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Title: Exploring breast cancer diagnosis and treatment experience amongst a sample of South African women who access primary healthcare

Abstract

Despite the known impact of a cancer diagnosis and related treatments on quality of life, and the complexity of patient journeys in low-resource settings, there has been little published research into the relevant issues faced by South African women living with breast cancer. In this study, we aimed to understand the experiences of breast cancer diagnosis and treatment amongst a sample of South African women who access primary healthcare. A convenience sample of 12 women between the ages of 48 and 66 years attending a primary healthcare facility, took part in our study. Women undergoing breast cancer treatment were invited to take part in face-to-face interviews. The interviews were semi-structured and guided by an interview schedule. Interviews were analysed thematically using ATLAS.ti v 8 computer software. We identified three important themes that explained how women experience diagnosis and treatment namely; 1) reactions to the diagnosis experience, 2) the importance of faith and the value in having a 3) sense of agency. Women's initial reaction to their cancer diagnosis was one of shock and disbelief. Despite these reactions,

faith and agency played an important role in how women in this study made sense of their illness experience and how they coped. Our findings demonstrate that women's experiences of breast cancer diagnosis and treatment were accompanied by some psychological distress for which they need support. Further, supporting women to make positive choices about coping and valuing the role of religion when appropriate, should form part of any therapeutic engagement, medical or otherwise.

Keywords: Breast cancer, diagnosis, treatment, qualitative, South Africa

With more than 1.7 million new cases per year, breast cancer is the most commonly diagnosed cancer in women and the leading cause of cancer related deaths worldwide (Ferlay et al., 2015; Torre et al., 2015) with the majority of cases found in developing countries (Al-Azri, Al-Awisi, & Al-Moundhri, 2009). In South Africa, breast cancer is estimated to account for 16% of deaths in adult women (Moodley, Cairncross, Naiker, & Momberg, 2016). The South African National Cancer Registry (SANAC) estimates a 1 in 27 lifetime risk of developing breast cancer among women in the country (South African National Cancer Registry [SANAC], 2012). Early detection of breast cancer results in a survival rate of $\geq 80\%$, however limited screening, and poor access to treatment facilities contributes to delayed diagnosis (Vorobiof, Sitas, & Vorobiof, 2001).

In the last decade, due to the major health burden of and steadily increasing rates of cancer in the South African (SA) population, SA healthcare services have evolved to offer a more integrated, and comprehensive healthcare system (Moodley et al., 2016). For example, gold standard adjuvant systemic therapy including chemotherapy and radiation are available for the treatment of breast cancer (often combined with partial/full mastectomy or lumpectomy).

Despite these advances in the diagnosis and treatment of breast cancer globally and in South Africa, studies show that women's experiences of a

diagnosis of breast cancer and treatment is characterised by numerous physical, emotional and psychological challenges (Smit, Coetzee, Roomaney, Bradshaw, & Swartz, 2019). Physically, the associated side effects such as vomiting, fatigue and pain, significantly affect the quality of life of individuals undergoing treatment (Liu et al., 2013; Mollica, Nemeth, Newman, & Mueller, 2015). Emotionally, a diagnosis of breast cancer has been met with shock and disbelief as well as a fear of dying (Sprung, Janotha, & Steckel, 2011), causing heightened levels of psychological distress (Liamputtong & Suwankhong, 2015).

In a review by Al-Azri et al. (2009), exploring coping responses to breast cancer, the authors identified that paid work, education and financial stability were predictors of more confidence in coping with breast cancer. These findings have significant implications for those in developing countries where such protective factors do not apply to a large proportion of the population (Al-Azri et al., 2009). However, positive engagement with religion or faith was found to be the most commonly reported coping strategy amongst those with breast cancer, consistently associated with a range of improved outcomes. This finding is particularly relevant to the sub-Saharan culture due to the dominant and continuously expanding religious population (Schoeman, 2017). Religion and spirituality (R/S) are frequently cited in the literature as coping strategies, especially when faced with extreme ill health (Gall, Guirguis-Younger,

Charbonneau, & Florack, 2009; Holland et al., 1999; Shaw et al., 2007). Gall et al. (2005) argue that spirituality is multidimensional and involves an individual's beliefs (spiritual person factors), spiritual appraisal and coping behaviours. Indeed, these components, they argue, are all attempts at meaning making and predominantly assist the individual to minimise the initial shock or distress experienced by an event, or diagnosis of cancer in this instance.

