

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study
AUTHORS	Moodley, Jennifer; Cairncross, Lydia; Naiker, Thurandrie; Momberg, Mariette

VERSION 1 - REVIEW

REVIEWER	Sally Guttmacher New York University USA
REVIEW RETURNED	29-Sep-2015

GENERAL COMMENTS	<p>To put the issue in context, I think that the authors should make it clear that the use of mammography for screening purposes is not common practice in RSA.</p> <p>on p. 4 the authors might note that the rise in the rate of breast cancer is to some extent due to better diagnostic capabilities.</p> <p>A slightly more detailed description of the sample would be helpful for the reader ie age range, parity range</p>
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REVIEWER	Elizabeth Davies King's College London, UK
REVIEW RETURNED	19-Oct-2015

GENERAL COMMENTS	<p>Thank you. This is a well-written paper describing a clearly designed and executed study using an appropriate theoretical model which has important implications for the study of women presenting with breast cancer symptoms in Africa and attempts to improve earlier diagnosis.</p> <p>There are a few aspects that it would be useful to have more description of in order to 1) provide enough detail on how the analysis was carried out by the team so that others could replicate the study methods and 2) to expand a little on some of the findings if possible.</p> <p>1) Although the author contribution describes the roles of the authors in the analysis, there should be more of this in the actual methods section of the paper. This section needs to make clear whether the interviewer was involved in coding and development of the themes, and exactly how the team came to conclusions about what the themes were using the software and how they dealt with disagreement. The software does not decide that for the team, rather it organises the data. When, for example, did the clinical views become applied to the analyses, were any patient otherwise</p>
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	<p>involved or did anyone have more of a say in concluding from the analysis what was happening for the women than others in the team or was this consensus?</p> <p>2) The themes explaining delay are clearly quite described but I would have liked a little more detail in places, for example, why some women felt they should not touch their breasts (religious, cultural, sexual reasons?) as this is critical to changing their behaviour. Also, was there any sense at all that the women knew of some general stigma associated with cancer? I note the finding that women did not feel devalued by their partners and husbands by disclosing symptoms that could be cancer and did not report this delayed their help. However, was their delay really just lack of knowledge or was there some element of denial of what little they did know? I ask this because some of the women do describe some anxiety causing them to present after experiencing worsening symptoms and I am wondering what they were anxious about if they had little knowledge of cancer. The interviews are also unusual in timing in that they are only a week after the women have been told that they have cancer. I wonder how much they have managed to glean in this time and what their understanding of cancer is now and how emotionally prepared they are to talk about their cancer or put their story into perspective ? How many of those approached declined to take part? There is a long period of health care system diagnostic delay and I wonder if there were more themes that could be drawn out here to identify system barriers.</p> <p>Finally I would suggest that lack of generalisability of the results is not an inherent feature of qualitative work which seeks to understand and explain. I would tend to replace that comment in the highlights section wa comment on the fact that women were from one area and one clinic as it is that factor which limits the generalisability rather than their qualitative nature. I would also suggest that reporting percentages in the text on an N of 20 is not necessary. It is best done where a sample is larger than 100 and is representative of a larger population.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
 Sally Guttmacher
 New York University

To put the issue in context, I think that the authors should make it clear that the use of mammography for screening purposes is not common practice in RSA.

The introduction has been revised to include the following sentence “As with most resource constrained countries, SA does not have a national mammography screening program.” Page 4

on p. 4 the authors might note that the rise in the rate of breast cancer is to some extent due to better diagnostic capabilities.

As recommended we have added the following sentence to the first paragraph. “In part the increasing breast cancer incidence can be attributed to better diagnostic capabilities.” Page 4

A slightly more detailed description of the sample would be helpful for the reader ie age range, parity range

The paper has been revised to include a more detailed description of the sample. Unfortunately we did not collect data on parity.

“Twenty-two women were approached to take part in the study; one declined and another was ineligible as she had been previously diagnosed with breast cancer. The mean age of the 20 women interviewed was 52 years (range 30 - 74 years). Thirteen participants were married, six were single and in a stable relationship and one was widowed. All but one participant had a high school or higher education. Five participants were employed, four were pensioners and the remaining eleven were unemployed. Ten women had late stage cancer (i.e. stage III or IV) at the time of diagnosis.” Pages 8

Thank you

Reviewer: 2
Elizabeth Davies
King's College London, UK

Thank you. This is a well-written paper describing a clearly designed and executed study using an appropriate theoretical model which has important implications for the study of women presenting with breast cancer symptoms in Africa and attempts to improve earlier diagnosis.

There are a few aspects that it would be useful to have more description of in order to 1) provide enough detail on how the analysis was carried out by the team so that others could replicate the study methods and 2) to expand a little on some of the findings if possible.

1) Although the author contribution describes the roles of the authors in the analysis, there should be more of this in the actual methods section of the paper. This section needs to make clear whether the interviewer was involved in coding and development of the themes, and exactly how the team came to conclusions about what the themes were using the software and how they dealt with disagreement. The software does not decide that for the team, rather it organises the data. When, for example, did the clinical views become applied to the analyses, were any patient otherwise involved or did anyone have more of a say in concluding from the analysis what was happening for the women than others in the team or was this consensus?

