

BMJ Open

Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2015-009905
Article Type:	Research
Date Submitted by the Author:	06-Sep-2015
Complete List of Authors:	Moodley, Jennifer; ; University of Cape Town, School of Public Health and Family Medicine Cairncross, Lydia; University of Cape Town, Department of Surgery Naiker, Thurandrie; University of Cape Town, Department of Radiation Oncology Momberg, Mariette; University of Cape Town, School of Public Health and Family Medicine
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research, Public health
Keywords:	PUBLIC HEALTH, Breast tumours < ONCOLOGY, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts

1
2
3 **Understanding pathways to breast cancer diagnosis among women in the**
4
5 **Western Cape Province, South Africa: a qualitative study**
6
7
8

9 Jennifer Moodley^{1,2}, Lydia Cairncross³, Thurandrie Naiker⁴, Mariette Momberg²

10
11 ¹Cancer Research Initiative, Faculty of Health Sciences, University of Cape Town;
12
13 Anzio Road. Observatory, 7925, South Africa

14
15
16 ²Women's Health Research Unit, School of Public Health and Family Medicine,
17
18 Faculty of Health Sciences, University of Cape Town; Anzio Road. Observatory,
19
20 7925, South Africa

21
22
23 ³Department of Surgery, University of Cape Town, Anzio Road. Observatory, 7925,
24
25 South Africa

26
27
28 ⁴Department of Radiation Oncology, University of Cape Town, Anzio Road.
29
30 Observatory, 7925, South Africa

31
32
33
34 Corresponding author: Jennifer Moodley, email: jennifer.moodley@uct.ac.za

35
36
37 **Keywords:** breast cancer, timely diagnosis, appraisal delay, breast cancer knowledge,
38
39 pathways to care

40
41 Word count:

42
43 Abstract: 234

44
45 Article: 3 612
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

ABSTRACT

Objectives: The aim of this study was to explore and understand women's pathways to breast cancer diagnosis and factors influencing this journey.

Design and setting: In-depth interviews were conducted with clients at a tertiary level breast cancer clinic in Cape Town, South Africa. A thematic analysis was performed underpinned by the theoretical concepts of the Model of Pathways to Treatment framework.

Participants: Twenty women were interviewed within one week of being diagnosed with breast cancer.

Results: The average time between discovery of breast changes to breast cancer diagnosis was 8.5 months. Deficits in breast self-awareness and knowledge of breast cancer symptoms delayed women's interpretation of bodily changes as being abnormal. All women first noticed breast lumps, however many did not perceive it as abnormal until additional symptoms were present. General good health, attribution of symptoms to ageing and past benign breast disease resulted in women being complacent about bodily changes. Disclosure to family members served as a trigger to seek health care. The initial type of primary level care services women accessed was influenced by perceptions of care each provided, finances, structural factors, and personal safety related to the physical location of services.

Conclusion: Symptom appraisal and interpretation contribute significantly to delayed presentation. To improve timely diagnosis of breast cancer, interventions that increase women's confidence in detecting breast changes, improve knowledge of breast cancer symptoms, address myths and encourage prompt help-seeking behavior are required.

STRENGTHS AND LIMITATIONS

- 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.
- The study provides a more in-depth and nuanced understanding of women's knowledge, experiences and factors influencing action; a strength of qualitative research.
- This study has limitations inherent to qualitative research in that finding cannot be generalized to the population.
- A limitation of the study is that it did not include women that did not access tertiary health care services.

FUNDING STATEMENT

This research was funded by the cancer Association of South Africa (CANSA) and the University of Cape Town, Faculty of Health Sciences.

COMPETING INTEREST

The authors declare that they have no competing interests.

INTRODUCTION

Breast cancer is a major public health burden and remains the commonest cancer among women worldwide with 1.7 million new cases diagnosed each year.[1] Global trends show that since 2008, breast cancer incidence has increased more than 20% and mortality by 14%. In 2012 the majority (53%) of new breast cancer cases were among women living in less developed countries,[1, 2] where the shift toward more affluent lifestyles, particularly those associated with dietary and reproductive risk factors, has been associated with a rising burden of cancers. Lack of early detection programs and access to treatment, place women in less developed regions at a high mortality risk.

Breast cancer is the commonest cancer among women in South Africa (SA) with an age-standardized incidence rate of 27 per 100 000 women,[3] and a major cause of cancer mortality, accounting for 16% of cancer deaths among women.[4] Since 1994, SA has transformed its health care system to one that is comprehensive, integrated and has a primary health care focus.[5] As with most resource constrained countries, SA does not have a national breast cancer screening program. Typically women with breast symptoms self-present to primary health care facilities and are referred to secondary or tertiary level health facilities if further diagnostic work-up is required to diagnose breast cancer. Similar to other developing countries, the majority of patients present with late stage disease[6-8] which is associated with a poorer prognosis. Appropriate recognition of breast symptoms, improved access to health facilities and accurate investigation of symptomatic women are essential to down stage breast cancer.

1
2
3 For people with potential symptoms of cancer the pathway to cancer diagnosis is
4 complex. Studies have shown that time to diagnosis may be influenced by several
5 factors including knowledge and awareness of cancer symptoms, the nature of the
6 symptoms, perception of risk, and physical, psychological, and socio-cultural barriers
7 to health care.[9-17] Understanding the influence of these factors on the pathway
8 women follow to breast cancer diagnosis is vital to the development of interventions.
9
10
11
12
13
14
15
16
17

18 Theoretical frameworks provide a systematic approach to understanding health
19 behavior and there have been calls for greater theoretical underpinning of help-
20 seeking research.[18, 19] The Model of Pathways to Treatment provides a useful
21 research framework to explore and understand patient's journeys as it takes into
22 account the complex and dynamic nature of help-seeking behavior.[19] The Model
23 identifies five key events in the pathway to care viz. detection of bodily changes;
24 perceived reasons to discuss symptoms with a health care provider; first consultation
25 with a health care provider; diagnosis and start of treatment, and four important
26 intervals between these events: the appraisal, help seeking, diagnostic and the pre-
27 treatment intervals. Importantly this framework can be used to identify targets for
28 interventions to promote timely diagnosis. Using the Model of Pathways to Treatment
29 framework, we explored patient's interpretation and understanding of breast cancer
30 symptoms and factors influencing their pathway to diagnosis.
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48

49 **METHODS**

50 The study was conducted at the Groote Schuur Hospital Combined Breast Clinic in
51 Cape Town, SA. The Breast Clinic is an open access, one stop diagnostic clinic where
52 women may present with a letter from a primary level provider (nurse practitioner or
53
54
55
56
57
58
59
60

1
2
3 doctor). It provides a same day clinical and cytological evaluation with immediate
4 referral to an on-site oncologist if the breast cytology is positive for malignancy.
5
6 Typically newly diagnosed patients are reviewed by a multidisciplinary team,
7 including surgeons, oncologists, radiologists and pathologists, within one week of
8 diagnosis to develop a management plan. In-depth interviews were conducted with 20
9 newly diagnosed breast cancer patients between May and July 2014. Women were
10 interviewed within one week of being diagnosed with breast cancer.
11
12
13
14
15
16
17
18
19

20
21 Data were collected using an interview guide that explored women's journey from
22 discovery of breast changes to presentation at the Breast Clinic. Issues explored
23 included: personal interpretation of breast changes, understanding of breast cancer
24 signs and symptoms; perceived risk; social and family support; triggers to seeking
25 care; access to health care; use of various levels of care (including alternative care);
26 and commonly held community beliefs. Using a calendar prompt, the time interval
27 between discovery of breast changes to diagnosis was elicited. A trained researcher
28 who was not part of the clinical management team, conducted interviews lasting
29 between 45 and 60 minutes, in the language of the respondent. All interviews were
30 digitally recorded with the permission of respondents and field notes were also taken.
31
32 Ethical approval to conduct the study was obtained from the Human Research Ethics
33 Committee, University of Cape Town. All study participants provided written
34 informed consent prior to the interview process.
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50

51
52 All recordings and field notes were translated into English where necessary and
53 transcribed. Data were entered into QSR NVivo 10 (a qualitative computer software
54
55
56
57
58
59
60

1
2
3 package). A thematic analysis was performed informed by the theoretical concepts of
4
5 the Model of Pathways to Treatment.[19]
6
7
8

9 10 **RESULTS**

11 The mean age of the women interviewed was 52 years, all but one participant had
12 high school or higher education, and 30% were employed. Fifty percent of women
13 had late stage cancer (i.e. stage III or IV) at the time of diagnosis. The average time
14 between discovery of breast changes and cancer diagnosis was 256 days; with an
15 average of 164 days between discovery of changes and presentation to the first health
16 care provider i.e. the appraisal and help-seeking interval, and 92 days between
17 assessment by the first health provider and diagnosis at the tertiary hospital breast
18 clinic i.e. the diagnostic interval.
19
20
21
22
23
24
25
26
27
28

29 30 31 32 **Breast cancer knowledge and perception of risk**

33 Many women reported no prior knowledge about breast cancer. As one participant
34 reported:
35
36

37
38 *“No, not at all so when I did find the lump which apparently I have been complaining*
39 *about two years ago it was difficult for me because I had no knowledge about breast*
40 *cancer”* (ID10)
41
42
43
44

45 A few had received information from a variety of sources including pamphlets at
46 health facilities; television and radio campaigns; health care professionals and from
47 friends or relatives who had been diagnosed with breast cancer. Information received
48 related to breast cancer symptoms and to a lesser extent breast self-examination.
49 However, most were only able to vaguely report on the information received and
50 generally felt it to be insufficient.
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5 “I did have knowledge [about breast cancer] but not the full content” (ID06)
6
7

8 “..not really, you read the pamphlets and you actually don’t understand it.” (ID01)
9
10

11
12 Many women did not perceive themselves as being at risk of breast cancer.