The personal impact of financially restrained medical resources on the SA woman's individual cancer journey is unclear. While there has been a surge of interest in pathways to diagnosis, treatment outcomes and epidemiological factors associated with outcome in the economically developing regions of sub-Saharan (Akuoko et al., 2017), there is a notable scarcity in the explorations of women's personal experiences of diagnosis and treatment of breast cancer. The experiences of breast cancer among Western cultures is well-documented (Al-Azri et al., 2009). Fewer qualitative studies are available exploring issues faced by women in resource-limited countries such as South Africa, where access to health care is considered poor (Smit et al., 2019). Available qualitative research has examined the psychosocial impact of breast cancer survivors in the context of cultural and socio-ecological factors (Lam & Fielding, 2003), however this was not extended to include a SA sample (Ashing-Giwa et al., 2004).

The aforementioned socio-economic conditions, cultural determinants such as religiosity, the role of families/community and beliefs about illness and medical treatment are potentially important factors in healthcare engagement for SA women (Yip et al., 2008). Yet, these factors remain neglected in this population. Further, personal and professional culturally and linguistically appropriate support have shown to be valued in healthcare, however more development and refinement in this area is necessary (Yip et al., 2008).

While we may tentatively extrapolate these findings to the SA culture, the untapped richness of ethnically diverse SA, with eleven official languages and a broad spectrum of religious practices, it is imperative that we explore the issues that are deemed important to SA women themselves. Understanding the relevant issues for SA women with breast cancer will have important implications for training, education and future development of services.

In this study, we aimed to explore the relevant issues faced by SA women with breast cancer in a low-resource setting, documenting the patient voice and experience with a view to drawing out common themes and shared experiences. To achieve this aim we asked women to describe what receiving their breast cancer diagnosis was like, and asked them to identify ways in which they coped with their diagnosis.

Method

Participants

The findings presented in this paper form part of a larger qualitative study exploring the experiences of diagnosis, treatment and fatigue amongst women living with breast cancer. In this study, we report on the findings pertaining to women's experiences of their breast cancer diagnosis and treatment and findings pertaining to experiences of fatigue in particular, will be reported elsewhere. We used convenience sampling to recruit women older than 18 years, and undergoing breast cancer treatment (for at least 3 months) at a clinic in the Western Cape. Eligibility for inclusion were that women be proficient in either English or Afrikaans, and have self-reported fatigue. Further, participants must not have previously been diagnosed with Chronic Fatigue Syndrome, or had any prior diagnosis of fatigue that is unrelated to the cancer, fibromyalgia or any pre-morbid diagnosis of depression and anxiety. In order to determine the presence and severity of fatigue, patients who met the other inclusion criteria were asked to complete a study-specific visual analogue scale to indicate their level of fatigue on a scale from 1 (no fatigue) to 10 (extreme fatigue). Those indicating that they considered their fatigue rating to be 7 or higher were invited to participate in the study.

Instruments

Demographic questionnaire. We captured data on age, marital status, employment status, income level as well as first language in order to describe the demographic characteristics of our sample.

Semi-structured interview schedule. We developed a semi-structured interview schedule to guide the interviews. Topics covered in the interview schedule were 1) diagnosis and treatment experience (the focus of this paper), 2) experience of any fatigue and 3) strategies used to manage fatigue.

Procedure

We employed research assistants to assist with recruitment and data collection for this study. Recruitment involved notification of the study (via flyers and posters) at the health care facility, setting up convenient appointment times for interviews, and conducting face-to face interviews with participants in a private room at the clinic.

Potential participants at the breast cancer clinic were handed an information sheet, informing them of the study and inviting them to participate. Interested participants were then asked to complete a contact permission form

in order to schedule interview dates and times. New participants were interviewed until data saturation occurred (Francis et al., 2010).

