“My experience has been a terrible one, something I could not run away from”: Zambian women’s experiences of advanced breast cancer

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ABSTRACT

Breast cancer is the most common cancer in women worldwide and the second most common cancer in women treated at the Cancer Diseases Hospital in Zambia. Unfortunately most women present with advanced disease, too late to be cured. The purpose of the study was to describe the experiences of Zambian women living with advanced breast cancer. We used a descriptive qualitative design and purposive sampling to select the participants. Ten in-depth interviews were conducted and thematic analyses assessed the data. Data saturation determined the sample size. The average age of the participants was 48.2 years and most (7 of 10) had Stage IV breast cancer. Four themes arose from the data: experiencing the signs and symptoms of breast cancer, learning about the diagnosis and treatment, undergoing the treatment and living with advanced breast cancer. The study has shown that living with advanced breast cancer comprises severe suffering which started before diagnosis with the inability to recognise the signs. In addition, participants experienced various losses such as femininity, physical strength and appearance, roles and support which changed the lives they had lived before becoming ill. They battled through the chemotherapy and feared stigmatisation, yet receiving treatment and care brought hope.

1. Background

Cancer is a highly complex disease that knows no borders, is devastating and adds a tremendous burden on patients and their families (Albrecht, 2006; World Health Organization & International Union Against Cancer, 2005). The International Agency for Research on Cancer and World Health Organization (2014) estimated there were 32.6 million people living with cancer in 2012. In the same year, an estimated 14.1 million people were newly diagnosed with cancer whilst 8.2 million died from this disease. Breast cancer is the second most common cancer in the world (after lung cancer) and the most common cancer in women, with an estimated 1.67 million newly diagnosed in 2012. Slightly more women living in the developing regions of the world are diagnosed with breast cancer than in developed regions. In addition, breast cancer is the most frequent cause of cancer deaths in women living in the less developed world. The International Agency for Research on Cancer and World Health Organization (2014) estimated that in 2012, 100 000 women living in Africa would be newly diagnosed with breast cancer and 42 000 would die from this disease. Unfortunately breast cancer is increasing, especially in developing countries (World Health Organization, 2015). This increased incidence poses a challenge to developing countries due to their low gross domestic product per capita and inadequate health care resources. Not only is health care either unavailable and/or unaffordable to the majority of the population, but technology is outdated (Igene, 2008). According to the World Health Organization (2015) most of the women living in developing countries are diagnosed in the late stages. This is illustrated by the fact that Porter (2009), in studies conducted in sub-Saharan Africa, found up to 90% of women present with Stage III and VI disease, large tumours with a median size of 10 cm and clinical evident lymph node disease. Patients with these late stage tumours cannot be treated successfully – not even in the most optimal setting. According to Porter (2008), the treatment of patients with metastatic breast cancer is already a challenge for the developed world and even a greater one in developing countries.

Breast cancer has no single cause and results from multiple factors including age, personal history of breast cancer, family history of breast cancer, genetic influences, hormonal factors and a history of receiving ionising radiation. The multimodality of the
causes of the disease results in an unpredictable future for individual patients (Payne, 2009). In addition, lack of knowledge and awareness of cancer can furthermore add to the risks as it results in delayed health seeking (Maree & Wright, 2010).

Treating breast cancer is not simple. Treatment is based on multiple individual factors and involves both local and systemic treatment. The goal of local treatments is to eradicate the cancer cells from the breast or axilla and consists of surgery, such as lumpectomy and mastectomy. Radiotherapy can be given to achieve local control or prevent local recurrence. Chemotherapy, which is systemic treatment, is given to destroy the cancer cells throughout the body and can be used as neoadjuvant, adjuvant and palliative treatment. Biological treatment targets and disrupts specific steps in the growth process of cancer. The outcome of breast cancer depends on various factors of which some are unknown. The stage of the disease, histologic type and grade, hormone status, HER-2/neu status, menopausal status and the general health condition of the patient influences the outcome of the disease. Unfortunately the five year survival rate of patients with advanced disease is not favourable, even with appropriate treatment. The survival rate for patients with Stage IV disease is only 7% and for those with Stage III disease 36% (Payne, 2009).