13 “No, it [breast cancer] didn’t worry me...It was almost like it [breast cancer] won’t
14
15 happen to me that kind of attitude that I had.” (ID11)
16
17
18
19

20
21 Some women had experience of family members having breast cancer, but this did not
22
23 lead to a perception of increased risk, not did it prompt women to seek early care.

24
25 “My other cousin had breast cancer...she ended up dying in 2011...I have seen the
26
27 pamphlets and adverts from the television about breast cancer but I was not that
28
29 interested and did not pay much attention ... I have never examined myself...I really
30
31 do not know anything about cancer.” (ID13)
32
33
34
35
36
37

38 **Discovery and initial appraisal of body changes**

39
40 For all women, a lump was the body change noticed. Some reported accidental
41
42 discovery of a breast lump, either by themselves or a partner. Others had breast
43
44 changes detected as part of a clinician visit for an unrelated problem e.g. “I was at a
45
46 neurologist just for my head...she checked my breasts” (ID11)
47
48
49

50
51 A few women were aware of the practice of breast self-examination, either from being
52
53 informed by a health professional or through watching television. Some had
54
55 discovered their lump during a breast self-examination.
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

“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)

“I first noticed while self examining my breasts because I heard from the television that one of the symptoms of cancer is a lump and how to check your breasts.” (ID17)

However, some women reported feeling uncomfortable palpating their own breasts.

As one participant remarked:

“I don’t think it is right to feel your breasts.” (ID14)

Prior experience of breast conditions caused some women to interpret their symptoms as being benign.

“Another thing that made me not pay attention was because I am used to have abscesses in my breasts but then they would heal and disappear but this one didn’t go away and my breast started getting darker and I decided to go to the clinic.” (ID17)

“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)

1
2
3 For many, the lack of accompanying symptoms such as pain or skin changes led to a
4 misinterpretation of the initial symptom, false sense of reassurance and delay in
5 seeking medical care.
6
7

8
9
10 *“I have heard that sometimes the skin around the breast that has a problem become*
11 *red and swollen. My breast is soft and not swollen.”* (ID06)
12

13
14 *“I didn’t pay attention to the lump because it wasn’t painful when it started*
15 *showing.”* (ID16)
16
17

18
19 *“I stood in the mirror and looked and I was like it’s okay for one of your breasts to*
20 *be bigger than the other and that’s normal and I didn’t see the redness or any signs*
21 *that one looks for and then I thought it was not breast cancer because there weren’t*
22 *any of those signs of breast cancer.”* (ID10)
23
24
25
26
27

28
29
30
31 Most women reported being in good health and therefore were less likely to be
32 concerned about symptoms. Other had noticed general symptoms such as loss of
33 appetite and weight but attributed this to ageing.
34
35

36
37 *“I really do not feel sick at all.”* (ID08)
38

39
40 *“..... but we thought with age comes losing weight and eating less.”* (ID09)
41
42
43
44

45
46 Women reported being fearful and anxious upon discovery of initial breast changes.

47 This caused some to deny or rationalize the seriousness of the symptoms, or hope that
48 it would go away.
49

50
51 *“I felt like you know what, whatever..... I am not going still bother about going. I*
52 *think I was a little bit scared because I would rather not know, than know what it is.*
53
54
55
56
57
58
59
60

1
2
3 *So if it's just painful and not affecting my health and I am not getting sick then it must*
4 *be okay.” (ID10)*
5
6
7
8

9 10 **Triggers to seeking care**

11 A few women sought medical care immediately on discovery of the initial symptom.
12 Most women however, monitored their initial symptoms and either persistence of
13 symptoms, an increase in size of the breast lump or experience of additional
14 symptoms such as pain or skin changes were a trigger to seek medical care.
15
16
17
18
19

20 *“I felt the little lump and I thought I am going to go, but postpone and so on. And then*
21 *the end of last year I felt that the lump was bigger and then I thought I needed to go*
22 *but also, you know I'll go, maybe during the recess, when we off work. In about two*
23 *months or maybe three months ago I saw the dent in my breast and there was a red*
24 *mark and I thought okay, I must go” (ID07)*
25
26
27
28
29
30
31
32
33

34 Disclosure to family members influenced some participants to seek medical care.

35 *“Because she [mother] nagged me I came.” (ID01)*
36
37
38

39 *“In February or March the lump started growing bigger and I told my husband and*
40 *he took me to the doctor.” (ID06)*
41
42
43
44
45

46 **Access to health care**

47 Most women attended public healthcare facilities for financial reasons including low
48 transport costs as facilities were located close to their homes and the benefit of free
49 public sector services. Women who sought care through the private sector did so
50 because of convenience, in terms of speed at which they are likely to be seen and
51 longer opening times; as well as perceived better care and safety.
52
53
54
55
56
57
58
59
60

1
2
3 “Because you don’t have to queue when you visit them (private practitioner). At the
4 clinic you have to wake up early and you might not even be seen by a doctor.” (ID13)

5
6
7 “[at public hospital there is] a problem of gangsters.” (ID11)

8
9
10 Some believed that there was little difference between private and public doctor
11 services. The few women who reported seeking care from a traditional healer did so
12 in conjunction with receiving care from mainstream physicians, often after being
13 influenced by others or if they did not perceive their symptoms improving.
14
15 Participants who sought care from a traditional healer did so when they were visiting
16 relatives in more rural areas in the Eastern Cape Province.
17
18
19
20
21
22
23
24

25
26 Once women sought help for the breast symptoms, many were quickly referred for
27 appropriate assessment and management to a secondary or tertiary level health
28 service. However, a few felt they had been misdiagnosed (in both private and public
29 health facilities) and that this delayed final diagnosis and treatment.
30
31
32
33

34
35 “I examined myself and I felt a small like a pea size lump here in my breast. So I went
36 to the doctor and he told me that it was a gland and that’s all...As time went on... I
37 started to find that it was growing and it was growing great, so I went to the doctor
38 again, the same surgery and there was the other doctor there a lady doctor... so she
39 sent me to the Day Hospital.” (ID12)
40
41
42
43
44
45

46
47 “They just assumed that it is a fat gland that has hardened and I should not worry
48 about it and I left...about two months ago I knew something was wrong this is not fat
49 at all ...it’s starting to get soft and it’s moving to the nipple... something is not right
50 here and that is when came back to Groote Schuur to be checked.” (ID01)
51
52
53
54
55
56
57
58
59
60

1
2
3 *“It was last year and she was misdiagnosed by the doctor. She went to a doctor*
4 *because she felt something small in her breast and then the doctor said she might*
5 *have picked up something heavy. She was given pain tablets.” (ID06)*
6
7
8
9

10 11 12 **Competing priorities**

13
14 There was some evidence that women delayed in seeking care due to work
15 commitments. However for one participant disclosure to a work manager resulted in
16 influence to promptly seek care.
17
18
19

20 21 22 **Community views and support mechanisms**

23
24 Many women mentioned that cancer and breast cancer in particular was not
25 something that was generally discussed in the community, moreover general
26 knowledge about breast cancer seemed to be limited in the community.
27
28
29

30
31
32 *“I don’t want to lie, I have never heard people talking about it [breast cancer]... It*
33 *[breast cancer] is something that’s not talked about...” (ID13)*
34

35
36
37 *“People do not really talk about it [breast cancer]. My friends never talk about it*
38 *[breast cancer].” (ID10)*
39

40
41
42
43 Most women chose to tell both their immediate family and close friends of their
44 diagnosis and appeared to have adequate support structures in place. Participants
45 reported that family members were an important source of emotional and practical
46 support.
47
48
49
50
51
52
53
54
55
56
57
58
59
60

