



Original Article

In their voices: Kenyan women's experiences with cancer treatment-related side effects

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ABSTRACT

Objective: This article reports on a secondary analysis of a qualitative study conducted in Nairobi, Kenya that reported several initial themes. In this article, the authors explore the theme of treatment-related side effect management by women receiving treatment for breast or cervical cancer.**Methods:** Women were interviewed at three points during their active treatment trajectory. Participants were purposefully selected and saturation was reached when interviews did not yield any new themes. The interviews were transcribed and analyzed for internal consistency, frequency, extensiveness, intensity and specificity. The Nvivo pro 12 software was used in organizing and managing the data to facilitate analysis.**Results:** Eighteen women were interviewed. Major side effects reported by participants included fatigue, alopecia, skin and nail changes as well as nausea and vomiting. Women who received information prior to treatment were more comfortable managing side effects. Participants described the impact of side effects on their daily life, body image, and many sought comfort through faith. Some women provided suggestions on strategies for patient education.**Conclusions:** This study attempted to capture the cancer treatment-related experiences of Kenyan women in their own voices and present strategies for future intervention and research. The care of individuals receiving treatment can be enhanced through the advancement of health human resources, the development of nationally accessible patient education materials and research on regionally relevant strategies to manage cancer treatment-related side effects.

Introduction

Cervical and breast cancers are leading causes of death for women on a world-wide basis. While these diseases vary across countries, global disease burden studies¹ report that the population in Sub-Saharan Africa (SSA) has an increased number of cases.² Twahir et al.³ report that breast cancer is one of the most frequently diagnosed malignancies and one of the most common causes of cancer-related deaths across several African countries including Kenya. Perez-Guzman et al.⁴ report that while preventable, SSA experiences the highest incidence of cervical cancer for a global region.

Countries like Kenya face several hurdles when dealing with the cancer burden for their populations. These challenges include lack of

screening, treatment gaps, disparities in health care infrastructure, lack of cancer-related guidelines, limitations in medical research and training, substandard public health initiatives, and constrained health-related human resources.^{3,5} Thus, women seeking care for cervical and breast cancer in Kenya face challenges with treatment and management of treatment-related side effects.

The treatment for cancer in SSA is complex. Cancer treatments include surgery, radiation therapy, chemotherapy, and immunotherapy. However, many low-income countries⁶ (LIC) have yet to see and/or benefit from the advances in surgery, radiotherapy, and chemotherapy.⁷ Most patients in LIC present with advanced stage disease and conservative surgery, the norm for many cancers like breast cancer in high-income

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countries, is out of question.⁸ In most LIC, there are a lack of surgeons, few hospitals equipped with operating rooms, and patients' limited ability to access and pay for surgical services.

Additionally, in most LIC, radiotherapy is either not available or in short supply, yet most cancer patients require radiotherapy to the primary and/or metastatic sites. Older equipment like cobalt 60 machines make it impossible to implement current radiotherapy protocols and this lack of radiotherapy facilities becomes a challenge that needs resolution to improve cancer care.⁹⁻¹¹

In most cases, cancer chemotherapy is not available in LIC. Drugs are expensive, unaffordable to most patients, and difficult to administer. Prescribing and delivering chemotherapy is not as simple as writing a prescription for drugs. There is a need to monitor and assess patients continually while they receive chemotherapy. Side effects and symptom management concerns from chemotherapy are extensive, requiring specific nursing knowledge and patient education. The delivery of cancer chemotherapy in SSA is hindered by the widespread lack of health care professionals skilled in administration of chemotherapeutic agents, access to laboratories for blood count analyses, effective antiemetic treatments, and extensive patient education.^{7,12}

Finally, immunotherapy is used less frequently than chemotherapy in SSA. The challenge is like the concerns about chemotherapy. Immunotherapy requires biologic tools to predict treatment response prior to administration. The lack of these biologic tools threatens the safety and efficacy in the use of immunotherapy. Additional training for management of immunotherapy-related adverse effects is also necessary. Laboratory techniques to identify patients best suited for immunotherapy and incorporation of immunotherapy training into clinical education may be prerequisites for wider, effective adoption of this cancer treatment technique in SSA.¹³

Treatment for breast and cervical cancers may be administered within the hospital but much of the follow-up care and side-effect management is done in the patient's home community. Most cancer treatments are delivered on an outpatient basis, requiring patients to manage treatment-related side effects at home. It is therefore important that patients are equipped with self-care skills and support to manage their care at home.¹⁴

The purpose of this article is to report on a secondary analysis of qualitative data conducted in Nairobi, Kenya and published in 2022.¹⁵ In the initial study, themes such as fear and finances were identified including side effects experienced by women newly diagnosed with breast or cervical cancer and receiving treatment. This article reports on the theme of treatment-related side effects and to date there is little information in the published literature on this topic in LIC.