Breast cancer is the second most common cancer in women treated at the Cancer Diseases Hospital in Zambia. In 2007, 93 of the 719 cancer patients treated at this hospital were diagnosed with breast cancer, whilst 205 of the 1204 patients treated in 2008 had breast cancer (Cancer Diseases Hospital, 2008). Most of these patients had advanced disease leading to admission to the University Teaching Hospital. It is not clear why women present with such advanced disease, what they know and understand of breast cancer or what they experience once they have detected an abnormality in their breast, as this phenomenon has not been explored in the Zambian context. In addition, literature from Africa highlighting these problems seems to be limited. The purpose of the study was to explore the experiences of Zambian women living with advanced breast cancer.

2. Materials and methods

2.1. The study

We selected a descriptive qualitative design for this study, as according to Sandelowski (2000), qualitative description enables researchers to present an accurate version of the meanings participants ascribe to specific events. This design was applicable to the study as we wished to present a comprehensive summary of what women living with advanced breast cancer experienced.

The study setting was the Cancer Diseases Hospital and University Teaching Hospital in Lusaka, Zambia. At the Cancer Diseases Hospital, cancer patients receive comprehensive cancer treatment and care on an out-patient basis. External beam radiation, brachytherapy and chemotherapy are available to patients. Patients who are too sick to be treated as outpatients are admitted to the University Teaching Hospital and treated at the Cancer Diseases Hospital which is next to the teaching hospital.

2.2. The participants

The participants were 10 purposively selected patients with breast cancer, admitted to the University Teaching Hospital in Lusaka, Zambia. The ages of the participants ranged from 29 to 66, with an average of 48.2 years. Seven of the participants had Stage IV breast cancer whilst three had Stage IIIB breast cancer. Two participants had no formal schooling, two had some primary education, three went to high school and three completed college education. Half the participants lived in rural areas and most (6 of 10) did not have a personal income. All the participants were treated with surgery, radiotherapy and chemotherapy.

2.3. Data gathering and analyses

After we obtained ethical clearance from the universities and permission from the hospitals, the second author, an oncology nurse, approached women 18 years and older, diagnosed with Stage IIIB and IV breast cancer, who were admitted to the hospital, explained the study to them and invited them to participate. Participation was voluntary and upon accepting the invitation, informed consent was obtained in writing. Interviews were conducted in a private room with only the second author and the participant present and were recorded with their permission. Participants were addressed by their preferred names, which were removed during the transcription of the data to protect their identity and a pseudonym was given to each. No harm was intended, however, due to the sensitive nature of the study emotional discomfort could have been experienced. The services of a counsellor were organised before the interviews to counsel women warranting intervention. In this instance, none of the participants were referred for counselling.

A total of ten in-depth interviews, in English and audio-recorded, were conducted between January and April 2014. Each interview lasted approximately 50 min. An opening question “Please tell what you experience now that you have this disease” was asked. The interviewer used probes and prompting questions to encourage the participants to expand on their experiences. The first interview pre-tested the question, which was well understood by the participant. Data saturation determined the sample size. The interviews were transcribed by the second author verbatim immediately after the interview; an excel spread sheet was used to capture the general information of the participants. The interviewer wrote field notes during and immediately after the interviews and inserted them at relevant points during the transcription of the data. Thematic analysis, the preferred analysis method for descriptive qualitative studies (Sandelowski, 2000), was used to analyse the data. Thematic analysis is a flexible approach which minimally organises data and allows a rich description. In addition this approach enabled us to identify, analyse and report themes within the data. To familiarise ourselves with the data, we read and re-read the transcribed data and wrote initial ideas in the margins. We then coded interesting features across the entire dataset and organised the codes into potential themes. We checked the emerging themes against the dataset and named them. Both the authors analysed the data and we used reflexivity to become self-aware of who we are, our preconceptions resulting from our theoretical knowledge, personal and professional experiences (Malterud, 2001; Pillow, 2003) and how this might affect the study findings.

