Original Article

# Caring for Patients with Advanced Breast Cancer: The Experiences of Zambian Nurses

Johanna Elizabeth Maree[1], Jennipher Kombe Mulonda[2]

[1]Department of Nursing Education, University of the Witwatersrand, Johannesburg, South Africa [2]Cancer Diseases Hospital, Lusaka, Zambia

**Corresponding author:** Johanna Elizabeth Maree, RN, DCur, FANSA

Head Department of Nursing Education, University of the Witwatersrand

Address: 7 York Avenue, Parktown 2193, Johannesburg, South Africa

Tel: +27 11 488 4196; Fax: +27 11 488 4195

E-mail: Lize.maree@wits.ac.za

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## ABSTRACT

**Objective:** The objective of this study was to describe the experiences of Zambian nurses caring for women with advanced breast cancer. **Methods:** We used a qualitative descriptive design and purposive sampling. Seventeen in-depth interviews were conducted with registered nurses practicing in the Cancer Diseases Hospital and the University Teaching Hospital, Lusaka, Zambia, and analyzed using thematic analyses. **Results:** Two themes emerged from the data - caring for women with advanced breast cancer is challenging and the good outweighs the bad. The majority of the participants agreed that caring for women with advanced breast cancer and witnessing their suffering were challenging. Not having formal education and training in oncology nursing was disempowering, and one of the various frustrations participants experienced. The work environment, learning opportunities, positive patient outcomes, and the opportunity to establish good nurse–patient experiences were positive experiences. **Conclusions:** Although negative experiences seemed to be overwhelming, participants reported some meaningful experiences while caring for women with advanced breast cancer. The lack of formal oncology nursing education and training was a major factor contributing to their negative experiences and perceived as the key to rendering the quality of care patients deserved. Ways to fulfill the educational needs of nurses should be explored and instituted, and nurses should be remunerated according to their levels of practice.

**Key words:** Advanced breast cancer, experiences, Zambia, Zambian nurses

## Introduction

Little is known about the experiences of Africa's registered nurses caring for women with advanced breast cancer as no literature focusing on this phenomenon, not only in Zambia but also in the rest of Africa, seems to be available.[1] This study focuses on this knowledge gap, in its objective to describe the experiences of Zambian nurses caring for these women.

Despite the absence of systematic population-based cancer registries and a dearth of breast cancer research, breast cancer is not unknown to Africa.[2] According to

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Parkin and Bray,[3] breast cancer is the most prevalent cancer in Africa's women, contributing 27.6% to the total cancer burden in women and 25.5% in women living in Sub-Saharan Africa. The breast cancer burden in Zambia does not seem to be this high, as Zyaambo *et al.*,[4] when analyzing the National Cancer Registry of 1990 to 2020, found breast cancer is the second most prevalent cancer after cervical cancer, contributing 11.4% to the total number of cancers reported in women.

The unique challenges Africa faces in terms of cancer control also influence nursing. For instance, breast cancer on the increase[5] leading to an increased number of women presenting with advanced disease. Small studies conducted in Sub-Saharan Africa found up to 90% of women are diagnosed with Stage III and IV disease, large tumors with a median size of 10 cm, and clinical evident lymph node disease. Breast cancer is synonymous with suffering[6] because these women cannot be treated successfully in even the best cancer care settings,[7] let alone in Africa where treatment, in many instances, is less than optimal.[8] Zambian nurses are often confronted with the suffering of women before diagnosis due to their inability to recognize the signs of breast cancer,[9] as they have to manage their various losses which include physical strength, their roles, femininity, and even support due to their support structure's fear of stigmatization. Therefore, it might not be unreasonable to say that these nurses are confronted with "everything" breast cancer changes in the lives of women including the way they view themselves, their relationships, and independency, as they become dependent on their significant other and health-care professionals.[6]

The Cancer Diseases Hospital, the only center offering comprehensive cancer care in Zambia, opened in July 2006. Consequently, cancer nursing is in its infancy, and only a small number of nurses underwent formal oncology nursing education and training in South Africa. South Africa offers oncology nursing as a First Degree, Honors Degree, or Master's Degree after registration as a general nurse. These courses are lectured, cover nursing across the cancer continuum (from prevention to palliative care), are typically offered over 2 years due to the extensive work-integrated learning component, and normally lead to registration as a specialist oncology nurse in African countries with specialist nursing registries.