Methods

Participants and study sites

Women receiving treatment at the Aga Khan University Hospital, Nairobi (AKUHN) or Kenyatta National Hospital (KNH) in Nairobi were recruited for the study. Both sites are acute care hospitals in Nairobi, Kenya offering comprehensive cancer care ranging from screening, diagnostics, treatment, post-treatment care and palliation. AKUHN is a private tertiary, teaching and referral hospital funded by a global non-governmental organization and KNH is a public teaching hospital funded by the Government of Kenya. A purposive sample of 18 women receiving treatment for breast or cervical cancer at either site participated in the study. Seven women were diagnosed with cervical cancer and 11 with breast cancer.

Data collection

The women participated in a three-stage interview: at diagnosis, a follow-up interview at 4–6 weeks post diagnosis, and a final interview at 12 weeks post diagnosis. Given the nature of their treatments, a single interview at a point in time would not capture the complete experience of

these women. The second and third interviews were informed by the findings from the first interview. Table 1 provides the first interview guide.

Women participated in semi-structured interviews if they were of Kenyan descent, diagnosed with breast or cervical cancer stages 1–4 as a primary malignancy, and spoke English or Kiswahili (Kenyan National language).

Interviews were conducted in English and Kiswahili, audiotaped, transcribed, and reviewed for accuracy. All transcriptions were reviewed and amended to include verbal and non-verbal cues such as pauses, laughter, or other emotions expressed during the interviews.

Data analysis

Interviews were transcribed, and transcripts were de-identified. A thematic approach was used for analysis. Study team members read transcripts and listened for (1) frequency – how often or frequently is a point being made; (2) extensiveness – how extensively does the participant describe specific aspects of health information; (3) intensity – how intensely are certain topics discussed; and (4) specificity – how specific is the discussion about the health information. The data were reviewed for within interview findings, across-interview findings, and between-interview findings. The analysis ensured the reliability, validity, and trustworthiness of the data and the study conclusions.

Ethical considerations

Approval for the study was received by the Research Ethics Committees of the two institutions. Participants were recruited from the hospital outpatient cancer treatment clinics. A research permit was obtained from the Kenya National Council for Science and Technology. Study participants received a participant information sheet and informed consent document. All participants provided written informed consent. All participant information was anonymized using number codes for each individual.

Research rigor

The conduct and reporting of the research findings followed consolidated criteria for reporting qualitative research guidelines to ensure that the study met quality standards for qualitative research.¹⁶ Nvivo pro 12 software was used in organizing and managing the data to facilitate analysis. Interview transcripts were imported into Nvivo

Table 1
Semi-structured interview guide.

Interview questions
1. Events leading to diagnosis
(1) Tell me about how long you have been unwell.
(2) When did you first go to the clinic or the hospital and why (name) _____ hospital.
(3) What made you want to see the doctor?
2. Current understanding of illness, treatment, and medicines
(1) What did the doctor/nurse explain to you when you went to the hospital?
(2) Tell me what you understand/understood about what they said about what you were experiencing and what they said might be wrong?
(3) Can you tell me in your own words what you think is wrong?
(4) Did they give you any instruction or medicines to take home? Can you show them to me and tell me what you understand about the medicines/instructions?
3. Cultural beliefs
(1) Apart from what the doctor said will help you, do you have any other beliefs about things that will help you get better?
(2) Are you also consulting a traditional healer and how have they explained things?
4. Reflections
(1) What could the doctor/nurse have done differently to help you better understand your illness/medicines/instructions?

and manually coded following the interview guide. The coded transcripts were grouped and themes were identified across the various interviews. The complete data set included tapes, researcher notes and transcripts. The coding team met on multiple occasions to reach consensus on the code book.