The methods section has been revised to include more details on the data coding and analysis process.

“All recordings and field notes were translated into English where necessary and transcribed. Transcripts were reviewed by JM and data collection stopped once data saturation was reached. Data were entered into QSR NVivo 10 (a qualitative computer software package). A thematic analysis was performed. Initial coding categories for analyzing data were drawn from the interview guides and from the theoretical concepts of the Model of Pathways to Treatment.[19]. JM and MM read through all the transcripts and developed initial coding categories. MM coded the data and JM reviewed the coded data. Once all the text segments had been given basic codes, the codes were categorized into basic themes by placing similar codes together. No additional themes emerged from this process. Themes were then discussed with the clinical team members (LC and TN).” Page 7

2) The themes explaining delay are clearly quite described but I would have liked a little more detail in places, for example, why some women felt they should not touch their breasts (religious, cultural, sexual reasons?) as this is critical to changing their behaviour.

The women that were uncomfortable touching their breasts were also uneasy with the discussion on breast self-examination and we were unable to elicit reasons for this discomfort. The point that this is critical to behavior change is well taken.

We have revised the results section to indicate this uneasiness as follows:

“However, a few women found the discussion on breast self-examination awkward, and reported feeling uncomfortable palpating their own breasts.” page 10

In addition we have included the following sentence in the results section:

“Further research that explores why women felt discomfort in touching their breasts is required as this is key to changing health behavior.” page 15

Also, was there any sense at all that the women knew of some general stigma associated with cancer? I note the finding that women did not feel devalued by their partners and husbands by disclosing symptoms that could be cancer and did not report this delayed their help. However, was their delay really just lack of knowledge or was there some element of denial of what little they did know? I ask this because some of the women do describe some anxiety causing them to present after experiencing worsening symptoms and I am wondering what they were anxious about if they had little knowledge of cancer.

We did not get a sense of stigma associated with cancer, however the little community discussion on cancer focused on the terminal nature and poor prognosis of cancer. Fear and anxiety among women could be due to these fatalistic views. It is possible that women were in denial because they feared the worst.

We have added the following quotation to illustrate the negative discussion around cancer:

“A few women said that when cancer was mentioned in the community, 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) page 14

We have also discussed this as follows:

“Our findings show that limited discussions on cancer, including breast cancer, occur at a community level. Further when discussions take place they tend to center on cancer as a terminal disease. Community views on the poor prognosis of cancer, could have resulted in initial denial of a possible cancer diagnosis, causing some to only seek help when symptoms worsened. Findings highlight the importance of breast cancer awareness campaigns expanding the target audience from women to all members in the community and including messages on the improved prognosis associated with an early diagnosis” page 17

The interviews are also unusual in timing in that they are only a week after the women have been told that they have cancer. I wonder how much they have managed to glean in this time and what their understanding of cancer is now and how emotionally prepared they are to talk about their cancer or put their story into perspective ?

We conducted interviews within a week of diagnosis to avoid retrospective recall bias. However the issue of emotional preparedness at this stage is noted. We have revised the discussion section to reflect this limitation:

“Although retrospective recall could have affected accurate reporting of symptoms and health seeking behavior, conducting interviews within one week of diagnosis and using a calendar prompt is likely to have minimized recall bias. However, conducting the interviews within one week of diagnosis could also have meant that some participants were not emotionally prepared to put their story into perspective.” Page 18

How many of those approached declined to take part?

Apologies, we had meant to include this information. We have added the following to the results section:

“Twenty-two women were approached to take part in the study; one declined and another was ineligible as she had been previously diagnosed with breast cancer.” Page 8

There is a long period of health care system diagnostic delay and I wonder if there were more themes that could be drawn out here to identify system barriers.

The diagnostic delay was long. Unfortunately we were unable to elicit any further themes. We plan on

addressing this in future research.

Finally I would suggest that lack of generalisability of the results is not an inherent feature of qualitative work which seeks to understand and explain. I would tend to replace that comment in the highlights section with a comment on the fact that women were from one area and one clinic as it is that factor which limits the generalisability rather than their qualitative nature.

The paper has been revised as suggested in both the Highlights and Discussion sections.

“This study it was conducted at one clinic in the Western Cape Province which limits generalizability.”

Page 3

“Our study was conducted at one clinic in the Western Cape Province which limits generalizability.”

Page 18

I would also suggest that reporting percentages in the text on an N of 20 is not necessary. It is best done where a sample is larger than 100 and is representative of a larger population.

All percentages have been removed and numbers are reported.

VERSION 2 – REVIEW

REVIEWER	Elizabeth Davies King's College London
REVIEW RETURNED	03-Dec-2015

GENERAL COMMENTS	Thank you. I am very happy with these careful revisions and have no further comments or suggestions.
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