The interviews were semi-structured and ranged between 28 and 72 minutes, and lasted on average 44 minutes. On completion of the interview participants received a R100 (~6GBP) gift voucher as a token of appreciation, and all travel costs were reimbursed.

Ethical considerations

This study was approved by the Health Research Ethics Committee at Stellenbosch University (N16/04/055) and the Western Cape Department of Health. All participants provided written informed consent prior to participation. Participants were informed that participation was voluntary. Participants were also informed that psychological support services were available.

Data analysis

To ensure quality of the interviewing process by the research assistants, each assistant's first interview was listened to in full by all four authors, following which detailed feedback was delivered in a scheduled meeting. Once all interviews were complete, they were transcribed verbatim and those in Afrikaans were translated into English. Translated transcripts were distributed

amongst the four authors and checked for accuracy. Interviews were analysed using ATLAS.ti v 8. The data were analysed by all of the authors and using procedures consistent with thematic analysis (Braun & Clarke, 2006).

This study was a cross-continent collaboration amongst researchers from the UK and researchers from South Africa. All of the authors had regular contact during the course of the study, and face-to-face contact during the initial analysis phase of the study took. The initial phase of the analysis entailed codebook development. As a first step in codebook development, each of the authors were provided with three copies of the same transcripts. The authors read through and coded these interviews manually using the margin area of the documents. Once initial coding of these transcripts was complete, authors met to discuss the similarities and differences in what was coded, and what code names were used. Establishing consensus amongst coders on the development of the codebook entailed several conversations regarding how the data were being interpreted and which codes provided the best overall description for the different quotations selected. Once the codebook was developed, each of the authors were then allocated an equal number of transcripts to be coded. This coding was completed by each author using ATLAS.ti v8. All of the authors then met to discuss the themes that emerged from the coding. Theme generation involved revisiting the transcripts multiple times and looking for patterns across

cases. We established dependability and credibility by using peer-debriefing during data collection and a structured approach to our analysis (i.e. Thematic Analysis) (Lincoln & Guba, 1985).

Results

Participant characteristics

Participants were 12 women who reported experiencing fatigue since commencing treatment for breast cancer. Women's ages ranged between 48 and 66 years (mean age = 58 years). Most of the participants were married (n=5), three were divorced, two were single and two were widowed. Most of the women were currently unemployed (n=5), while three were retired, three were employed fulltime and one was employed on a part-time basis. In terms of income, most participants (n=7) reported earning between R2500 (~149GBP) and R5000 (~299GBP), three participants reported earnings below 149GBP and two participants earned between R5000 (~300GBP) and R10 000 (~598 GBP) per month. In terms of first language, two spoke English, nine spoke Afrikaans and one spoke isiXhosa (one of the 12 indigenous languages in South Africa and spoken widely in the Western Cape region). At the time of the interviews, time since diagnosis ranged from 4 months to 18 years since first diagnosed,

with 9 participants having received their diagnosis in the past year. Further, all of the women were undergoing treatment at the time of the interview.

Themes

We identified three overarching themes that provided insights into women's experiences of breast cancer diagnosis and treatment. These broad themes covered the 1) reactions to diagnosis experience, 2) importance of the role of faith in helping women make sense of their experiences and 3) role of agency and control in important decisions along the treatment journey. Pseudonyms are used throughout to protect participant identities.

Reactions to diagnosis experience

Women reflected on their diagnosis experience by recounting the first time they noticed a lump or change in one of their breasts. Only two women did not initially discover a lump, but reported to healthcare facilities with complaints of bleeding nipples in one case, and severe back pain in the other. Nearly all of the women sought immediate medical attention following their discovery. One woman, however, reported that she had purposefully delayed seeking treatment in the hopes that the lump would disappear on its own and that she believed, "the Lord will heal me, I believe, I believe."

Women described receipt of their diagnosis as unexpected and initially attributed their symptoms to more benign explanations. For example, June, a 58 year old woman with cancer in her left breast explained:

I felt like, I wasn't actually expecting it. I thought it was just an abscess that was seeping. I thought it was an abscess or something, because I didn't feel any pain or anything.