# Methods

## *The study and participants*

We selected a descriptive qualitative design which allowed us to present an accurate, comprehensive summary of the meanings, participants ascribe to specific events.[10] The study setting was two public hospitals in Lusaka, Zambia: The Cancer Diseases Hospital and the University Teaching Hospital, which is situated next to the Cancer Diseases Hospital. The Cancer Diseases Hospital serves the total population of Zambia and delivers external beam radiation, brachytherapy, chemotherapy, and palliative care[11] free to Zambian citizens on an outpatient basis. The chemotherapy suite can host forty patients at a time. The University Teaching Hospital, the largest hospital, is the main referral health institution in Zambia and is the primary teaching hospital for nurses, medical doctors, and other health-care professionals providing primary, secondary, and tertiary health care. The hospital has 1655 beds[12] and a catchment area of approximately 2 million people. The Cancer Diseases Hospital has an agreement with the University Teaching Hospital and uses a 25-bed ward for inpatient treatment and care of cancer patients who needs hospitalization. Hospitalization is also free of cost if motivated, while patients who can afford to, pay for these services. The Cancer Diseases Hospital is currently expanding and once completed will be able to admit 269 inpatients.

The participants consisted of 17 purposively selected registered nurses; ten were female and seven male; eight practiced at the University Teaching Hospital and nine at the Cancer Diseases Hospital; their ages ranged from 25 to 52 with an average of 31.7 years; their experience with cancer nursing ranged from 2 to 6 years with an average of 4 years. Three had completed a Baccalaureate Degree in Oncology Nursing, whereas the remainder had a Diploma in General Nursing.

## *Data gathering and analyses*

After obtaining ethical clearance and permission from the university's and hospitals' review boards, the second author, a Baccalaureate, prepared oncology nurse who has been practicing at the Cancer Diseases Hospital for 5 years before the gathering of the data, approached registered nurses during their normal shifts, explained the study to them, and invited them to participate. All those recruited agreed to participate and complete the interview during a normal lunch hour. Participation was voluntary, and after obtaining informed consent in writing, the interviews were conducted, in privacy, by the second author. The participants were addressed by their chosen names, which were removed during the transcription of the interviews to protect their identity. No harm was intended, and the participants received an information leaflet explaining the study and their rights as participants. Seventeen in-depth interviews were conducted in English, lasting approximately 45 min, between January and June 2014. One question, "Please tell me how you experience nursing patients with advanced cancer of the breast" was asked, where after

probes and prompting questions[13] were used to encourage participants to expand on their experiences. Data saturation determined the sample size.

The interviews were transcribed verbatim, and the data analyzed using thematic analyses.[14] We familiarized ourselves with the data by reading and re-reading the transcripts. Interesting features were noted in the margins, which served as initial codes. We grouped the codes into themes, checked these against the raw data, and then named the themes. Both authors analyzed the data. We used reflexivity[15] to become aware of our assumptions, personal, and educational experiences, the roles we fulfill and how they might influence the findings of the study.

### Establishing rigor

We applied trustworthiness principles[16,17] to enhance rigor throughout the study. To enhance credibility, we used well-known research methods, which were applied during the study and described in a research proposal that was submitted for peer scrutiny. An early familiarization with the culture of the participating organizations was established, voluntary participation enhanced informant honesty, and member checks were used during the interviews. Both investigators are experienced oncology nurses and one an experienced researcher. Transferability was enhanced by describing the number of people involved in the data collection, the data collection method used, the duration of the interviews, and the period of data collection. Describing the research design and implementation and how the data were collected enhanced dependability, while an audit trail enhanced confirmability.

## Results

Two themes emerged from the data: Caring for women with advanced breast cancer is challenging and the good outweighs the bad.

### Caring for women with advanced breast cancer is a challenge: "I didn't realize for me it would turn out to be this huge challenge"

The majority of the participants agreed caring for women with advanced breast cancer was challenging. Some were of the opinion, it was a negative experience and described it as "not very nice" and "not good." Rotation through the wards and not being able to choose to practice in cancer care added to their challenges. Most of the participants felt ill-equipped, as they were uneducated in oncology nursing and lacked specialist knowledge. Participants said:

"My sister, ahhhh! I didn't realise for me it would turn out to be this huge challenge caring for (these) patients… maybe if I was trained in oncology nursing it was going to be much easier for me…" (RN, 5)

"I didn't choose to work in this ward…but we normally rotate between wards, that's how come I found myself in this ward…it is not a very nice experience to nurse these patients… So it's so stressing and draining on my part to have to give specialised care to such patients; I have to rely on my experience and a bit of theory I received while in training as a general nurse on breast cancer…" (RN, 1)