DISCUSSION

Understanding pathways to cancer diagnosis is vital to the development of effective interventions to promote timely diagnosis.[19-21] To our knowledge 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. Similar to other studies, an important component of delayed presentation in our study was the long appraisal and help-seeking interval.[9, 14, 16, 17, 22, 23] The first event in this interval, the detection of bodily changes requires women to be aware of normal body morphology, have knowledge of and feel comfortable with breast self-examination, and have confidence in the ability to detect changes. Many women in our study lacked such knowledge and confidence. Further women reported anxiety on discovery of breast changes and as reported elsewhere this resulted in conflicting outcomes causing some to deny the seriousness of bodily changes and dismiss it as normal and others to seek care promptly.[24] Our study points to a clear need for targeted interventions to increase women's ability and confidence to detect breast changes. Interventions will need to take into account possible discomfort with touching oneself, reported both in our and other studies,[16, 25, 26] and the fear of self-detection of breast cancer.[25, 27, 28]

Women with low breast cancer awareness are more likely to delay in presenting to a health care provider.[13, 16, 17, 29, 30] In our study a major deficit in knowledge of the symptoms of breast cancer delayed women's interpretation of body changes as being abnormal. Although the initial change reported by all women was a breast lump, many did not perceive it as abnormal until additional symptoms, such as pain and skin changes, were experienced. Pain associated with breast lumps has been

1
2
3 shown to influence women's help seeking behavior in different ways.[14, 16, 17, 23,
4
5 24] For some women, as in our study, the absence of pain results in a
6
7 misinterpretation of the lump as benign and can contribute to delays in seeking care,
8
9 whilst others have reported that some women regard absence of pain as sinister and is
10
11 a trigger for action.
12

13
14
15
16 The Common Sense Model of Illness Self-regulation suggests that for bodily changes
17
18 to be perceived as a symptom i.e. as abnormal, the changes need to exceed an
19
20 inference threshold, resulting in a more complete appraisal of the symptom.[31]
21
22 Bodily changes below the threshold are normalized. In our study both a sense of
23
24 overall good health and attribution of more general symptoms such as loss of weight
25
26 to ageing resulted in women being complacent about bodily changes and delayed help
27
28 seeking. Women with a past history of benign breast disease exhibited an optimistic
29
30 bias[19] in interpreting symptoms, and for some this was reinforced by downplaying
31
32 of symptoms by health care providers.
33
34
35
36
37

38
39 A family history of cancer not only influence beliefs about cancer curability but can
40
41 also have opposing effects on perceived risk of breast cancer.[23] Despite having a
42
43 family history of breast cancer, many of our participants did not perceive themselves
44
45 at increased risk, not did influence the interpretation of a breast lump as abnormal.
46
47
48

49
50 Most women reported a period of monitoring of symptoms before deciding to seek
51
52 care. Decisions to seek care were sometimes not acted upon immediately because of
53
54 contextual factors such as work priorities and relocation. The tendency for women to
55
56 put other priorities ahead of their own health has been reported.[32-34] Limited
57
58
59
60

1
2
3 research is available on how job conditions may impact on health seeking behavior
4 among women with cancer symptoms.[35] Employers could play an important role in
5 helping women manage work-health seeking conflicts. For at least one participant in
6 our study, disclosure to a manager was an important trigger to seeking care,
7 suggesting that occupational settings could serve as an important site for education on
8 breast cancer symptoms, further increasing the likelihood of early presentation of
9 breast cancer.
10
11
12
13
14
15
16
17
18
19

20
21 Our study confirms the findings of others on the important role that family and
22 community members play in encouraging timely presentation as well as sanctioning
23 ill health.[19, 32] Disclosure to family members was an important trigger to seek
24 health care. Further, where detection of breast changes was made by others, usually
25 by a close family member, women had prompt entry to health services. In contrast to
26 other studies[13, 16] women did not report being fearful of isolation or abandonment
27 in disclosing symptoms to husbands and other close family members. Most
28 participants reported family members had offered emotional and social support for
29 future planned breast cancer treatment. These findings highlight the importance of
30 breast cancer awareness campaigns expanding the target audience from women to all
31 members in the community.
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

48 The type of primary level care services (public clinics or private general practitioners)
49 women accessed for initial appraisal of their symptoms was influenced by perceptions
50 of care each provided, finances, structural factors such as long queues, and personal
51 safety in terms of the physical location of services. It was difficult to ascertain
52 whether these factors led to a delay in entry to health care, however, other studies
53
54
55
56
57
58
59
60

1
2
3 have shown that such factors can hinder timely medical care.[24, 30, 36] There were
4
5 some reports of possible initial misdiagnosis by public and private sector
6
7 practitioners, causing a delay in diagnosis. Further research to explore the need for
8
9 provider training in assessment of symptoms suggestive of breast cancer is required.
10
11 In our study women reported limited use of traditional healers, however such
12
13 practitioners could play a larger role in entry into health care in rural communities.
14
15

16
17
18 This study has limitations inherent to qualitative research in that finding cannot be
19
20 generalized to the population. Further quantitative studies are required to confirm
21
22 findings. However it does provide a more in-depth and nuanced understanding of
23
24 women's knowledge, experiences and factors influencing action; a strength of
25
26 qualitative research. Although retrospective recall could have affected accurate
27
28 reporting of symptoms and health seeking behavior, conducting interviews within one
29
30 week of diagnosis and using a calendar prompt is likely to have minimized recall bias.
31
32 A limitation of the study is that it only includes women that have accessed health care.
33
34 Awareness of breast changes and factors influencing symptom interpretation and
35
36 management among women that have not accessed care needs to be explored.
37
38
39
40
41
42

43 **CONCLUSION**

44
45 Symptom appraisal and interpretation contribute significantly to delayed presentation.
46
47 To improve timely diagnosis of breast cancer, interventions that increase women's
48
49 confidence in detecting breast changes, improve knowledge of breast cancer
50
51 symptoms among women and the general community, address notions that lead to
52
53 misinterpretation of symptoms and encourage prompt help-seeking behavior are
54
55 required.
56
57
58
59
60

AUTHOR CONTRIBUTIONS

JM initiated the study and developed the study protocol. LC and TN reviewed the protocol and provided clinical oversight. MM and JM coded and analyzed the data analysis. JM prepared the first draft, incorporated revisions and prepared the final draft. All authors reviewed drafts and approved the manuscript.

ACKNOWLEDGEMENTS

We thank the patients for sharing their journey to cancer diagnosis, the staff at the Breast Cancer Clinic for their support, Rosemary Jacobs for assistance in data collections and Vedantha Singh for assistance in preparation of the article.

DATA SHARING STATEMENT

No unpublished data available.

REFERENCES

1. Ferlay J, Soerjomataram I, Ervik M, et al. Globocan 2012, Cancer incidence and mortality worldwide. International Agency for Research on Cancer. 2013 <http://globocan.iarc.fr>.(accessed 28 June 2015).
2. Torre LA, Bray F, Siegel RL, et al. Global cancer statistics, 2012. *CA: A Cancer Journal for Clinicians* 2015;65(2):87-108.
3. National Cancer Registry. Cancer in South Africa 2009 Full Report. 2015. www.nioh.ac.za.(accessed 28 June 2015).