2.4. Establishing rigour

To enhance the study’s rigour, we applied trustworthiness principles throughout the study. Specifically, we applied Lincoln and Guba’s strategies for trustworthiness explained by Shenton (2004) to promote an authentic reflection of the women’s experiences. Before the study was conducted, credibility was promoted by an early familiarity with the culture of the participating organisation, as the second author practiced as a registered nurse at the Cancer Diseases Hospital prior to and during the gathering of the data. In addition, a research proposal adapting a well-known research method was developed and subjected to peer-review. The research proposal contained an in-depth methodological description allowing for scrutiny of the research results thus
enhancing confirmability. During the recruitment phase, confirmability was enhanced by giving participants the opportunity to decline to participate in the study so that only those willing to offer data freely and honestly could be included. Using probes to elicit detailed data and on the spot member checks improved confirmability during the data gathering phase. Transferability was enhanced by presenting a detailed description of the context, the number of participants, data gathering methods and limitations when writing the research report. Dependability was enhanced by giving a detailed explanation of the research design and implementation of the methods and throughout all the phases of the study an audit trail was kept.

3. Findings

Four themes arose from the data: experiencing the signs and symptoms of breast cancer, learning the diagnoses, undergoing the treatment and living with advanced breast cancer.

3.1. Experiencing the signs and symptoms of breast cancer: “I thought the lump would go away”

In addition to a lump in the breast, participants experienced a variety of breast cancer related signs and symptoms including dimpling of the skin, nipple discharge, changes in the size of the breast and fungating lesions. Not all the participants realised the changes in their breasts could be signs of breast cancer. Sena (43) said: “My cancer started with a yellowish discharge from the nipple then later I noticed my skin on the breast was becoming thick and hard. Initially what I knew was that breast cancer starts with a sore on the breast that does not heal… I never heard of any one with breast cancer…”

Suria (52) explained her experience: “I had lumps on both breasts… at first you know it didn’t bother me, I thought the lump would go away… at some point I even felt some pain in my armpit but I ignored because I thought maybe it was because I changed my roll on…”

It was not only the participants who were unable to link their signs with breast cancer, but health care professionals also failed to recognise the signs and symptoms some participants presented with as those of breast cancer.

Fumina (52) said: “My cancer started with a small pimple on my breast, at first it didn’t bother me… I noticed it was growing in size, becoming darker and painful so I squeezed it… it seems like it was healing and I forgot about it. After a month or so I noticed another pimple on the same spot, this time it was more like an abscess though it was not warm to touch. I decided to go to the hospital where it was squeezed and cleaned nicely, I was even give pain killers and capsules which I was told could prevent the wound for getting infected. I went home and continued to clean every day as I was instructed… to my surprise this wound was not showing any signs of healing so I went back to the hospital for review… I remember the nurse who attended me was so upset with me saying I was not taking care of the wound properly that’s why is wasn’t healing, so the doctor gave me more capsules, some solution to use and some bandages. A month passed without improvement, in fact I developed pain in my armpit and when I try to touch I could feel something hard in the armpit… I had no much knowledge about breast cancer, all I knew was that it was a disease of the breast which does not heal.”

Alice (37) had a similar experience. She explained: “My cancer started with a thickening, dimpling of the skin, and bloody discharge from the nipple. The problem got worse when I was expecting my third child… I was told when I went to the hospital that it was nothing to worry about it was because of the hormones which were stabilising in my body, that is why I was experiencing pain on the breast…”

After becoming aware of the lumps in their breasts, participants managed their situations in various ways. Some consulted friends to guide them on what to do, whilst others used home remedies and traditional medicine in an attempt to rid themselves of the problem. Suria (52) explained: “I asked my friends at church and some told me it was because I stopped having my periods so with time the lump would go away… I wasn’t worried… I agreed with them because the lump was not painful and there were no other signs…”

Banyama (29) applied creams to her breast. She said: “My cancer started with one breast which was growing bigger than the other one, it was painful. There was a big lump and I noticed a bloody discharge from the nipple. I applied some self-prescribed creams on my own but it was only getting worse…”

Erickah (65) used traditional medicines. She explained: “At one point I had tried traditional medicines and they never worked at all, they just made things worse…”

Participants had various signs and symptoms of breast cancer and did not associate the changes in their breasts with breast cancer. Some were also not concerned about the lumps in their breasts as what they experienced did not coincide with what they believed breast cancer was. Health care professionals did also not recognise the breast cancer signs some participants presented with and mismanged the women. Friends were also not helpful and gave wrong advice based on their own limited knowledge.