It was difficult for the participants to see how the women suffered. Having to care for patients with pain and other distressing symptoms such as fungating lesions, lymphedema, and dyspnea and those who were abandoned, dying, and lost hope resulted in emotional distress. The many investigations the women had to undergo to confirm their diagnosis, the time it took before treatment could start and the lengthy treatment patients had to undergo added to participants' emotional distress. Participants explained:

"…some patients come with fungating tumors which will smell very badly on the ward, and we have to work on a smelly ward all day every day of the week…Some patients go for debulking…or they start with radiation to shrink the tumor…or you now put them on chemo… such long treatments for these patients, it's never easy." (RN, 1)

"…at times its depressing as I see them every day in pain, abandoned and dying…they tend to improve at some point then later deteriorate and die on you after you have developed an attachment with them, then you feel very bad, very bad…" (RN, 8)

Participants experienced various frustrations. The few who were formally educated and trained as oncology nurses mentioned the burden other colleagues placed on them. They were also unhappy about earning the same salary as those who were not specialists. Staff shortages and lack of time added to participants' challenges and the occasional shortages of consumables and pain medication hindered them from rendering optimal nursing care. Participants expressed their frustrations:

"Other frustrations are lack of adequate working equipment or medical-surgical supplies…also lack of oncology nursing skills from my untrained colleagues. Especially you find that they don't know what specific things to lookout for when caring for patients…" (ON, 1)

"…due to low staffing levels I find myself inadequate to attend to the many patients that may require my service at the same time…you find that so many patients will require your attention…I can only manage to attend to one patient's needs at a particular time…" (RN, 6)

"I know that we need to administer very strong analgesics…but that becomes impossible most of the time because we do not have enough supplies of such strong analgesics…when we want to order enough we are told we can only be given so much at a particular time. It is very

unfair on the part of the patient who should receive proper care especially when they are admitted…" (RN, 14)

Caring for women with advanced breast cancer was challenging and not a positive experience for most participants. Their lack of formal oncology nursing education and training hindered them in providing the care they thought patients deserved. The suffering of the patients resulted in emotional distress, and the frustrations experienced added to their challenges.

### *The good outweighs the bad: "My benefits are more, hence I forge ahead"*

Even the participants who did not consider caring for women with advanced breast cancer positive, reported some meaningful experiences. Some considered the work environment to be supportive, offering learning opportunities, and the opportunity to grow and develop. The good relationships with other team members were also appreciated. The fact that the Cancer Diseases Hospital was new, with new equipment, was also experienced as positive. Respondents elucidated:

"…most members of the multidisciplinary team are supportive in that they know that we are not trained in giving specialized care to these cancer patients so they try as much as they can to guide us on how to care for these patients… we are normally called when they have presentations…and there we learn one or two things…" (RN, 1)

"…we have a privilege of working in a brand new hospital with most of the new equipment which gives good morale as we carry out our duties…" (ON, 2)

The participants were very conscious of their roles as nurses practicing in cancer care. Most highlighted their roles as providing psychological care and counseling, health education about the patient's condition, managing pain and other symptoms, and administering treatment. The roles that awarded them the opportunity to establish therapeutic relationships were positive experiences and gave them a sense of personal achievement. This was described as follows:

"What I enjoy doing the most, like giving health education to these women with advanced breast cancer because I end up learning a lot at the end of the day and it helps me understand my patients…" (ON, 2)

"I enjoy cannulating my patients with advanced breast cancer because that is the time I find to get to know each and every one personally and that's the time I give counseling and psychological care." (RN, 4)

"The most important of my roles is to do patient assessment so as for me to carry out proper patient care and in doing this I have achieved so much personally…" (RN, 3)

Positive patient outcomes, despite knowing women with advanced breast cancer cannot be cured, made caring for them a "good," "interesting," and "nice" experience. Participants considered the good nurse–patient relationship they were able to establish and the difference they made to the lives of the patients worth the challenges and frustrations they experienced. They believed they lessened the suffering of the patients as they witnessed patients responding well to treatment, pain relief, lessened anxiety, and developing hope. They also valued the appreciation the patients and families displayed and the opportunity to care for these patients without being stigmatized. Participants said:

"…my experience with these women with advanced breast cancer is a good one because I feel a sense of satisfaction knowing that I have contributed and made a difference in my breast cancer patients…If I were to weigh my benefits versus loses in my experience I would say my benefits are more, hence I forge ahead…so my experience with these women is a great one …" (ON, 1)

"…we see these patients get relieved of their pain, the anxiety is lessened, they develop hope… even those whose disease has really advanced so much…" (RN, 7)

Despite all their challenges, most participants were able to find something positive in caring for women with advanced breast cancer. Good nurse–patient relationships and support of members of the health-care team were positive. Being able to get to know the patients through specific roles were also enjoyable experiences, while positive patient outcomes made the nursing experience more positive than negative.