Results

Demographics

Eighteen women were interviewed during this study (Table 2). Eleven were receiving treatment for breast cancer and seven for cervical cancer (Table 3). On average, the women were 45.33 years of age, with 83.3% being in a monogamous marriage. Most of the women worked full time and there was an equal representation of women from urban and rural areas. All the participants received at least one cancer treatment modality, that is, chemotherapy or radiotherapy or a combination of both and a few were treated with hormonal therapy. The majority of women in both groups had Stage II disease (Table 4).

Treatment-related side effect themes

Most of the study participants experienced varying degrees of treatment side effects. Some coped with a greater burden of side effects while others had minimal issues. Major treatment-related themes from the interviews included fatigue, alopecia, skin, and nail changes, as well as nausea and vomiting. The women also described the emotional impact of these bodily changes.

Fatigue

Many of the women experienced fatigue and described its impact on their daily lives. They found ways of coping to help them continue with school or other daily responsibilities. The following are a few statements from women describing their experience of fatigue.

“All the time, I am feeling tired, even if I have not done any work”. (AFO1BC)

Table 2
Participant sociodemographic characteristics (N = 18).

Characteristics	n	Percentage
Religion		
Muslim	1	5.6%
Christian	17	94.4%
Education		
Below secondary school	3	16.7%
Secondary school diploma	9	50.0%
College/university	6	33.3%
Marital status		
Single	1	5.6%
Married	15	83.3%
Separated	2	11.1%
Type of marriage		
Monogamous	14	77.8%
Polygamous	1	5.6%
No response	3	16.7%
Employment		
Full-time	9	50.0%
Part-time	2	11.1%
Retired	1	5.6%
Not working	6	33.3%
Income		
High	2	11.1%
Middle	9	50.0%
Low	7	38.9%
Residence		
Urban	9	50.0%
Rural	9	50.0%

Table 3
Study participants from the two sites.

Study site	Breast cancer	Cervical cancer
Private, tertiary care hospital	6	4
Public, referral hospital	5	3
Total	11	7

Table 4
Participant-reported disease status (n = 18).

Stage	Breast cancer	Cervical cancer	Total
I	2	1	3
II	5	5	10
III	2	0	2
IV	0	0	0
Unknown	1	1	2
0	1	0	1
Total	11	7	18

“Sometimes I get very tired, but I try and eat well and take my medicine” (AFO3BC)

“I do just go through fatigue, but even at my worse am still what able to walk. I can still go to school, am still able to go. There is no point I can say that fatigue made me not even wakeup. Yes. I feel it but even at worse I can still go to the school and get back to the house. When I read about other women and what kind of fatigue they are talking about, and they are not even able to anything, I think that one just makes me to thank God yes am ok. That is not I am going through. Mine is mild.” (AF07BC)

Body image

Women in this study also talked about side effects affecting their body image, namely, alopecia and skin and nail changes. Most of the women were impacted by alopecia. Some of them experienced profound distress and sought comfort through God. See the following quotes from women who describe their experiences and their focus on body image.

“What is it, or what else drug that could be that doesn't have the effects that it's causing the hair to fall. They need to be using that one. you know for the woman to lose hair that is something very big to her. Because the first thing when you start chemo, the first side-effect is that your hair falls.” (KF01BC)

“Even it has fallen recentlyGod I told you I do not what to see this hair fall. But if you have seen it worthy for it to fall. I said its ok.” (KF07BC)

I don't have my hair. Mmm but I thank God because am not in pain. I keep on telling myself, am safe only hair.” (AK07BC)

In addition to alopecia, some women experienced skin and nail changes. The women struggled with the resultant changes in body image.

“I am disturbed when I look at my skin. It has started turning black.” (AF05BC)

After taking the chemo? It has changed me. I see the tongue has turned black my fingers have black.” (AF06BC)

“I had actually what darkened but now they are coming back to normal. I am thanking God for that ... as I was brushing ... my teeth ... my tongue was getting black that one kind of hit me ... and I said let me just thank God not even a whole tongue.” (AF07BC)

Nausea and vomiting

Nausea and vomiting, a common side effect associated with many cancer treatments was troublesome for many women and some were

challenged with management strategies as evidenced by the following quotes.

