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Characterization of Distressing Symptoms among Breast Cancer Patients under Treatment at Kenyatta National Hospital

Joystacy Kendi Mutegi[1], Samuel Kimani[2], Emmah Matheka[2], Mitheu Henry[3]

[1,2]Department of Nursing Sciences, University of Nairobi, Nairobi, Kenya.
[3]School of Nursing Sciences, Daystar University, Kenya.

Corresponding Author: Joystacy Kendi Mutegi

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ABSTRACT

Background: Cancer is a major health concern globally with breast cancer being a leading cause of death. Patients with breast cancer may experience various distressing symptoms related to the cancer diagnosis and treatment.
Objective: To characterize distressing symptoms among breast cancer patients under treatment at Kenyatta National Hospital.
Methodology: This was a descriptive cross-sectional study that utilized both qualitative and quantitative research methods. The target population was breast cancer patients on treatment and follow-up at the Kenyatta National Hospital's Cancer Treatment Centre. The sample size comprised of 92 participants selected using simple random sampling method. A questionnaire and a focused group discussion were used in data collection. The study tools were pretested to verify their reliability and validity. Quantitative data was analyzed using various descriptive statistics including percentages and frequencies with findings presented in tables while qualitative data was probed thematically. Data was analysed using SPSS version 23. Appropriate ethical approvals were obtained.
Results: The study's response rate was 100%. Majority of the respondents were married (65.2%), Christians (91.2%), with a monthly household income of below KES 10,000 (55.4%) and had a mean age of 48.49 years. The most common distressing symptoms experienced were fatigue, pain, lack of appetite, drowsiness, nausea, anxiety, vomiting, depression, diarrhoea, and constipation while the least experienced symptom was shortness of breath. Of these, anxiety, lack of appetite, loss of wellbeing, fatigue, nausea, pain and drowsiness were particularly severe.
Conclusion: Patients with breast cancer experienced numerous distressing symptoms with fatigue, pain and anxiety being quite common.

Keywords: breast cancer, distressing symptoms, characterization, patients

INTRODUCTION

Cancer is ranked as the second leading cause of death globally, after cardiovascular diseases, with about 19 million new cases diagnosed in 2020 and accounting for about 10 million deaths in 2020.[1] The number of new cases in Africa is estimated to be about 1.1 million cases and 42,116 of these were from Kenya.[1] As cancer episodes continue to increase, the proportion of cancer patients

on various therapy modalities including radiotherapy and chemotherapy also increases.[2]

The Global Cancer Registry indicates that, in terms of incidence and mortality among women, breast cancer leads followed by others including colorectal, lung, and cervical cancers.[1] It is also notable that cancer of the breast was the most common type of cancer amongst African women in 2020 affecting 129,000 women, 6,799 of whom were from Kenya. [1,3]

During diagnosis, treatment and recovery, patients with breast cancer may experience a wide spectrum of physical and emotional symptoms that are distressing. Despite their influence on daily functioning, distressing symptoms in patients with cancer are often neglected and undertreated potentially resulting in poor treatment compliance and survival. Some of the leading distressing symptoms on cancer diagnosis are fatigue, pain, anxiety, depression, self-image concerns and anger.[4]

Distressing symptoms are those that might make a person feel dissatisfied, fearful, depressed, nervous, or isolated.[5] The National Cancer Institute (NCI) defines them as emotional, spiritual, social, or bodily pain or suffering. People suffering distressing symptoms may find it difficult to control or cope with changes brought on by everyday activities or by the diagnosis of a condition, such as cancer, which makes it difficult for them to deal with their disease's diagnosis or treatment.[6] Distressing symptoms also entail uncontrolled undesired side effects related to cancer and its treatment modalities and often vary from person to person.[2]