3.2. Learning about the diagnosis and treatment: “Breast cancer is the end of someone”

The participants described various reactions when they learnt of their diagnoses. Participants experienced “mental torture” which included shock, fear, depression, sadness and disbelief. In addition, participants realised what they believed about breast cancer was not necessarily accurate. Banyama (29) explained: “…I was depressed because from a long time ago I thought breast cancer was for older women, my heart was at pains… I was shocked and lost in my own world, I felt hot in my head and wasn’t thinking properly…”

Suria (52) said: “I was told the lumps were cancerous, after doing some more tests I was told it was in fact stage four… what scared me was the fact that I used to think breast cancer was associated with dying, you know…to me breast cancer was the end of someone… that’s the end…”

Erickah (65) believed breast cancer was a disease for older women and she was not surprised to learn she had breast cancer. She explained: “…what I know of breast cancer is that it is a disease of the elderly women… when I was told in the hospital it was breast cancer and it had attacked my liver a bit I was not surprised… am 65 years old, so I thought just like high blood pressure and sugar disease are diseases of the elder, so it this one…”

Thandi (51) could initially not believe she had breast cancer. She said: “…at first it sounded like a joke when I was told that I have Stage IV breast cancer because apart from the lump, the pain in my shoulder and unexplained weight loss there was nothing else to cause alarm…”

Learning about the treatment was equally traumatic. It was the thought of having to undergo a mastectomy that was most distressing. Lusungu (58) explained: “…the results were showing that the lump was cancer so they had to remove the whole breast… I was so shocked… I had never seen or heard of any one in my village who had their breast removed… everyone in the village think if they remove your breast then you die… I had plans of running away and never to return to the hospital again because I was not feeling sick… I was just OK… I felt no, no, I won’t do the operation…”

One of the participants was of the opinion she was informed in a casual manner about the mastectomy. Another was dissatisfied...
about not being informed about treatment options and not allowing her to decide what would be best for her. Fumina (52) explained: “...sister, [keeps quiet and eyes fill with tears]... I was told so casually as if removing my breast was as simple as cutting someone’s nails... to me it was a big deal... it was so painful (in my) heart...

Suria (52) said: “...I haven’t been offered any option or choice to choose what I would prefer or just to tell me what is available... it would have been nice if we could have been asked what we think about certain options, or which one I would be comfortable with... I was told the only treatment available is to remove the breast, though in the end I ended up with bilateral mastectomy...”

When learning that they have breast cancer some participants blamed themselves for not seeking health care timeously. Suria (52) said: “...I wished I had gone to see a professional the very first time and not ask my lay friends who didn’t know a thing... I should have known better and gone to the hospital in the first place... I’m certain if I had done that I shouldn’t have reached this stage...”

Learning of their diagnoses and the extent of the disease was not easy and experienced as emotional torture. Some blamed themselves for allowing their disease to advance and not seeking health care timeously. Having to undergo a mastectomy added to their emotional distress. In addition, learning of the mastectomy in a casual manner, not being fully informed about treatment options and not being involved in the treatment choices added to their suffering.

3.3. Undergoing the treatment: “I don’t even know how I can express in words what I went through”

Having to live with an altered body as a result of the mastectomy added to the emotional distress the participants experienced. Most were of the opinion that the mastectomy robbed them of being a woman. Banyama (29) explained: “... looking at my past medical history I know now that I was not longer a woman...this was very sad for me...” Fumina (52) added: “...I would never feel like a complete woman even if my husband was late...”

In contrast to the radiotherapy participants received, receiving the chemotherapy was the worst experience for most. Suria (52) said: “...the time I was receiving chemo, my sister, it is like you are in another world... I don’t even know how I can express it in words for you to understand what I went through... your whole life changes, your diet, your routine, including your physical body and mind... sister it is easy to talk about them or to be counselled about them... experiencing them is another thing...”

Dindi (29) explained her experience with the chemotherapy she received: “... when I was receiving chemotherapy... ohhhhh my dear it was something else... my life was really affected... everything changed... I had to stop doing my usual business... I was almost becoming depressed, I couldn’t travel for my business like before... I felt like I was disappointing my family...”

Thandi (51) did not experience the chemotherapy as negatively as the other participants. She said: “...I had minimal side-effects and I had no side effects and I had no serious issues with physical side effects following the chemo...”