- 1
2
3 4. Bradshaw D, Schneider M, Norman R, et al. Mortality patterns of chronic diseases
4 of lifestyle in South Africa. In: Steyn K, Fourie J, Temple N, eds. *Chronic Diseases of*
5 *Lifestyle in South Africa: 1995 - 2005*. Cape Town: South African Medical Research
6 Council 2006:127-50.
7
8
- 9
10 5. Coovadia H, Jewkes R, Barron P, et al. The health and health system of South
11 Africa: historical roots of current public health challenges. *The Lancet*
12 2009;374(9692):817-34.
13
14
- 15 6. Vorobiof DA, Sitas F, Vorobiof G. Breast cancer incidence in South Africa. *J Clin*
16 *Oncol* 2001;9(18 Suppl):125S-7S.
17
18
- 19 7. Elgaili EM, Abuidris DO, Rahman M, et al. Breast cancer burden in central Sudan.
20 *Int J Womens Health* 2010;2:77-82.
21
22
- 23 8. Dickens C, Joffe M, Jacobson J, et al. Stage at breast cancer diagnosis and distance
24 from diagnostic hospital in a periurban setting: A South African public hospital case
25 series of over 1,000 women. *Int J Cancer* 2014;135(9):2173-82.
26
27
- 28 9. Burgess CC, Ramirez AJ, Richards MA, et al. Who and what influences delayed
29 presentation in breast cancer. *Br J Cancer* 1998;77(8):1343-8.
30
31
- 32 10. Nosarti C, Crayford T, Roberts JV, et al. Delay in presentation of symptomatic
33 referrals to a breast clinic: patient and system factors. *Br J Cancer* 2000;82(3):742-8.
34
35
- 36 11. Rauscher GH, Ferrans CE, Kaiser K, et al. Misconceptions about breast lumps and
37 delayed medical presentation in urban breast cancer patients. *Cancer Epidemiol*
38 *Biomarkers Prev* 2010;19(3):640-7.
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 12. Simon AE, Waller J, Robb K, et al. Patient delay in presentation of possible
4 cancer symptoms: the contribution of knowledge and attitudes in a population sample
5 from the United Kingdom. *Cancer Epidemiol Biomarkers Prev* 2010;19(9):2272-7.
6
7
8
9
10
11 13. Norsa'adah B, Rampal KG, Rahmah MA, et al. Diagnosis delay of breast cancer
12 and its associated factors in Malaysian women. *BMC Cancer* 2011;11:141-7
13
14
15
16 14. Dye TD, Bogale S, Hobden C, et al. Experience of initial symptoms of breast
17 cancer and triggers for action in Ethiopia. *Int J Breast Cancer* 2012; 908547.
18
19
20
21
22 15. Forbes L, Warburton F, Richards M, et al. Risk factors for delay in symptomatic
23 presentation: a survey of cancer patients. *Br J Cancer* 2014;111(3):581-8.
24
25
26
27
28 16. Jones CE, Maben J, Jack RH, et al. A systematic review of barriers to early
29 presentation and diagnosis with breast cancer among black women. *BMJ Open*
30 2014;4(2):e004076,2013-004076.
31
32
33
34
35 17. Jones CE, Maben J, Lucas G, et al. Barriers to early diagnosis of symptomatic
36 breast cancer: a qualitative study of black African, black Caribbean and white British
37 women living in the UK. *BMJ Open* 2015;5(3):e006944,2014-006944.
38
39
40
41
42
43 18. Scott S, Walter F. Studying help-seeking for symptoms: the challenges of methods
44 and models. *Soc Personal Psychol Compass* 2010;4(8):531-47.
45
46
47
48
49 19. Scott S, Walter F, Webster A, Sutton S, Emery J. The model of pathways to
50 treatment: conceptualization and integration with existing theory. *Brit J Health*
51 *Psychol* 2013;18(1):45-65.
52
53
54
55
56
57
58
59
60

- 1
2
3 20. Andersen RS, Vedsted P, Olesen F, et al. Patient delay in cancer studies: a
4 discussion of methods and measures. *BMC Health Serv Res* 2009;9:189-93.
5
6
7
8
9 21. Walter F, Webster A, Scott S, et al. The Andersen Model of Total Patient Delay: a
10 systematic review of its application in cancer diagnosis. *J Health Serv Res Policy*
11 2012; 17(2):110-8.
12
13
14
15
16 22. de Nooijer J, Lechner L, de Vries H. A qualitative study on detecting cancer
17 symptoms and seeking medical help; an application of Andersen's model of total
18 patient delay. *Patient Educ Couns* 2001;42(2):145-57.
19
20
21
22
23
24 23. Khakbazan Z, Taghipour A, Roudsari RL, et al. Help seeking behavior of women
25 with self-discovered breast cancer symptoms: A meta-ethnographic synthesis of
26 patient delay. *PloS One* 2014;9(12):e110262.
27
28
29
30
31
32 24. Unger-Saldaña K, Infante-Castañeda CB. Breast cancer delay: a grounded model
33 of help-seeking behaviour. *Soc Sci Med* 2011;72(7):1096-104.
34
35
36
37
38 25. Naghibi SA, Shojaizadeh D, Montazeri A, et al. Sociocultural Factors Associated
39 with Breast Self-Examination among Iranian Women. *Acta Med Iran* 2015;53(1):62-
40 8.
41
42
43
44
45 26. Yang RJ, Huang LH, Hsieh YS, et al. Motivations and reasons for women
46 attending a breast self-examination training program: A qualitative study. *BMC*
47 *Womens Health* 2010; Jul 10;10:23,6874-85.
48
49
50
51
52
53 27. Consedine NS, Magai C, Krivoshekova YS, et al. Fear, anxiety, worry, and breast
54 cancer screening behavior: a critical review. *Cancer Epidemiol Biomarkers Prev*
55 2004;13(4):501-10.
56
57
58
59
60

- 1
2
3 28. Al-Naggar RA, Al-Naggar DH, Bobryshev YV, et al. Practice and barriers toward
4 breast self-examination among young Malaysian women. *Asian Pac J Cancer Prev*
5 2011;12(5):1173-8.
6
7
8
9
10 29. Ramirez A, Westcombe A, Burgess C, et al. Factors predicting delayed
11 presentation of symptomatic breast cancer: a systematic review. *The Lancet*
12 1999;353(9159):1127-31.
13
14
15
16
17 30. Taib NA, Yip C, Low W. Recognising symptoms of breast Cancer as a reason for
18 delayed presentation in Asian women-The Psycho-socio-cultural Model for breast
19 symptom appraisal: opportunities for intervention. *Asian Pac J Cancer Prev*
20 2011;12(6):1601-8.
21
22
23
24
25
26
27 31. Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-
28 regulation of health and illness. In: Cameron LD, Leventhal H, eds. *The self-*
29 *regulation of health and illness behaviour*. New York: Routledge 2003:41–65.
30
31
32
33 32. Burgess C, Hunter MS, Ramirez AJ. A qualitative study of delay among women
34 reporting symptoms of breast cancer. *Br J Gen Pract* 2001;51(473):967-71.
35
36
37 33. Majaj L, Nassar M, De Allegri M. "It's not easy to acknowledge that I'm ill": a
38 qualitative investigation into the health seeking behavior of rural Palestinian women.
39 *BMC Womens Health* 2013; 13:26.
40
41
42
43 34. Taha H, Al-Qutob R, Nystrom L, et al. "Voices of fear and safety" women's
44 ambivalence towards breast cancer and breast health: a qualitative study from Jordan.
45 *BMC Womens Health* 2012; 12:21,6874-78.
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 35. Vanderpool RC, Swanberg JE, Chambers MD. A narrative review of the
4
5 confluence of breast cancer and low-wage employment and its impact on receipt of
6
7 guideline-recommended treatment. *Glob Adv Health Med.* 2013;2(5):75-85.
8
9

10
11 36. Lam WW, Tsuchiya M, Chan M, et al. Help-seeking patterns in Chinese women
12
13 with symptoms of breast disease: a qualitative study. *J Public Health (Oxf)*
14
15 2009;(1):59-68.
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

BMJ Open

Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2015-009905.R1
Article Type:	Research
Date Submitted by the Author:	04-Nov-2015
Complete List of Authors:	Moodley, Jennifer; University of Cape Town, Cancer Research Initiative, Faculty of Health Sciences; University of Cape Town, Women's Health Research Unit, School of Public Health and Family Medicine Cairncross, Lydia; University of Cape Town, Department of Surgery Naiker, Thurandrie; University of Cape Town, Department of Radiation Oncology Momberg, Mariette; University of Cape Town, Women's Health Research Unit, School of Public Health and Family Medicine
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research, Public health
Keywords:	PUBLIC HEALTH, Breast tumours < ONCOLOGY, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts

1
2
3 **Understanding pathways to breast cancer diagnosis among women in the**
4 **Western Cape Province, South Africa: a qualitative study**
5
6
7
8

9 Jennifer Moodley^{1,2}, Lydia Cairncross³, Thurandrie Naiker⁴, Mariette Momberg²

10
11 ¹Cancer Research Initiative, Faculty of Health Sciences, University of Cape Town;
12 Anzio Road. Observatory, 7925, South Africa
13

14
15 ²Women's Health Research Unit, School of Public Health and Family Medicine,
16 Faculty of Health Sciences, University of Cape Town; Anzio Road. Observatory,
17 7925, South Africa
18
19

20
21 ³Department of Surgery, University of Cape Town, Anzio Road. Observatory, 7925,
22 South Africa
23

24
25 ⁴Department of Radiation Oncology, University of Cape Town, Anzio Road.
26 Observatory, 7925, South Africa
27
28

29
30 Corresponding author: Jennifer Moodley, email: jennifer.moodley@uct.ac.za
31
32

33
34 **Keywords:** breast cancer, timely diagnosis, appraisal delay, breast cancer knowledge,
35 pathways to care
36
37

38
39 Word count:
40

41
42 Abstract: 234
43

44
45 Article: 3998
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

ABSTRACT

Objectives: The aim of this study was to explore and understand women's pathways to breast cancer diagnosis and factors influencing this journey.

Design and setting: In-depth interviews were conducted with clients at a tertiary level breast cancer clinic in Cape Town, South Africa. A thematic analysis was performed underpinned by the theoretical concepts of the Model of Pathways to Treatment framework.

Participants: Twenty women were interviewed within one week of being diagnosed with breast cancer.