Patients with breast cancer who are on treatment regularly experience a variety of symptoms that may give them excessive distress and interfere with their daily activities. These distressing symptoms are mainly associated with cytotoxic drugs and radiotherapy.[5] However, while breast cancer therapies increase cancer survivability, the side effects of the treatments frequently result in major physical and psychological consequences.[7]

Patients with breast cancer are plagued by numerous symptoms connected to the disease or the side effects of its numerous treatment options.[8] Moreover, after initiation of the treatment patients experience pain, fatigue, nausea, vomiting, breathlessness, confusion, insomnia, constipation and diarrhea in addition to symptoms that are related to the disease process at the time of diagnosis.[9] These symptoms may also cause treatment to be interrupted and have a detrimental impact on its effectiveness.[10] If the forementioned symptoms are not well managed, patients' quality of life, ability to function including performance of the activities of daily living and ability to adhere to their treatment are severely harmed by the unresolved symptoms.[5]

Effective symptom management, as demonstrated in various studies, calls for regular and accurate symptom evaluation and communication between patients and health care practitioners.[10] Effective symptom management is linked to higher patient and family satisfaction, better treatment adherence, and possibly even survival benefits. Despite these positives, symptoms are regularly mismanaged and/or under treated, underlining the need for further care improvements.[5]

In Kenya, cancer is the third largest cause of death after infectious and cardiovascular ailments and breast cancer is rated first followed by cervical, prostate, esophageal and colorectal cancers.[1] As breast cancer cases increase, more patients are being initiated on treatment which have got various symptoms and side effects that need to be addressed.[2] Characterizing the symptoms helps the healthcare workers to pick them early and address them hence improving these patients' compliance to treatment and quality of life.[8] Addressing distressing symptoms is also a component of evidence-based practice and helps improve patients' treatment outcomes and care experience.[11,12]

Symptom distress is associated to a lower quality of life, reduced treatment adherence and efficacy, death and a higher risk of suicide. As a result, healthcare workers should work to improve patients' quality of life while also lowering medical expenditures by reducing patient suffering.[13] At Kenyatta National Hospital (KNH), the only data that existed was on the number of patients with breast cancer and the type of the treatment they were under but there were no records for the symptoms experienced by these patients as a result of the treatment they were receiving. Consequently, the aim of the study was to characterize distressing symptoms among breast cancer patients under treatment at Kenyatta National Hospital.

MATERIALS & METHODS

***Study Design*:** The study adopted descriptive cross-sectional study design and utilized both qualitative and quantitative research methods.

***Study Area*:** The study was carried out in the Cancer Treatment Centre (CTC) of Kenyatta National Hospital. Founded in 1901, Kenyatta National Hospital (KNH) is the oldest and largest public teaching and referral hospital in Kenya. It is located about four kilometers from the Nairobi city center, off Ngong road on Hospital Road, has a bed capacity of over 2,000 beds and is served by over 6,000 medical and non-medical staff. It offers specialized care to patients from across the country and from east and central Africa in its various specialized units. It also facilitates medical training and research and supports national healthcare planning. The hospital is a leading centre for comprehensive cancer care. The CTC comprises of various oncology care clinics where patients diagnosed with cancer receive treatment. KNH was an ideal location as it caters for a large number of breast cancer patients seeking cancer related care.

***Study Population and Sample*:** The study population comprised of patients diagnosed with breast cancer on treatment or follow up at the CTC in KNH during the study period. An aggregate of 92 patients with breast cancer was sampled using simple random sampling method.

***Inclusion and Exclusion Criteria*:** All female breast cancer patients who consented to take part in the study and had been on active management for a period of more than three months were included in the study. However, breast cancer patients who failed to consent to take part in the study, those who had started treatment in less than three-month period by the time of the study and those who were mentally unstable or in coma at the time of the study were excluded.

***Research Instruments*:** The study utilized a structured questionnaire and a focus group discussion (FGD) to collect data. The questionnaire was self-administered while the FGD was conducted by the principal researcher among 10 randomly selected study participants. The questionnaire had three main sections which were respondents' sociodemographic characteristics, distressing symptoms and severity of the distressing symptoms. The FGD equally sought to obtain participants' views as to experienced symptoms and their severity.