“ ..., you don't eat, you vomit. The nausea the vomiting and the tiredness, just too weak you can't eat you are just looking at people. Food you don't want to eat”. (AF09CC)

I was vomiting, vomiting, vomiting, vomiting, with chest pains, back pains, feeling bad in my head. Yes. Then I felt pains from here, then it relocates to the leg. When you see something you just vomit.” (KF06BC)

“Vomiting it's a lot but if you ate lemons, pineapples, apples, grapes, you won't feel those effects. So, you may find yourself not experiencing nausea ... and I prayed God very much to help me with money for fruits and not to miss them.” (KF01BC)

Patient education

Despite experiencing symptom distress, many women in this study described the benefit of education in helping them manage treatment-related side effects. The following are themes from women sharing their insights.

“It is good that the doctor does the introduction to the individual on how she will continue and what she shall experience but it is not the doctor who has experienced it. He has just said what is written on paper. Like now if I may ask you question you will benefit from reading and you will explain to me. But if you ask me, I will tell you; because I have experienced, what I have felt because I have taken drugs ...” (AF02BC)

“Because when I started the first chemo they took me all through the information very well the side effects and everything, so I had the information. So, the health team has been very good with the information and all this side ...” (AF03BC)

“The(y) explained it will be able to fight the cancer germs and its side effects. It will make hair fall, vomiting, loss of appetite. They tell you all those side effects.” (KF08CC)

Ok. I was told there will be side effects ... there will be vomiting, diarrhea and all those but aaaa just I must go on.” (AF10CC)

Conversely, some participants identified the need for patient education and were unaware of the anticipated side effects of cancer treatment and how to manage them. One woman even provided suggestions on a possible intervention.

“Sometimes with the outcomes. What do we call them? ...the side effects. Sometimes you are not prepared. You don't get enough information. Especially after the chemo.” (KF03CC)

“We need to be taught. Like the TV screen out there sometimes it shows some programs and one wonders what is it for? Instead, it should be showing us the programs related to cancer even though you are not hearing what they are saying you can see the pictures.” (AFO2BC)

Discussion

The provision of cancer treatment in Kenya is difficult in the face of a myriad of challenges including treatment gaps and disparities in health care infrastructure, lack of guidelines, limitations in health care research and training, substandard public health initiatives and limited health human resources.^{3,5} Effects of these challenges are reflected in the voices of women participating in this study.

The women spoke about coping with fatigue and found ways to help them continue with their educational and other daily responsibilities. A systematic review by Ramon et al.¹⁷ describes cancer-related fatigue as a common, incapacitating symptom impacting quality of life. The literature

describes several interventions to manage cancer-related fatigue including patient/family education, physical activity, and psychosocial support.^{17,18}

Women in this study also reported concern over the change in body image resulting from treatments. This concern is consistent with findings from another study done at KNH in which 66% of participants reported distress related to bodily changes due to chemotherapy.¹⁹ Hassan et al.²⁰ also reported similar findings in their Egyptian study of women with cervical cancer and recommended patient education to address issues of body image. This area of research should be addressed in follow-up studies.

In addition to impact of side effect management on quality of life, additional ways in which patients are affected must also be appreciated. The work of Sherman and Okungu²¹ in Mombasa County, Kenya, and that of Bosire, Mageto and Kimani¹⁹ at KHN acknowledge the cultural element of stigma described by women in their studies. While our interview guide included questions specific to culture, the participants did not report cultural or stigma-related responses when talking about treatment-related side effects.

Treatment-associated nausea and vomiting is another distressing side effect reported by the women in this study and in the literature by Bosire et al.¹⁹ This is a side effect that profoundly impacts patient quality of life.²² Effective management of nausea and vomiting can be achieved by pharmacological agents, non-pharmacological means, and supported through patient/family education by oncology nurses.²³ However, in Kenya and other countries in SSA, the ability to obtain and pay for these pharmacological agents may be improbable from a cost perspective.

Finally, women in this study acknowledged the benefit of education in helping them cope with treatment-related side effects. Evidence from the literature supports the fact that patient education prior to treatment makes patients more comfortable in managing the side effects.^{24,25} In addition, researchers found that involving patients and family in the early treatment phases resulted in better patient outcomes.²⁵

Limitations

There is limited generalizability of this study since this was a qualitative study. Our sample was small, consisting of only 18 participants diagnosed with breast and cervical cancers. The sample came from two acute care hospitals in Nairobi, a capital city with a large urban population, yet half the women in the study were from rural areas. Additional quantitative research is needed to understand the symptoms and side effects experienced by patients treated in Kenya beyond Nairobi.