For June, a malignant tumour of the left breast did not make sense as she had expected a cancerous growth to be accompanied with severe pain. Shock at diagnosis was common and appeared to be an important part of the diagnosis experience, not only for the women in our study but for their family members as well.

While the unexpected nature of the diagnosis was common amongst women in this study, there was some disparity in the way in which women coped with and came to terms with the diagnosis. While many described a sadness, upset and even hopelessness at the point of diagnosis ("*I was crying, sad*" [Evelyn], "*I was very upset*" [Jane]), others reported a distance and dissociation on receipt of the news. For example, Veronica, a 54 year old woman, explained that she adopted a 'positive' response to the diagnosis which she admits was difficult for others to accommodate:

Everyone was so shocked because I, I said I told them with a smile on my face I said because why? I can get healthy. I believe I can get healthy. I'm not going to sit on the corner and say I have cancer, I'm going to die now. It isn't [so] ...I'm too positive about it.

Janice, a 65 year old woman, reported an emotional distance which enabled her to 'normalise' the experience and limit any acknowledgment of the seriousness of the situation:

...and they took my breast off. I had no pain after the breast was removed, I went in chatting and chatting and I came out chatting and chatting. And I wasn't even..., I just stayed in one night.

For Janice, 'chatting' may have been a way of maintaining a positive approach to the situation and limiting the need to demonstrate any concern. Other instances of women's attempts at minimising the seriousness of their illness were evidenced through repeated phrases of, 'I'm fine, now'. For some women the need to 'be fine' and 'ok' was important in reclaiming some of their former independence. Women reported the inconvenience of the practical implications

of the diagnosis and felt cancer to be a real intrusion on their lives. As Elise stated:

I went for a lot of tests and they had to give me some treatment ... I stayed here 5 and a half weeks and then I went home and came back and then I came back, I came for a check-up and then they told me they're going to give me radiation also...

Women also spoke of how this intrusion meant that they had to stop working. The decision to stop working was largely attributed to the number of hospital visits during the diagnosis and treatment phases, and the pain and side effects associated with recovery after a treatment visit. The side effects associated with recovery after a dose of chemo or radiation were described by women as “terrible” (participant 7), and “handicapping” (participant 10). Elise explained:

Yes, the chemo affected me very, very, very much, because it causes a lot of problems, handicapping me doing things and I was very, very sick.

Not being able to work added to some women’s feelings of a loss of former identity and independence, and also forced some to take up residence with close family members as a result of financial instability. The decision to stop

working was particularly salient amongst women who were employed in highly physical, manual jobs which were made difficult due to cancer treatment. As June articulated:

...yes because I should have, the work that we do, it's work that you, how can I explain, everything is, we work with table grapes and we work with peaches, trees, plum trees. And it [her breast] was already sore. And so I went to speak to my boss, and I said I don't think that I can carry on with this work because I might injure myself. And I am already sore.

The role of religion in illness sense-making, coping and acceptance

Nearly all of the women in our study made reference to God and prayer as a way to attribute meaning to or find purpose in and cope with what they were experiencing. While we did not purposefully recruit only Christian women, it is not surprising that women were Christian given the large Christian following in the Western Cape. Further, attributing meaning in this way helped to alleviate uncertainty about the outcome of their health. Jane explained:

My faith is what carries me. As I believe, the Lord has already paid with His blood for our healing. So my healing is there.[...] There are those

who do not have the experience through the word of God which I made it through with... I accept it [the breast cancer], this is why. Do you know why I accept it? I accept that God is taking me back... That's what keeps me going. He made me a new person.

Prayer in particular helped women to cope with steps in the treatment journey. For example, June articulated that prayer allowed her to be calm, and to prepare for her surgery:

You know the morning of the operation I was so calm, because I had asked God for guidance the night before and early that morning. And I was so calm, I felt nothing, nothing, nothing. When they pushed me into the operation ward, I just marvelled at everything.

Prayer also helped women to find motivation to get up and be mobile after painful surgeries as many of the women ascribed their day-to-day strength and energy as something they prayed for. Belinda stated:

The Lord protected me you know, really I pray and I believe in the Lord Jesus Christ and if it wasn't for him that kept me up you know and give me strength you know, I wouldn't be, have been able to get through it all.

