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“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 analysed 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.

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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

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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

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