Participants experienced various side effects of the chemotherapy including fatigue, nausea and vomiting, oral mucositis, anorexia and alopecia which changed the way they lived their lives. Thandi (51) explained how the side-effects she experienced influenced her life: “...the hair loss is the one thing that bothered me a lot... it was not easy to keep up with my looks, I had to use wigs and makeup my face when I going for work and this made me very uncomfortable and artificial... my eyebrows were all gone... I could not do high heels because I was like tired most of the time. My nails became dark including my palms and heels, so I could not put on sandals even when it was hot...”

Fumina (52) added: “Chemo was bad... I was given some medicines to stop the nausea and vomiting... unfortunately for me it did not work... I could spend most of the time in the toilet vomiting very much... aside from that I become breathless, couldn’t eat enough because of the nausea, abdominal upsets and most of all my bloods could drop... I was getting transfusions many times which I wasn’t so comfortable with but I had no other choice...”

Having to undergo the treatment was a traumatic experience for the participants. The altered body they had to live with as a result of the mastectomy they had to undergo had a negative influence on the way they perceived themselves as women. The radiotherapy they received was well tolerated but the chemotherapy was a negative experience associated with various side effects which added to their suffering. Not having input in their treatment and control over the side effects led to helplessness.

3.4. Living with advanced breast cancer: “My experience has been a terrible one”

Having to live with advanced breast cancer changed the life known to participants. Fulfilling their roles as adult women, mothers and wives were important to them. However, being diagnosed with cancer added the role of the cancer patient, which made it difficult for them to fulfil their other roles. Dindi (29) said: “I told you I am a mother and a wife and to perform those roles including the fact I am now a cancer patient on treatment it’s a bit tricky...”

Sena (43) said: “This has affected me negatively since I could no longer carry out womanly duties. It was strange for me as that is what I am supposed to do as a woman and mother at home... after receiving all the treatments I was somehow restricted in what I could and could not do.”

Some participants were supported by their families and friends whilst others did not receive support. The church played a supportive role in some participants’ lives whilst others preferred not to tell the church members due to their fear of being stigmatized. Suria (52) explained: “My family made things a bit easy for me because they prepared themselves from the word go. They were by my side all the time and helped me to through the ordeal, especially my husband... my husband said he couldn’t imagine the pain and suffering I am going through... he is always there for me and very supportive... aside from him my children are very supportive as well including my friends...”

Lusungu (58) was one of the women who was not privileged to be supported by her family. She said: “... it was very sad for me... I had no other person to help me out apart from the student nurses... in my family we are not so close to each other, I can’t even remember the last time my sisters visited me... and my children, one is a nun, most of the time she is in the convent, my son is working in a place far away and doesn’t visit often, my other daughter is married and is leading her own life now... so you can see now that is would just be me and the church, full stop...”

Dindi (29) preferred not to tell members of the church as she was scared the members would victimise her. She said: “... if I had to tell the church, ahh, you know how people are, they would have made a big deal out of nothing. And other am sure would have even started stigmatizing me and feeling unnecessary pity on me... so to avoid the drama my husband and I decided to keep the illness to ourselves and just tell those who matter...”

Stigma was a real threat to the participants. Alice (37) said: “... other thing I haven’t liked about my cancer is stigma, many people will tend to stigmatise you once they know you have cancer as if it were infectious... many people know that Stage IV is advanced and it is not curable... most patients in this stage die, so you find that most people will get so surprised once they see you, others will even tell you in your face to say you are still alive? It’s such a bad experience as if they want you dead...”
Being hospitalised was a positive experience for some participants. The treatment they received and the care provided by nurses gave them hope. Banyama (29) said: “...I not only have breast cancer, but advanced breast cancer, I have HIV, I have no child, I have fibroids and my husband is dead...I had given up on life and thought I only deserved to die...so my experience has been a terrible one something I could not run away from, however, I am appreciating the care and attention I am receiving here at the hospital...at least now am able to even move out of bed and able to talk compared to the times past when I was very ill and depressed at home. Now I have hope...”

Having to live with advanced breast cancer changed the lives of the women. They were unable to fulfill their roles as adult women, mothers and wives—something that was very important to them. Support varied, some were supported by their families whilst others were not, some received support from the church whilst others preferred not to tell the members as they feared they would be victimised, a fear that many shared. Being admitted to hospital and receiving treatment and nursing care brought hope.