Women remarked on the importance of regaining a certain level of functioning after surgery or treatment, which we interpreted as means to return to their identity before the diagnosis. As noted previously, many women were uncomfortable with their perceived loss of independence as a result of debilitating side effects, and disliked having to rely on others. However, similar to others, Elise concluded that perhaps the change she had undergone through her cancer journey was Gods way of showing her that is it OK to rely on others and ask for help:

...because I've never been like that. I was always assisting my family. I was always there for them and [...] I was there I did everything for myself. So I thank God that he gave me those days, those weeks to realize I am only human.

A strong sense of faith also meant that women were able to gain access to emotional support via their links to the church. The support offered and accepted by the church was not only practical, but also emotional and spiritual. In light of this support women reported feeling different and better able to cope with their situation. Gillian reported:

They [people at the church] support me so much, really. They come and fetch me to take me to church. Sometimes they will see that I can't walk so well, then they will bring me, [and] they pray for me so much.

Susan recounted a similar experience of support from member of her church:

Yes if I don't feel good on a Sunday morning, ...and they phone to say are you coming to church and I say "man I don't feel for it this morning" and when I come I see there's a car in front of the door it's a Woman's Action, one of the ladies that come. Interviewer: Oh they come and fetch you I see. Participant: Fetch me yes and then I feel different.

Importance of a sense of agency in the face of illness

As noted previously, an important emotional consequence of the cancer journey was women's perceptions of a loss of identity and their discomfort associated with not being as independent as they were before their diagnosis.

As Susan recounted:

I'm not the same person in my house anymore, I won't stand up and just go wash a load of washing. My mother-in-law does it for me. I won't

move a bed or a cupboard, because I'm a bit scared it might cut my breast, and actually scared about the sickness that will knock me. Do you see?

In many ways, this disruption of normalcy and impact on identity manifested emotionally as well as physically and was particularly evidenced by women's withdrawal from things that previously brought them joy, especially interpersonal interactions with friends and family. As June stated:

There were many times I told my daughter, ah, just to tell people that I'm not in the mood [to visit]. I am not good company today.

Gail too articulated the noticeable impact of this experience on her identity:

...I said to them, "I'm not an invalid, don't treat me like one"[...]. It's not that they want to take everything out of my hands, but the thing is they can see what I'm going through and they don't know me like this.[...] I don't know myself.

Women made several attempts to regain control and a sense of normalcy in their lives again. In our study we understood these attempts as agency. As

such, a sense of agency was understood as women's subjective experiences of a sense of control in their lives in the face of illness. Taking an active role in their recovery and making the decision to undergo treatment was one such example of agency. As Susan stated:

oh Father that was awful, the chemo took me. But I told myself, if I want to live I must do it. And I came in and [I] took my first round.

Similarly Elise reported:

I have to help myself to get better, by God's grace, because I asked Him to make me feel better and give me back my strength, so I have to do something. I get out of bed, walk down to the kitchen, sit at the TV maybe.

A sense of agency or control was also evidenced by seeking appropriate confirmation of diagnosis and subsequent treatment when it was not offered routinely, "...so I said, "No, send me for a mammogram" and she [the doctor] did that...[Gillian]. For some women, a sense of agency or control over their illness was also realised through maintaining a positive attitude towards their diagnosis and treatment.

Discussion

We identified three overarching themes that provided insights into women's experiences of breast cancer diagnosis and treatment; reactions to diagnosis experience, the role of religion in illness sense-making, coping and acceptance and the importance of a sense of agency in the face of illness. Taken together these themes offered important insights into how a group of women with breast cancer in South Africa experienced their diagnosis and treatment, and how they come to terms with their illness.