Conclusions

In this article, the authors explored the experiences of a group of Kenyan women receiving treatment for breast or cervical cancer. Many of the study participants experienced treatment-related side effects and described their experiences at various points in the treatment trajectory. There is much to be done to enhance cancer care for women in Kenya to ensure that the participant voices in this study are truly heard. It is important to note that information must be tailored to the regional context and reflect the local culture.²⁶ While participants in our study did not mention stigma related to body change, it is important that oncology training programs address this important cultural phenomenon. Women who received education prior to treatment were better prepared to manage the side effects. Although cancer care in Kenya is advancing, there remain a number of challenges that impact the care of patients receiving treatment.

Health professionals providing cancer care in Kenya now have access to a number of important guidelines developed by the national government.²⁷ These documents address the provision of cancer care across a wide spectrum ranging from strategic planning to treatment protocols for a number of malignancies. It is noteworthy however, that patient education on side effects is only mentioned in the National Guidelines for

Establishment of Cancer Management Centers as a patient right "... to detailed information on his/her condition, treatment options including clinical trials, side effects, expected outcome and prognosis" (p. 16) while the National Treatment Protocols document mandates that patients should be offered information and support to cope with cancer. The National Cancer Institute of Kenya website (www.ncikenya.or.ke) supports all the documents cited and provides basic cancer information but does not include patient education material on the spectrum of cancer care, including that specific to treatment-related side effects.

In addition to a paucity of patient education resources for cancer treatment side effect management, cancer care providers also deal with limited health human resources. The Ministry of Health guiding documents mention oncology nurses and it is noted that oncology nursing specialization is recognized by the Nursing Council of Kenya.²⁸ Nevertheless, Kenya still faces an acute shortage of health human resources and oncology nursing is offered at a diploma level in only two institutions and at a Masters level in one university.²⁸

In addition to enhancing oncology health human resources, health care providers can consider the adoption of technology to enhance patient education and support. The collaborative work of Shaikh et al.²⁹ with stakeholders from the public and private sector to create a web-based portal to better understand the psychosocial needs of women with breast cancer is one such example. The site content, designed specifically for Kenyan women with breast cancer was accessed almost 8000 times over two years. This is a promising avenue for developing patient education on the management of treatment-related side effects.

The work of the National Cancer Institute, the various oncology nursing education programs and the collaboration among stakeholder groups are strong examples of the commitments by government, academic institutions, and the public-private health sector to advance the cancer care agenda. Other opportunities to advance cancer care include further research into the management of treatment-related side effects through the application of regionally relevant solutions accessible to all women challenged by breast and cervical cancers.

Ethics statement

Approval for the study was received by the Research Ethics Committees of the two institutions (IRB No. 2017/REC-07; KNH P 156/03/2018). Participants were recruited from the hospital outpatient cancer treatment clinics. A research permit was obtained from the Kenya National Council for Science and Technology (IRB No. NACOSTI/P/17/44682/17818). Study participants received a participant information sheet and informed consent document. All participants provided written informed consent. All participant information was anonymized using number codes for each individual.

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CRediT authorship contribution statement

Tayreez Mushani: Conceptualization, Methodology, Formal analysis, Writing – Original Draft, Writing – Review & editing, Visualization, Funding acquisition. **Dinah Kassaman:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – Review & editing, Project administration, Funding acquisition. **Sharon Brownie:** Conceptualization, Methodology, Resources, Writing – Review & editing, Supervision, Funding acquisition. **Peterson Kiraithe:** Software, Formal analysis, Investigation, Data curation, Writing – Review & editing. **Margaret Barton-Burke:** Conceptualization, Methodology, Resources, Writing – Review & editing, Supervision. All the study data was accessible to all authors. The first author had final responsibility to submit for

publication and attests that all listed authors meet authorship criteria and that none meeting the criteria were omitted.

Declaration of competing interest

The authors declare no conflict of interest. The corresponding author, Professor Margaret Barton-Burke, serves as a member of the editorial board of the Asia-Pacific Journal of Oncology Nursing. The article has undergone the journal's standard publication procedures.

Data availability statement

The authors confirm that the data supporting the findings of this study are available within the article.

Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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