4. Discussion

The study provided evidence that the women lacked knowledge of breast cancer. Despite experiencing the signs they were unable to recognise it as what they experienced did not coincide with what they believed breast cancer was. Some believed the lump was not serious and would go away whilst others applied self-care or used traditional medicine to rid them from their breast cancer signs. Whether acknowledging the seriousness of a lump in the breast could have protected them from developing advanced breast cancer might be unlikely as Maree and Wright (2010), in a study conducted in South Africa, found that despite regarding a lump in the breast as serious, only a small number of women associate it with breast cancer. In addition, various studies conducted on the African continent indicate that women lack knowledge of breast cancer (Oluwatosin & Olatade, 2006; Mukupo & Mubita-Ngoma, 2007; Mataiele & Van den Heever, 2008; Opoku, Benwell, & Yarney, 2012; Sambanje & Mafuvadze, 2012; Maree, Wright, & Lu, 2013; Mbuka-Ongona & Tumbo, 2013).

It was not only the participants who lacked knowledge of breast cancer, but as supported by “I was told...it was nothing to worry about it,” it seemed as if health care professionals also failed to recognise the signs of breast cancer. This is not unique as Akhigbe and Omuemho (2009), when exploring breast cancer knowledge in female nurses, doctors, radiographers, laboratory scientists and pharmacists, in an urban hospital in Nigeria, found a low level of knowledge in the study population. In addition, various studies conducted on the African continent indicate that women lack knowledge of breast cancer (Oluwatosin & Olatade, 2006; Mukupo & Mubita-Ngoma, 2007; Mataiele & Van den Heever, 2008; Opoku, Benwell, & Yarney, 2012; Sambanje & Mafuvadze, 2012; Maree, Wright, & Lu, 2013; Mbuka-Ongona & Tumbo, 2013).

Perreault and Bourbonnais (2005), in an Australian study exploring the psychosocial impact of being newly diagnosed with advanced breast cancer, found approximately one quarter of their participants felt betrayed because of failure to diagnose them. It was interesting to find that not being given treatment options supported by “I haven’t been offered any option or choice” also happens in the developed world (Turner et al., 2005). Clegg-Lamptey, Dakubo, and Attobra (2009), in a study conducted in Ghana, explain this phenomenon in cultural terms by stating that cultural practices where women prefer the doctor to decide what the best treatment would be, make the mistake of not giving women adequate information about the treatment.

As supported by “I should have known better,” some participants blamed themselves for allowing their breast cancer to advance. Self-blame is not new to cancer and according to Friedman et al. (2007), many cancer patients attribute their cancer to a variety of personal factors. Houlind, Jacobsen, and Lowery (1995), in a study investigating the relationship between self-blame and adjustment to breast cancer, found that 30% of the respondents reported some self-blame. In addition, these participants seemed to be less adjusted to their illness. Bennett, Compas, Beckjord, and Glinder (2005) found that behavioural self-blame, as seen in the current study, influences psychological adjustment to breast cancer and is associated with anxiety and depression, not only shortly after diagnosis but even one year later with the stage of the disease the most powerful predictor of depressive symptoms, which in turn can have a negative influence on the daily lives of the patients (Sperry, 2009). Houlind et al. (1995) urge nurses to assess self-blame in patients with breast cancer and discourage its use by means of patient education.

Having to undergo a mastectomy added to the participants suffering. As supported by “I know now that I was not longer a woman,” some participants felt the mastectomy robbed them from being a woman. This finding is supported by Fallbörk, Karlsson, Salander, and Rasmussen (2010) who, in a study conducted in Sweden, found for some women losing a breast meant losing their femininity and losing themselves as a person and Perreault and Bourbonnais (2005) who, in a study conducted in Canada, found that women experienced humiliation and loss of wholeness. Odige et al. (2010), in a study conducted in Nigeria, found most of the women in their study felt inadequate as a woman resulting from difficulty in breast feeding with only one breast, feelings of altered body image and a decrease in affection from their husbands. Whether these factors would also add to Zambian women’s experiences of being inadequate as women after having had a mastectomy is unclear as culture influences have not been investigated.

