful and not affecting my health and I am not getting sick then it must be ok.” (ID10).

**Acting on breast changes**

Once a woman interprets a breast change as being a possible cause for concern, the next question is ‘what are the potential triggers for women to seek out a health care provider?’ In our study very few women sought medical care immediately on discovery of the initial symptom; most women monitored their initial symptoms and once there was a persistence of symptoms, for instance an increase in the size of the lump or additional symptoms arising (such as pain or skin changes), the women were more likely to seek out medical care. One woman stated that,

“I felt the little lump and I thought I am going to go, but postpone and so on. And then the end of last year I felt that the lump was bigger and then I thought I needed to go but also, you know I'll go, maybe during the recess when we off work. In about two months or maybe three months ago I saw the dent in my breast and there was a red mark and I thought okay, I must go.” (ID07).

Family and friends played an important role in persuading women to seek medical care.

**Accessing health care**

Once symptoms are recognized as serious enough to seek out help, access to healthcare can play a role in the speed at which a diagnosis is made. For some women, delay in diagnosis occurred within the healthcare system when symptoms were initially misdiagnosed, as one participant noted that,

“I examined myself and I felt a small like a pea size lump here in my breast. So I went to the doctor and he told me that it was a gland and that's all… As time went on… I started to find that it was growing and it was growing great, so I went to the doctor again, the same surgery and there was the other doctor there a lady doctor… so she sent me to the Day Hospital” (ID12).
Most women attended public healthcare facilities as facilities were located close to their homes and services are free. Fewer first sought out private healthcare facilities, usually because of convenience, in terms of the prompt doctor services and the longer opening times. While some of the women in this study believed there was little difference between private and public doctor services, women seemed to feel less comfortable in the public sector facilities, one woman stated that

“At the public hospital there is a problem of gangsters” (ID11).

The long queues in the public clinics were also a reason to rather attend private health services.

“at the clinic you have to wake up early and you might not even be seen by a doctor” (ID13).

The role of communities
Generally cancer, including breast cancer, was not discussed in the community. On the few occasions that cancer was discussed, it was usually related to the death of family member or friend.

“People never talk about it at all. It only when we hear that someone has got cancer or someone has died of cancer. People do not actually talk about their views about cancer. I think that people know that cancer kills people but they do not look down upon you. Another thing we hear about it when someone has died already.” (ID08)

Most women in this study chose to tell their immediate family and close friends of their symptoms, and encouragingly appeared to have adequate support structures in place. Those participants reported that family members were an important source of emotional and practical support. One participant mentioned,

“my mother nagged me and I came in” (ID01) when she was asked why she sought out care.

Another woman said that “as the lump started growing bigger and I told my husband, he took me to the doctor” (ID06).
Some conclusions
This is the first study exploring women's pathway to breast cancer diagnosis in South Africa using the Model of Pathways to Treatment as a theoretical framework. Key findings were:
• The long appraisal and help-seeking interval that contributed significantly to delayed presentation to health care;
• There is a need for targeted interventions to increase knowledge of breast cancer signs and symptoms and women's ability and confidence to detect breast changes;
• Strategies to increase public awareness and dialogue on breast cancer could assist in promoting timely entry into the health care system;
• Breast cancer messages need to emphasize that:
  o Breast cancer can present as a painless or painful lump;
  o Previous benign disease does not equate with a decreased risk of breast cancer;
  o Waiting for additional symptoms negatively influences treatment options and outcomes;
  o Early presentation is associated with promising results
• It is important to evaluate how the above messages are understood by the community.

Study 2 - Women's pathways to breast cancer diagnosis and care: quantitative research

Ongoing research
The findings from this first part of our research have been used to guide the second quantitative phase of the study. For this phase a cross-sectional study was conducted at a tertiary hospital in the Western Cape Province, SA, between May 2015 and May 2016. Using a structured questionnaire, 201 newly diagnosed breast cancer patients were interviewed to determine patients:
• socio-demographic profile;
• knowledge of risk factors, signs and symptoms;
• habits and beliefs;
• clinical profile;
• key time events in the diagnostic journey and associated factors.

Factors identified in the qualitative research were explored in this larger group of participants. For example, in our qualitative research women appeared to have very limited knowledge on risk factors and signs of breast cancer. In the cross-sectional survey we used a set of questions to measure in detail the level of knowledge. This will enable us to pinpoint areas of focus for educational intervention programs.
The quantitative survey has been completed and data is currently being analysed. This research will provide information on the average time patients take to appraise their symptoms, as well as the average time between first presenting to a health care provider and a diagnosis being made. We will be able to identify factors associated with longer time intervals. This will enable us to identify opportunities for targeted interventions to promote earlier diagnosis of breast cancer.

**Study 3 - Breast cancer symptom awareness: community level**

Studies have shown that for symptomatic breast cancer shorter time to presentation to a health care provider is associated with early stage disease and better breast cancer survival. Understanding women's knowledge of breast cancer symptoms and how women would interpret and act on any breast changes are important in developing interventions to promote timely cancer diagnosis. Whilst the 2 studies described above focus on understanding perspectives of breast cancer patients, this next study will explore the perspectives of community members before development of breast changes.

In the initial phase of the research we will be developing and validating a questionnaire to measure cancer symptom awareness in Africa. Once the questionnaire is developed we will conduct a community based survey to measure women's symptom awareness and help-seeking behavior in urban and rural settings in South Africa and Uganda. In addition we will be conducting qualitative research with primary level health care providers to better understand how symptoms suggestive of breast cancer are managed at a primary health care level. Results from this study will be available in 2020.

**Conclusion**

It is envisaged that findings from this body of qualitative and quantitative research will inform the development of interventions to promote the timely diagnosis of breast cancer and improve morbidity and mortality from the disease.
Useful readings


Acknowledgements

We thank the patients for sharing their journey to cancer diagnosis, and the staff at the Breast Cancer Clinic for their support.

Thank you to Alexandra Payne and Jennifer Githaiga who assisted in preparing this booklet.

Research reported in this brief is/was supported by CANSA; the University of Cape Town, and; the Strategic Health Innovation Partnerships (SHIP) Unit of the South African Medical Research Council with funds received from the South African National Department of Health, GlaxoSmithKline R&D, and the UK Medical Research Council and with funds from the UK Government's Newton fund.

---

**Prof Jennifer Moodley**

Professor and Director of the Cancer Research Initiative: Faculty of Health Sciences, University of Cape Town (UCT), Observatory 7925, South Africa and Women’s Health Research Unit, School of Public Health and Family Medicine, University of Cape Town, Observatory 7925, South Africa

Email: jennifer.moodley@uct.ac.za

Tel: (W) +27 (0)21 650 5489