Results: The average time between discovery of bodily changes to breast cancer diagnosis was 8.5 months. Deficits in breast self-awareness and knowledge of breast cancer symptoms delayed women's interpretation of bodily changes as being abnormal. All women first noticed breast lumps, however many did not perceive it as abnormal until additional symptoms were present. General good health, attribution of symptoms to ageing and past benign breast disease resulted in women being complacent about bodily changes. Disclosure to family members served as a trigger to seek health care. The initial type of primary level care services women accessed was influenced by perceptions of care each provided, finances, structural factors, and personal safety related to the physical location of services.

Conclusion: Symptom appraisal and interpretation contributed significantly to delayed presentation. To improve timely diagnosis of breast cancer, interventions that increase women's confidence in detecting breast changes, improve knowledge of breast cancer symptoms, address myths and encourage prompt help-seeking behavior are required.

STRENGTHS AND LIMITATIONS

- 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.
- The study provides a more in-depth and nuanced understanding of women's knowledge, experiences and factors influencing action; a strength of qualitative research.
- This study was conducted at one clinic in the Western Cape Province which limits generalizability.
- A limitation of the study is that it did not include women that did not access tertiary health care services.

INTRODUCTION

Breast cancer is a major public health burden and remains the commonest cancer among women worldwide with 1.7 million new cases diagnosed each year.[1] Global trends show that since 2008, breast cancer incidence has increased more than 20% and mortality by 14%. In part the increasing breast cancer incidence can be attributed to better diagnostic capabilities.[2] In 2012 the majority (53%) of new breast cancer cases were among women living in less developed countries,[1, 2] where the shift toward more affluent lifestyles, particularly those associated with dietary and reproductive risk factors, has been associated with a rising burden of cancers. Lack of early detection programs and access to treatment, place women in less developed regions at a high mortality risk.

Breast cancer is the commonest cancer among women in South Africa (SA) with an age-standardized incidence rate of 27 per 100 000 women,[3] and a major cause of cancer mortality, accounting for 16% of cancer deaths among women.[4] Since 1994, SA has transformed its health care system to one that is comprehensive, integrated and has a primary health care focus.[5] As with most resource constrained countries, SA does not have a national mammography screening program. Typically women with breast symptoms self-present to primary health care facilities and are referred to secondary or tertiary level health facilities if further diagnostic work-up is required to diagnose breast cancer. Similar to other developing countries, the majority of patients present with late stage disease[6-8] which is associated with a poorer prognosis. Appropriate recognition of breast symptoms, improved access to health facilities and accurate investigation of symptomatic women are essential to down stage breast cancer.

1
2
3
4
5 For people with potential symptoms of cancer the pathway to cancer diagnosis is
6 complex. Studies have shown that time to diagnosis may be influenced by several
7 factors including knowledge and awareness of cancer symptoms, the nature of the
8 symptoms, perception of risk, and health system, psychological, and socio-cultural
9 barriers to health care.[9-17] Understanding the influence of these factors on the
10 pathway women follow to breast cancer diagnosis is vital to the development of
11 interventions.
12
13
14
15
16
17
18
19

20
21
22
23 Theoretical frameworks provide a systematic approach to understanding health
24 behavior and there have been calls for greater theoretical underpinning of help-
25 seeking research.[18, 19] The Model of Pathways to Treatment provides a useful
26 research framework to explore and understand patient's journeys as it takes into
27 account the complex and dynamic nature of help-seeking behavior.[19] The Model
28 identifies five key events in the pathway to care viz. detection of bodily changes;
29 perceived reasons to discuss symptoms with a health care provider; first consultation
30 with a health care provider; diagnosis and start of treatment, and four important
31 intervals between these events: the appraisal, help seeking, diagnostic and the pre-
32 treatment intervals. Importantly this framework can be used to identify targets for
33 interventions to promote timely diagnosis. Using the Model of Pathways to Treatment
34 framework, we explored patient's interpretation and understanding of breast cancer
35 symptoms and factors influencing their pathway to diagnosis. Little is known about
36 the pathway that women follow in reaching a breast cancer diagnosis in South Africa.
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60 Initial exploration using qualitative research techniques were considered most

1
2
3 appropriate as the methodology allows for a more subtle and detailed understanding
4
5 of complex issues.
6
7
8

9 10 **METHODS**

11 The study was conducted at the Groote Schuur Hospital Combined Breast Clinic in
12 Cape Town, SA. The Breast Clinic is an open access, one stop diagnostic clinic where
13 women may present with a letter from a primary level provider (nurse practitioner or
14 doctor). It provides a same day clinical and cytological evaluation with immediate
15 referral to an on-site oncologist if the breast cytology is positive for malignancy.
16 Typically newly diagnosed patients are reviewed by a multidisciplinary team,
17 including surgeons, oncologists, radiologists and pathologists, within one week of
18 diagnosis to develop a management plan. In-depth interviews were conducted with 20
19 purposively selected newly diagnosed breast cancer patients between May and July
20 2014. Women were interviewed within one week of being diagnosed with breast
21 cancer.
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Data were collected using an interview guide that explored women's journey from
discovery of breast changes to presentation at the Breast Clinic. Issues explored
included: personal 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; use of various levels of care (including alternative care);
and commonly held community beliefs. Using a calendar prompt, the time interval
between discovery of bodily changes to breast cancer diagnosis was elicited. The
interview guide was pilot tested with two newly diagnosed breast cancer patients and
minor modifications to the wording of some questions were made. A female Xhosa-

1
2
3 speaking research nurse trained in qualitative research methods, who was not part of
4
5 the clinical management team, approached clients to take part in the study. All study
6
7 participants provided written informed consent prior to the interview process. The
8
9 research nurse conducted interviews lasting between 45 and 60 minutes, in the
10
11 language of the respondent in a private room at the Breast Clinic. Six participants
12
13 were accompanied by a family member or friend, and with the consent of the
14
15 participant were present during the interviews. All interviews were digitally recorded
16
17 with the permission of respondents and field notes were also taken. Ethical approval
18
19 to conduct the study was obtained from the Human Research Ethics Committee,
20
21 University of Cape Town.
22
23
24
25
26

27 All recordings and field notes were translated into English where necessary and
28
29 transcribed. Transcripts were reviewed by JM and data collection stopped once data
30
31 saturation was reached. Data were entered into QSR NVivo 10 (a qualitative
32
33 computer software package). A thematic analysis was performed. Initial coding
34
35 categories for analyzing data were drawn from the interview guides and from the
36
37 theoretical concepts of the Model of Pathways to Treatment.[19]. JM and MM read
38
39 through all the transcripts and developed initial coding categories. MM coded the data
40
41 and JM reviewed the coded data. Once all the text segments had been given basic
42
43 codes, the codes were categorized into basic themes by placing similar codes together.
44
45 No additional themes emerged from this process. Themes were then discussed with
46
47
48 the clinical team members (LC and TN).
49
50
51
52
53
54
55
56
57
58
59
60

RESULTS

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. The average time between discovery of breast changes and cancer diagnosis was 256 days; with an average of 164 days between discovery of changes and presentation to the first health care provider i.e. the appraisal and help-seeking interval, and 92 days between assessment by the first health provider and diagnosis at the tertiary hospital breast clinic i.e. the diagnostic interval.

Breast cancer knowledge and perception of risk

Many women reported no prior knowledge about breast cancer. As one participant reported:

“No, not at all so when I did find the lump which apparently I have been complaining about two years ago it was difficult for me because I had no knowledge about breast cancer” (ID10)

A few had received information from: pamphlets distributed at health facilities; television and radio campaigns; health care professionals and from friends or relatives who had been diagnosed with breast cancer. Information received related to breast cancer symptoms and to a lesser extent breast self-examination. However, most were

1
2
3 only able to vaguely report on the information received and generally felt it to be
4
5 insufficient.

6
7 *“I did have knowledge [about breast cancer] but not the full content”* (ID06)

8
9
10 *“..not really, you read the pamphlets and you actually don’t understand it.”* (ID01)

11
12
13
14
15 Many women did not perceive themselves as being at risk of breast cancer.

16
17 *“No, it [breast cancer] didn’t worry me...It was almost like it [breast cancer] won’t*
18
19 *happen to me that kind of attitude that I had.”* (ID11)

20
21
22
23
24 Some women had experience of family members having breast cancer, but this did not
25
26 lead to a perception of increased risk, not did it prompt women to seek early care.