Women's experience of cancer diagnosis in our study echoed findings from previous qualitative studies in LMIC (Ashing-Giwa et al., 2004; Liamputtong & Suwankhong, 2015; Vilhauer, 2008) where women's narratives of the breast cancer experience typically include shock at diagnosis and even fear, anxiety and hopelessness (Liamputtong & Suwankhong, 2015). In the literature, a diagnosis of cancer has been characterised as a personal 'catastrophe' (Brennan & Moynihan, 2004, p.16), due to the potentially traumatic interruptions to an individual's expected life trajectory. Indeed women experience much emotional debility in the face of a breast cancer diagnosis (Banning, Hassan, Faisal, & Hafeez, 2010). The 'shock' commonly experienced at the point of diagnosis is often underpinned by the anticipated consequences of what a

diagnosis of cancer may mean to that individual. For the women in our study, their initial reactions to their diagnosis prompted varied emotional responses, with some being notably sad and others preferring to avoid or distance themselves from the reality of their diagnosis. Despite the broad spectrum of emotional responses that often accompany a diagnosis (Drageset, Lindstrøm, & Underlid, 2010), there is a universality and unity in how those diagnosed struggle to absorb the enormity of the diagnosis and subsequent treatment of cancer (Brennan & Moynihan, 2004), whether through avoidance or integration. The disparity between these two different emotional coping responses reflects an avoidance vs. openness to the emotional integration of diagnosis (Brennan & Moynihan, 2004). What is interesting is that this separation into those who distance themselves and those who express an emotional response is seen cross-culturally and is a common division in response to a Cancer diagnosis (Drageset et al., 2010).

In our study, religion played an important role in helping women to cope with their diagnosis, make meaning of it and also accept it. Our findings demonstrated that religion helped women to make sense of their illness experience and come to terms with their 'new' identities, in particular coming to terms with relying on others for assistance and not being able to work and

socialise as before. There is extensive literature on the role of religion and spirituality (R/S) in breast cancer in the literature, and it is well documented that these are considered core coping strategies amongst women with breast cancer, and amongst individuals with chronic ill health (Schreiber & Brockopp, 2012). Schreiber and Brockopp (2012) note that there is insufficient evidence available to determine whether coping with the diagnosis differs at different disease phase (diagnosis, pre-treatment, post-treatment and survivorship). However, there is emerging evidence to suggest that religious coping during chemotherapy is predictor of positive affects several months later (Kaliampos & Roussi, 2017).

While Schreiber et al. (2012) were not able to demonstrate meaningful relationships between R/S and well-being, there is much qualitative data, including the findings from this study to indicate R/S is fundamental to coping, adjustment and acceptance of breast cancer diagnosis amongst women, globally (Liamputtong & Suwankhong, 2015; Sabado, Tanjasiri, Alii, & Hanneman, 2010). For example, qualitative work among women with breast cancer in Chile identified religion as an important coping strategy; where women viewed God as their resource for healing and guidance, used prayer as a means to calm down and used religion as a means to gain social support and meaning in their illness (Choumanova, Wanat, Barrett, & Koopman, 2006). Our

findings demonstrate that the impact of religion and faith on South African women's health outcomes cannot be overlooked and warrants further investigation. Other notable links to well-being and improved health outcomes were the emotional support women were able to access through their church groups. These findings are echoed in the literature (Crane, 2009). This study has several limitations. First, while our sample size may be deemed small, we adhered to principles of qualitative research and sampled to saturation. Second, women in our study were predominantly Christian women, and therefore we were not able to ascertain whether religion and spirituality might play as an important role for women from other religious groups or even non-religious women. Thirdly, we only included women who were fluent in English and Afrikaans. While this criterion likely excluded a large portion of the population we deemed this a necessity in order to capture participants' own words and meanings and limit translation error. Finally, despite recruiting as many participants as necessary to ensure data saturation, there is always the likelihood that an additional interview may have found contradictory or additional findings. Consequently, the data presented in this paper cannot be generalised and considered a complete representation of the diagnosis and treatment experience of women living with breast cancer in South Africa.

Conclusion

Our findings provide important insights into the diagnosis and treatment experiences of women with breast cancer in South Africa. Most notably, our findings demonstrated that religion and spirituality play integral roles in patient coping, adjustment and acceptance of the illness and are important protective factors for this sample of South African women. Our findings have clear implications for clinical work. Faith, spirituality and agency presented as crucial components of acceptance and adjustment to breast cancer diagnosis amongst women in our study. Given the importance placed on these dimensions by women in our study, health practitioners are encouraged to incorporate these aspects into patient-centred care.

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