## Discussion

Our study provided evidence of the burden nurses experienced in caring for women with advanced breast cancer. Lacking formal oncology nurse education and training was a major challenge. Those not educated and trained as oncology nurses believed their lack of specialist knowledge hindered them rendering optimal nursing care, while the few who had received education were burdened by those not able to provide specialist care. This situation is not unique to Zambia and studies from both the developed and developing world report nurses' concern about their knowledge and skills, which mismatched optimal nursing care.[18-20] Grunfeld *et al.*,[21] in a study investigating job stress and satisfaction of health-care professionals and support staff working in cancer care, found being responsible for the quality of work of others a source of job stress. Although not specifically investigated, this responsibility could have added to the burden of the oncology-educated participants. In addition, Grunfeld *et al.*[21] support the participants' experiences of staff shortages, a lack of adequate equipment, and not being remunerated adequately by identifying them as job stressors, while Zuzelo[22] identified

practicing in a situation where staffing was unsafe as a cause of moral distress.

It was not easy for the participants to witness the suffering patients experienced. Literature describing the experiences of nurses caring for cancer patients in acute care settings is scant.[23] Corner[23] acknowledges practicing in cancer care is difficult and stressful, with the stress increasing as the number of deaths increase, while White *et al*.[24] describe the effect of patient's unrelieved suffering on nurses as "enormous." LeBaron *et al*.[20] agree with this finding, as their study conducted in India revealed nurses felt "bad" about patients suffering, with situations such as the sudden death of a patient causing significant moral distress.

Unrelieved pain and the odor of fungating lesions were only two of the symptoms causing nurse distress. Recognizing the pain needs of patients is a positive finding, as nurses play an important role in pain management, which starts with identifying pain needs. Except for recognizing their pain, patients expect nurses to be present, supportive, talk to and educate them about their pain and pain medication, and administer pain medication[25] as seen in this study. Unfortunately, malignant fungating wounds are associated with odor which, according to Alexander,[26] is the "worst aspect" of such a wound and, as supported by the current study, has a devastating influence on the quality of life of nurses.

It was encouraging to find the participants, despite being overawed with negative experiences, could identify some meaningful experiences. This finding is not unique, as various studies report challenges, as well as rewards, in caring for cancer patients.[23,27,28] Interestingly, Van Rooyen *et al*.,[29] in a study exploring the experiential world of the oncology nurse, state nurses choosing to practice in cancer care are usually passionate about their work, while those who are "forced" to work in these care settings often experience discomfort. Therefore, it might be possible that the participants in the current study who chose to practice in cancer care, reported more positive, meaningful experiences than those who could not choose. This is a mere speculation and should be investigated before conclusions can be made.

It was also encouraging that the nononcology nursing educated participants were aware of their roles and that these included more than just tasks focusing on physical care. As seen in the current study, participants used the available opportunities to build therapeutic relationships with patients – situations they found rewarding. Mok and Chiu[30] support this finding by stating nurses find satisfaction and are enriched through nurse–patient relationships in the context of palliative care, while Grunfeld *et al*.[21] identified good relationships with patients the most important factor contributing to job satisfaction.

## Limitations

A once-off study may not be adequate to give a thorough understanding of nurses' experiences in caring for women with advanced breast cancer. Further research focusing on this phenomenon should be conducted in Zambia and other countries who face the same challenges in terms of resources, late presentation with breast cancer, and limited access to oncology nurse education to attain a deeper understanding of nurses' experiences.

## Conclusion

Although negative experiences seemed to be overwhelming, participants reported some meaningful experiences while caring for women with advanced breast cancer. The lack of formal oncology nursing education and training was a major factor contributing to their negative experiences and perceived as the key to rendering the quality of care patients deserved. Although formal education and training to become a specialist oncology nurse is the ideal, other ways to fulfill nurses' educational needs should be explored and instituted. For instance, a buddy system can be used involving specific members of the multiprofessional team to teach, coach, and mentor general nurses. Short learning programs using a blended and flexible learning approach could also be of benefit. In addition, to improve job satisfaction, nurses should be remunerated according to their levels of practice.

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### *Conflicts of interest*

There are no conflicts of interest.

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