27
28 *“My other cousin had breast cancer...she ended up dying in 2011...I have seen the*
29
30 *pamphlets and adverts from the television about breast cancer but I was not that*
31
32 *interested and did not pay much attention ... I have never examined myself...I really*
33
34 *do not know anything about cancer.”* (ID13)

35 36 37 38 39 40 **Discovery and initial appraisal of body changes**

41
42 For all women, a lump was the first body change noticed. Some reported accidental
43
44 discovery of a breast lump, either by themselves or a partner. Others had breast
45
46 changes detected as part of a clinician visit for an unrelated problem e.g. *“I was at a*
47
48 *neurologist just for my head...she checked my breasts”* (ID11)

1
2
3 A few women were aware of the practice of breast self-examination, either from being
4 informed by a health professional or through watching television. Some had
5 discovered their lump during a breast self-examination.
6
7

8
9
10 *“They also teach us when we sit there and waiting for the family planning clinic: how*
11 *to examine your breast clockwise and that and how to keep your hands on your breast*
12 *and when is the best time to do it and so on. Because of the knowledge that’s why I*
13 *examined myself I felt inconsistency on this one (pointing at right breast) that was not*
14 *here and so I went to the private doctor.” (ID 12)*
15
16

17
18
19
20
21 *“I first noticed while self examining my breasts because I heard from the television*
22 *that one of the symptoms of cancer is a lump and how to check your breasts.” (ID17)*
23
24

25
26
27
28 However, a few women found the discussion on breast self-examination awkward,
29 and reported feeling uncomfortable palpating their own breasts. As one participant
30 remarked:
31
32

33
34
35 *“I don’t think it is right to feel your breasts.” (ID14)*
36
37

38
39
40 Prior experience of breast conditions caused some women to interpret their symptoms
41 as being benign.
42

43
44 *“Another thing that made me not pay attention was because I am used to have*
45 *abscesses in my breasts but then they would heal and disappear but this one didn’t go*
46 *away and my breast started getting darker and I decided to go to the clinic.” (ID17)*
47
48

49
50
51 *“It is 6cm at the moment, so I didn’t take note of it because... reason being when I*
52 *was in high school I also found lumps in my breast and it was breast mice*
53 *[fibroadenoma], so automatically I thought it’s that again, so it’s nothing to worry*
54 *about.” (ID10)*
55
56
57
58
59
60

1
2
3 For many, the lack of accompanying symptoms such as pain or skin changes led to a
4
5 misinterpretation of the initial symptom, false sense of reassurance and delay in
6
7 seeking medical care.
8

9
10 *“I didn’t pay attention to the lump because it wasn’t painful when it started*
11
12 *showing.”* (ID16)
13

14
15 *“I stood in the mirror and looked and I was like it’s okay for one of your breasts to*
16
17 *be bigger than the other and that’s normal and I didn’t see the redness or any signs*
18
19 *that one looks for and then I thought it was not breast cancer because there weren’t*
20
21 *any of those signs of breast cancer.”* (ID10)
22
23

24
25
26 Most women reported being in good health and therefore were less likely to be
27
28 concerned about symptoms. Other had noticed general symptoms such as loss of
29
30 appetite and weight but attributed this to ageing.
31

32
33 *“I really do not feel sick at all.”* (ID08)
34

35
36 *“..... but we thought with age comes losing weight and eating less.”* (ID09)
37
38

39
40 Women reported being fearful upon discovery of initial breast changes. This caused
41
42 some to deny or rationalize the seriousness of the symptoms, or hope that it would go
43
44 away.
45

46
47 *“I felt like you know what, whatever..... I am not going still bother about going. I*
48
49 *think I was a little bit scared because I would rather not know, than know what it is.*
50
51 *So if it’s just painful and not affecting my health and I am not getting sick then it must*
52
53 *be okay.”* (ID10)
54
55
56
57
58
59
60

Triggers to seeking care

A few women sought medical care immediately on discovery of the initial symptom. Most women however, monitored their initial symptoms and either persistence of symptoms, an increase in size of the lump or experience of additional symptoms such as pain or skin changes were triggers to seek medical care.

“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)

Disclosure to family members influenced some participants to seek medical care.

“Because she [mother] nagged me I came.” (ID01)

“In February or March the lump started growing bigger and I told my husband and he took me to the doctor.” (ID06)

Access to health care

Most women attended public healthcare facilities for financial reasons including low transport costs as facilities were located close to their homes and the benefit of free public sector services. Women who sought care through the private sector did so because of convenience, in terms of speed at which they are seen and longer opening times; as well as perceived better care and safety.

“Because you don’t have to queue when you visit them (private practitioner). At the clinic you have to wake up early and you might not even be seen by a doctor.” (ID13)

“[at public hospital there is] a problem of gangsters.” (ID11)

1
2
3 Some believed that there was little difference between private and public doctor
4 services. The few women who reported seeking care from a traditional healer did so
5 in conjunction with receiving care from mainstream physicians, often after being
6 influenced by others or if they did not perceive their symptoms improving.
7
8 Participants who sought care from a traditional healer did so when they were visiting
9 relatives in more rural areas in the Eastern Cape Province.
10
11
12
13
14
15
16
17

18
19 Once women sought help for the breast symptoms, many were quickly referred for
20 appropriate assessment and management to a secondary or tertiary level health
21 service. However, a few felt they had been misdiagnosed (in both private and public
22 health facilities) and that this delayed final diagnosis and treatment.
23
24
25
26

27
28 *“I examined myself and I felt a small like a pea size lump here in my breast. So I went
29 to the doctor and he told me that it was a gland and that`s all...As time went on... I
30 started to find that it was growing and it was growing great, so I went to the doctor
31 again, the same surgery and there was the other doctor there a lady doctor... so she
32 sent me to the Day Hospital.” (ID12)*
33
34
35
36
37
38

39
40 *“It was last year and she was misdiagnosed by the doctor. She went to a doctor
41 because she felt something small in her breast and then the doctor said she might
42 have picked up something heavy. She was given pain tablets.” (ID06)*
43
44
45
46
47

48 **Competing priorities**

49
50 There was some evidence that women delayed in seeking care due to work
51 commitments. However for one participant disclosure to a work manager resulted in
52 influence to promptly seek care.
53
54
55
56
57
58
59
60

Community views and support mechanisms

Many women mentioned that cancer and breast cancer in particular was not something that was generally discussed in the community, moreover general knowledge about breast cancer seemed to be limited in the community.

“I don’t want to lie, I have never heard people talking about it [breast cancer]... It [breast cancer] is something that’s not talked about...” (ID13)

“People do not really talk about it [breast cancer]. My friends never talk about it [breast cancer].” (ID10)

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)

Most women chose to tell both their immediate family and close friends of their diagnosis and appeared to have adequate support structures in place. Participants reported that family members were an important source of emotional and practical support.

DISCUSSION

Understanding pathways to cancer diagnosis is vital to the development of effective interventions to promote timely diagnosis.[19-21] To our knowledge 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. Similar to other

1
2
3 studies, an important component of delayed presentation in our study was the long
4 appraisal and help-seeking interval.[9, 14, 16, 17, 22, 23] The first event in this
5 interval, the detection of bodily changes requires women to be aware of normal body
6 morphology, have knowledge of and feel comfortable with breast self-examination,
7 and have confidence in the ability to detect changes. Many women in our study lacked
8 such knowledge and confidence. Further research that explores why women felt
9 discomfort in touching their breasts is required as this is key to changing health
10 behavior. Women reported anxiety on discovery of breast changes and as reported
11 elsewhere this resulted in conflicting outcomes causing some to deny the seriousness
12 of bodily changes and dismiss it as normal and others to seek care promptly.[24] Our
13 study points to a clear need for targeted interventions to increase women's ability and
14 confidence to detect breast changes. Interventions will need to take into account
15 possible discomfort with touching oneself, reported both in our and other studies,[16,
16 25, 26] and the fear of self-detection of breast cancer.[25, 27, 28]

17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36 Women with low breast cancer awareness are more likely to delay in presenting to a
37 health care provider.[13, 16, 17, 29, 30] In our study a major deficit in knowledge of
38 the symptoms of breast cancer delayed women's interpretation of body changes as
39 being abnormal. Although the initial change reported by all women was a breast
40 lump, many did not perceive it as abnormal until additional symptoms, such as pain
41 and skin changes, were experienced. Pain associated with breast lumps has been
42 shown to influence women's help seeking behavior in different ways.[14, 16, 17, 23,
43 24] For some women, as in our study, the absence of pain results in a
44 misinterpretation of the lump as benign and can contribute to delays in seeking care,
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 whilst others have reported that some women regard absence of pain as sinister and is
4 a trigger for action.
5
6
7
8

9
10 The Common Sense Model of Illness Self-regulation suggests that for bodily changes
11 to be perceived as a symptom i.e. as abnormal, the changes need to exceed an
12 inference threshold, resulting in a more complete appraisal of the symptom.[31]
13 Bodily changes below the threshold are normalized. In our study both a sense of
14 overall good health and attribution of more general symptoms such as loss of weight
15 to ageing resulted in women being complacent about bodily changes and delayed help
16 seeking. Women with a past history of benign breast disease exhibited an optimistic
17 bias[19] in interpreting symptoms, and for some this was reinforced by downplaying
18 of symptoms by health care providers.
19
20
21
22
23
24
25
26
27
28
29