As supported by “it is easy to talk about them...experiencing them is another thing...” receiving chemotherapy was the worst experience for most of the participants. Participants experienced various side effects which had a negative influence on their activities of daily living. Clegg-Lamptey et al. (2009) found a similar trend and indicate that Ghanaian women found chemotherapy the most unpleasant aspect of breast cancer treatment. In addition, Ghanaian women were not informed about the complications of the chemotherapy which seemed not to be the case in the current study. It was sad to find that some cancer experiences are so bad that nurses are unable to prepare patients for them. Velji and Fitch (2001), in a study investigating women’s experiences of brachytherapy, found a similar trend as the patients in their study were also of the opinion that nothing could prepare them for the treatment.

The many losses participants experienced made living with advanced breast cancer a “terrible” experience. In addition to the loss of a body part and physical energy, which was also found by Perreault and Bourbonnais (2005), participants were unable to fulfil the roles which were so important to them. In addition, some participants lost the support of family, friends and the church due to fear of being stigmatised. A cancer diagnosis brings a desperate need for social support (Peters-Golden, 1982) and support from family and friends plays a major role in coping with the losses of breast cancer (Perreault & Bourbonnais, 2005). Unfortunately others might experience the same desperate need not to provide the support. Stigma, which is a reality in the cancer experience, often plays a significant role in avoidance behaviour and withdrawal of support. Intense fear is a major contributing factor in stigmatisation and cancer not only means death, but a spectacular death as mutilation is not only seen as part of the disease, but also of the treatment. In addition, cancer is seen as contagious and also punishment of some wrong doing (Peters-Golden, 1982). Stigma in cancer in the African context has not been well researched and little is known about this topic. The limited available literature reports a low incidence of stigma (Ohaeri, Campbell, Ilesanmi, & Ohaeri, 1998; Ohaeri, Campbell, Ilesanmi, & Omigbodun, 1999; Lebel & Devins, 2008) which does not seem to coincide with the experiences of the participants in this study.
As supported by “now I have hope,” it was positive to find that being admitted to hospital and being cared for and attended to brought hope to a situation where all seemed lost. Hope is said to be the heart of palliative care and as supported by the current study, can even thrive during terminal illness despite the fact no cure is possible (Chaplin & McIntyre, 2000).

Hope is important to terminally ill patients and a major component of their quality of life (Kylmä, Duggleby, Cooper, & Molander, 2009) psychosocial and psycho-spiritual wellbeing (McClement & Chochinov, 2008). Kylmä et al. (2009), when reviewing the literature on hope, found hope has two components described as “living in hope” and “living with hope” with the focus of hope “hoping for something.” Considering the life experiences of the participant, it might reasonable to conclude that she hoped to be cared for which allowed her to live in hope and with hope.

Lastly, it was interesting to find that despite having metastatic breast cancer, none of the participants raised issues pertaining to dying during the interviews. Although some associated a diagnosis of breast cancer with “dying” and the “end” none spoke about themselves as being in the final stages of their lives. It might have been quite possible that participants used denial to cope with their life situation as according to Vos and de Haes (2007), cancer patients not only deny their diagnosis but also the impact and effect of their disease. Watson, Greer, Blake, and Shappell (1984) found that denial is the most common response used by cancer patients allowing them to reduce a threatening part of reality so that they can function under less emotional stress. However, to conclude that participants denied the graveness of their disease by not mentioning it would not be possible as various factors, such as understanding of the disease and culture and ethnicity, could have prevented them from talking about their own death.

The severe suffering of the women in the current study emphasizes the importance of the prevention and early detection of breast cancer – both only possible when women are empowered with knowledge and self-care skills. Therefore, nurses practicing in Africa should fulfil their educational role and use every teachable moment to teach women about breast cancer. Nurses practicing in Africa should fulfil their educational role and use every teachable moment to teach women about breast cancer – both only possible when women are empowered with knowledge and self-care skills. Therefore, nurses practicing in Africa should fulfil their educational role and use every teachable moment to teach women about breast cancer. Nurses practicing in Africa should fulfil their educational role and use every teachable moment to teach women about breast cancer.

In conclusion, our study provides a summary of what women with breast cancer in Africa, as there are overlapping issues which might be applicable to other women living with advanced breast cancer. The authors would like to thank the Management of the Cancer Diseases Hospital for their support.

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References


Conflict of interest

No conflict of interest to declare.