30
31 A family history of cancer not only influences beliefs about cancer curability but can
32 also have opposing effects on perceived risk of breast cancer.[23] Despite having a
33 family history of breast cancer, many of our participants did not perceive themselves
34 at increased risk, not did influence the interpretation of a breast lump as abnormal.
35
36
37
38
39
40

41
42 Most women reported a period of monitoring of symptoms before deciding to seek
43 care. Decisions to seek care were sometimes not acted upon immediately because of
44 contextual factors such as work priorities and relocation. The tendency for women to
45 put other priorities ahead of their own health has been reported.[32-34] Limited
46 research is available on how job conditions may impact on health seeking behavior
47 among women with cancer symptoms.[35] Employers could play an important role in
48 helping women manage work-health seeking conflicts. For at least one participant in
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 our study, disclosure to a manager was an important trigger to seeking care,
4
5 suggesting that occupational settings could serve as an important site for education on
6
7 breast cancer symptoms, further increasing the likelihood of early presentation of
8
9 breast cancer.
10

11
12
13
14 Our study confirms the findings of others on the important role that family and
15
16 community members play in encouraging timely presentation as well as sanctioning
17
18 ill health.[19, 32] Disclosure to family members was an important trigger to seek
19
20 health care. Further, where detection of breast changes was made by others, usually
21
22 by a close family member, women had prompt entry to health services. In contrast to
23
24 other studies[13, 16] women did not report being fearful of isolation or abandonment
25
26 in disclosing symptoms to husbands and other close family members. Most
27
28 participants reported family members had offered emotional and social support for
29
30 future planned breast cancer treatment. Our findings show that limited discussions on
31
32 cancer, including breast cancer, occur at a community level. Further when discussions
33
34 take place they tend to center on cancer as a terminal disease. Community views on
35
36 the poor prognosis of cancer, could have resulted in initial denial of a possible cancer
37
38 diagnosis, causing some to only seek help when symptoms worsened. Findings
39
40 highlight the importance of breast cancer awareness campaigns expanding the target
41
42 audience from women to all members in the community and including messages on
43
44 the improved prognosis associated with an early diagnosis.
45
46
47
48
49
50

51
52 The type of primary level care services (public clinics or private general practitioners)
53
54 women accessed for initial appraisal of their symptoms was influenced by perceptions
55
56 of care each provided, finances, structural factors such as long queues, and personal
57
58
59
60

1
2
3 safety in terms of the physical location of services. It was difficult to ascertain
4 whether these factors led to a delay in entry to health care, however, other studies
5 have shown that such factors can hinder timely medical care.[24, 30, 36] There were
6 some reports of possible initial misdiagnosis by public and private sector
7 practitioners, causing a delay in diagnosis. Further research to explore the need for
8 provider training in assessment of symptoms suggestive of breast cancer is required.
9 In our study women reported limited use of traditional healers, however such
10 practitioners could play a larger role in entry into health care in rural communities.
11
12
13
14
15
16
17
18
19
20

21
22 Our study was conducted at one clinic in the Western Cape Province which limits
23 generalizability. However it does provide a more in-depth and nuanced understanding
24 of women's knowledge, experiences and factors influencing action; a strength of
25 qualitative research. Further quantitative studies are required to confirm findings.
26 Although retrospective recall could have affected accurate reporting of symptoms and
27 health seeking behavior, conducting interviews within one week of diagnosis and
28 using a calendar prompt is likely to have minimized recall bias. However, conducting
29 the interviews within one week of diagnosis could also have meant that some
30 participants were not emotionally prepared to put their story into perspective. A
31 limitation of the study is that it only includes women that have accessed health care.
32 Awareness of breast changes and factors influencing symptom interpretation and
33 management among women that have not accessed care needs to be explored.
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50

51 CONCLUSION

52 Symptom appraisal and interpretation contributed significantly to delayed
53 presentation. To improve timely diagnosis of breast cancer, interventions that increase
54
55
56
57
58
59
60

women's confidence in detecting breast changes, improve knowledge of breast cancer symptoms among women and the general community, address notions that lead to misinterpretation of symptoms and encourage prompt help-seeking behavior are required.

AUTHOR CONTRIBUTIONS

JM initiated the study and developed the study protocol. LC and TN reviewed the protocol and provided clinical oversight throughout the project. MM and JM read through the transcripts and developed initial coding categories. MM coded, and MM and JM analyzed the data. JM prepared the first draft, incorporated revisions and prepared the final draft. All authors reviewed drafts and approved the manuscript.

FUNDING STATEMENT

This research was funded by the Cancer Association of South Africa (CANSA) and the University of Cape Town, Faculty of Health Sciences.

COMPETING INTEREST

The authors declare that they have no competing interests.

ACKNOWLEDGEMENTS

We thank the patients for sharing their journey to cancer diagnosis, the staff at the Breast Cancer Clinic for their support, Rosemary Jacobs for assistance in data collection and Vedantha Singh for assistance in preparation of the article.

DATA SHARING STATEMENT

No unpublished data available.

REFERENCES

1. Ferlay J, Soerjomataram I, Ervik M, et al. Globocan 2012, Cancer incidence and mortality worldwide. International Agency for Research on Cancer. 2013
<http://globocan.iarc.fr>.(accessed 28 June 2015).
2. Torre LA, Bray F, Siegel RL, et al. Global cancer statistics, 2012. *CA: A Cancer Journal for Clinicians* 2015;65(2):87-108.
3. National Cancer Registry. Cancer in South Africa 2009 Full Report. 2015.
www.nioh.ac.za.(accessed 28 June 2015).
4. Bradshaw D, Schneider M, Norman R, et al. Mortality patterns of chronic diseases of lifestyle in South Africa. In: Steyn K, Fourie J, Temple N, eds. *Chronic Diseases of Lifestyle in South Africa: 1995 - 2005*. Cape Town: South African Medical Research Council 2006:127-50.
5. Coovadia H, Jewkes R, Barron P, et al. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet* 2009;374(9692):817-34.

- 1
2
3 6. Vorobiof DA, Sitas F, Vorobiof G. Breast cancer incidence in South Africa. *J Clin*
4
5 *Oncol* 2001;9(18 Suppl):125S-7S.
6
7
- 8
9 7. Elgaili EM, Abuidris DO, Rahman M, et al. Breast cancer burden in central Sudan.
10
11 *Int J Womens Health* 2010;2:77-82.
12
- 13
14 8. Dickens C, Joffe M, Jacobson J, et al. Stage at breast cancer diagnosis and distance
15
16 from diagnostic hospital in a periurban setting: A South African public hospital case
17
18 series of over 1,000 women. *Int J Cancer* 2014;135(9):2173-82.
19
- 20
21 9. Burgess CC, Ramirez AJ, Richards MA, et al. Who and what influences delayed
22
23 presentation in breast cancer. *Br J Cancer* 1998;77(8):1343-8.
24
25
- 26
27 10. Nosarti C, Crayford T, Roberts JV, et al. Delay in presentation of symptomatic
28
29 referrals to a breast clinic: patient and system factors. *Br J Cancer* 2000;82(3):742-8.
30
31
- 32
33 11. Rauscher GH, Ferrans CE, Kaiser K, et al. Misconceptions about breast lumps and
34
35 delayed medical presentation in urban breast cancer patients. *Cancer Epidemiol*
36
37 *Biomarkers Prev* 2010;19(3):640-7.
38
39
- 40
41 12. Simon AE, Waller J, Robb K, et al. Patient delay in presentation of possible
42
43 cancer symptoms: the contribution of knowledge and attitudes in a population sample
44
45 from the United Kingdom. *Cancer Epidemiol Biomarkers Prev* 2010;19(9):2272-7.
46
47
- 48
49 13. Norsa'adah B, Rampal KG, Rahmah MA, et al. Diagnosis delay of breast cancer
50
51 and its associated factors in Malaysian women. *BMC Cancer* 2011;11:141-7
52
- 53
54 14. Dye TD, Bogale S, Hobden C, et al. Experience of initial symptoms of breast
55
56 cancer and triggers for action in Ethiopia. *Int J Breast Cancer* 2012; 908547.
57
58
59
60

- 1
2
3 15. Forbes L, Warburton F, Richards M, et al. Risk factors for delay in symptomatic
4 presentation: a survey of cancer patients. *Br J Cancer* 2014;111(3):581-8.
5
6
7
8
9 16. Jones CE, Maben J, Jack RH, et al. A systematic review of barriers to early
10 presentation and diagnosis with breast cancer among black women. *BMJ Open*
11 2014;4(2):e004076,2013-004076.
12
13
14
15 17. Jones CE, Maben J, Lucas G, et al. Barriers to early diagnosis of symptomatic
16 breast cancer: a qualitative study of black African, black Caribbean and white British
17 women living in the UK. *BMJ Open* 2015;5(3):e006944,2014-006944.
18
19
20
21
22 18. Scott S, Walter F. Studying help-seeking for symptoms: the challenges of methods
23 and models. *Soc Personal Psychol Compass* 2010;4(8):531-47.
24
25
26
27
28
29 19. Scott S, Walter F, Webster A, Sutton S, Emery J. The model of pathways to
30 treatment: conceptualization and integration with existing theory. *Brit J Health*
31 *Psychol* 2013;18(1):45-65.
32
33
34
35
36
37 20. Andersen RS, Vedsted P, Olesen F, et al. Patient delay in cancer studies: a
38 discussion of methods and measures. *BMC Health Serv Res* 2009;9:189-93.
39
40
41
42
43 21. Walter F, Webster A, Scott S, et al. The Andersen Model of Total Patient Delay: a
44 systematic review of its application in cancer diagnosis. *J Health Serv Res Policy*
45 2012; 17(2):110-8.
46
47
48
49
50 22. de Nooijer J, Lechner L, de Vries H. A qualitative study on detecting cancer
51 symptoms and seeking medical help; an application of Andersen's model of total
52 patient delay. *Patient Educ Couns* 2001;42(2):145-57.
53
54
55
56
57
58
59
60

- 1
2
3 23. Khakbazan Z, Taghipour A, Roudsari RL, et al. Help seeking behavior of women
4 with self-discovered breast cancer symptoms: A meta-ethnographic synthesis of
5 patient delay. *PloS One* 2014;9(12):e110262.
6
7
8
9
10
11 24. Unger-Saldaña K, Infante-Castañeda CB. Breast cancer delay: a grounded model
12 of help-seeking behaviour. *Soc Sci Med* 2011;72(7):1096-104.
13
14
15
16 25. Naghibi SA, Shojaizadeh D, Montazeri A, et al. Sociocultural Factors Associated
17 with Breast Self-Examination among Iranian Women. *Acta Med Iran* 2015;53(1):62-
18 8.
19
20
21
22
23
24 26. Yang RJ, Huang LH, Hsieh YS, et al. Motivations and reasons for women
25 attending a breast self-examination training program: A qualitative study. *BMC*
26 *Womens Health* 2010; Jul 10;10:23,6874-85.
27
28
29
30
31
32 27. Consedine NS, Magai C, Krivoshekova YS, et al. Fear, anxiety, worry, and breast
33 cancer screening behavior: a critical review. *Cancer Epidemiol Biomarkers Prev*
34 2004;13(4):501-10.
35
36
37
38
39
40 28. Al-Naggar RA, Al-Naggar DH, Bobryshev YV, et al. Practice and barriers toward
41 breast self-examination among young Malaysian women. *Asian Pac J Cancer Prev*
42 2011;12(5):1173-8.
43
44
45
46
47
48 29. Ramirez A, Westcombe A, Burgess C, et al. Factors predicting delayed
49 presentation of symptomatic breast cancer: a systematic review. *The Lancet*
50 1999;353(9159):1127-31.
51
52
53
54
55
56 30. Taib NA, Yip C, Low W. Recognising symptoms of breast Cancer as a reason for
57 delayed presentation in Asian women-The Psycho-socio-cultural Model for breast
58
59
60

1
2
3 symptom appraisal: opportunities for intervention. *Asian Pac J Cancer Prev*
4
5 2011;12(6):1601-8.
6
7

8
9 31. Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-
10 regulation of health and illness. In: Cameron LD, Leventhal H, eds. The self-
11 regulation of health and illness behaviour. New York: Routledge 2003:41–65.
12
13

14
15 32. Burgess C, Hunter MS, Ramirez AJ. A qualitative study of delay among women
16 reporting symptoms of breast cancer. *Br J Gen Pract* 2001;51(473):967-71.
17
18

19
20 33. Majaj L, Nassar M, De Allegri M. "It's not easy to acknowledge that I'm ill": a
21 qualitative investigation into the health seeking behavior of rural Palestinian women.
22
23 *BMC Womens Health* 2013; 13:26.
24
25
26
27

28
29 34. Taha H, Al-Qutob R, Nystrom L, et al. "Voices of fear and safety" women's
30 ambivalence towards breast cancer and breast health: a qualitative study from Jordan.
31
32 *BMC Womens Health* 2012; 12:21,6874-78.
33
34
35

36
37 35. Vanderpool RC, Swanberg JE, Chambers MD. A narrative review of the
38 confluence of breast cancer and low-wage employment and its impact on receipt of
39 guideline-recommended treatment. *Glob Adv Health Med.* 2013;2(5):75-85.
40
41
42
43

44
45 36. Lam WW, Tsuchiya M, Chan M, et al. Help-seeking patterns in Chinese women
46 with symptoms of breast disease: a qualitative study. *J Public Health (Oxf)*
47
48 2009;(1):59-68.
49
50
51
52
53
54
55
56
57
58
59
60

Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study
 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Interviews were conducted by Rosemary Jacobs. She did not contribute to writing the paper, but is mentioned in the acknowledgements section. (page 19)
2.	Credentials	Diploma Midwifery, Diploma General Nursing, B.A, Hons. Business Management and Administration, Certificate in Project Management
3.	Occupation	Employed at the School of Public Health and Family Medicine, University of Cape Town as a researcher
4.	Gender	Female (page 6)
5.	Experience and training	The researcher is a nurse who has several years of experience in conducting in-depth interviews and focus groups.
Relationship with participants		
6.	Relationship established	No relationship was established prior to study commencement.
7.	Participant knowledge of the interviewer	Participants were provided with the following information as part of the consent process "Let me introduce myself, my name is..... I work at the University of Cape Town's Women's Health Research Unit. I am talking to women who have been newly diagnosed with breast cancer to find out more about their symptoms and challenges and experiences in getting to the Breast Clinic. It is important for us to understand what issues are important to you"
8.	Interviewer characteristics	The following characteristics were reported: trained qualitative interviewer, research nurse, Xhosa-speaking (pages 6 and 7).

No	Item	Guide questions/description
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	A thematic analysis was employed underpinned by the theoretical concepts of the Model of Pathways to Treatment framework. (page 7)
Participant selection		
10.	Sampling	Newly diagnosed breast cancer patients were purposively selected between May and July 2014 from the Breast Clinic. All participants were interviewed within one week of being diagnosed with breast cancer. (page 6)
11.	Method of approach	Newly diagnosed patients at the Breast Clinic were approached face-to face by the interviewer to take part in the research. (page 6)
12.	Sample size	Total sample size N=20. (pages 7 and 8)
13.	Non-participation	One participant declined to be interviewed and another was ineligible as she had been previously diagnosed with breast cancer. (page 8)
Setting		
14.	Setting of data collection	Interviews were conducted in a private room at the Breast Clinic. (page 7)
15.	Presence of non-participants	In some instances a family member (e.g husband or daughter) accompanied the participant and with the consent of the participant, were present for the duration of the interview. (page 7)
16.	Description of sample	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 1 was widowed. All but one participant had a high school or higher education. Five participants were

No	Item	Guide questions/description
		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. (page 8)
Data collection		
17.	Interview guide	A semi-structured interview guide was developed with questions, prompts and guides to explore the following themes: personal 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; use of various levels of care (including alternative care); and commonly held community beliefs. The interview guide was pilot tested on 2 newly diagnosed breast cancer clients. Minor revisions to the wording of questions and probes were made. (page 6)
18.	Repeat interviews	No repeat interviews were conducted.
19.	Audio/visual recording	Data was recorded using audio recorder. (page 7)
20.	Field notes	Field notes were made during and after the interviews. (page 7)
21.	Duration	Interviews lasted 45 to 60. (page 7)
22.	Data saturation	Interviews were transcribed immediately and reviewed by JM, data collection stopped once no new themes were emerging and data saturation had been reached.(page 7)
23.	Transcripts returned	Transcripts were not returned to participants for comment.
Domain 3: analysis and findings		
Data analysis		
24.	Number of data	MM coded the data, JM reviewed codes (page 7)

No	Item	Guide questions/description
	coders	
25.	Description of the coding tree	A coding tree was not developed. Themes were mapped to the Model of Pathways to Treatment framework.
26.	Derivation of themes	Initial themes were derived from the interview guide and were informed by the Model of Pathways to Treatment framework, which included the following: personal 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; use of various levels of care (including alternative care); and commonly held community beliefs. No additional themes emerged from data analysis. (page 7)
27.	Software	QRS Nvivo 10 was used to manage data analysis. (pages 6 and 7)
28.	Participant checking	Participants did not provide feedback on the findings.
Reporting		
29.	Quotations presented	Selected participant quotations were chosen to illustrate both themes and findings. Each quotation was identified using unique participant ID. (pages 8-14)
30.	Data and findings consistent	Data presented was consistent with study findings. (pages 8-14)
31.	Clarity of major themes	All major themes were clearly presented and discussed in the findings. (pages 8-14)
32.	Clarity of minor themes	Minor themes are reported under the major themes. (pages 8-14)