***Data Collection*:** The questionnaire was administered to the respondents on a self-reporting basis. The respondents had to offer their informed consent before taking part in the study through responding to the study questionnaire. Upon completing filling the questionnaire, the principal researcher received it back, checked it for completeness, thanked the respondent for taking part in the study and proceeded to the next respondent. This was repeated until the study sample size was achieved. For the FGD, the principal researcher with the help of two research assistants conducted the

FGD with one research assistant recording the discussion while the other alongside the principal researcher took notes during the discussion. Once the participants arrived, they were welcomed, introductions of all present done, they were informed of the purpose of the discussion and they were given an explanation of how the discussion would happen. Then the principal investigator requested for informed consent from the participants which was done through signing of the consent sheet. The whole group agreed on the pseudo names to be used during the discussion, all were encouraged to participate freely and the ground rules were set. Once everything was set, the research assistant in-charge of recording alerted the whole team that the recording was starting. The principal investigator moderated the discussion, took notes and clarified points that were not clear. All participants were given equal opportunities to participate and controlled the flow of the discussion to avoid deviating from the main points of discussion. Once the discussion was over the recording was stopped and the participants were informed and the researcher thanked them on agreeing to be part of the study. data from both the questionnaires and the FGD WAS safely stored in readiness for analysis.

***Data Analysis and Presentation*:** Data from the questionnaires was analyzed using descriptive statistics that included frequencies and percentages as well as mean and standard deviation. Association between the respondents' socio-demographic as well as socioeconomic attributes and severity of distressing symptoms was evaluated using chi-square test at a significance level of 5%. The analysis was performed using SPSS version 23 and results were shown in tables. Data from the FGD was utilized to complement the quantitative research findings and was analyzed using qualitative data analysis techniques with findings reported in verbatim.

***Ethical Considerations*:** Kenyatta National Hospital and University of Nairobi (KNH-UoN) Ethics and Research Committee (ERC) approved the study (Ref: KNH-ERC/A/387). Research permit was issued by NACOSTI (NACOSTI/P/22/20957). Data collection was authorized by the Head of KNH's CTC. The study participants offered their informed consent. Acquired study data was treated with utmost confidentiality and was processed and reported anonymously. Ethical principles of voluntary participation, autonomy, anonymity and confidentiality, non-maleficence, beneficence and justice were observed.

RESULTS

A total of 92 respondents took part in the study through responding to the study questionnaire while 10 participants took part in the focus group discussion.

Socio-Demographic Characteristics of the Respondents

Most (55.4%) of the respondents had a monthly household income of below KES 10,000. The respondents' age ranged from 24 to 78 years with a mean age of 48.49 years. Most of the respondents were married (65.2%) while a majority were Christians (91.3%). Further, most had Stage 2 breast cancer (45.7%). The mean duration since diagnosis was 37.14 months (SD = 46.268 months). The respondents had received diverse forms of treatment modalities with the most common being chemotherapy (93.5%) and the least common being immunotherapy (46.7%). In most, the treatment goal was curative (77.2%). Most of the respondents reported that they received support for treatment from family, National Health Insurance Fund (NHIF) and from friends and relatives. Results were as illustrated in Table 1.

Table 1: Socio-demographic characteristics of the respondents (n = 92)

Socio demographic characteristics		Frequency (n)	Percentage (%)
Monthly household income (KES)	Below 10,000	51	55.4
	10,000 - 50,000	37	40.2
	50,000 - 100,000	3	3.3
	Above 100,000	1	1.1
Age (in years)	N		92
	Mean		48.49
	Standard Deviation		12.533
	Minimum		24
	Maximum		78
Marital status	Single	6	6.5
	Married	60	65.2
	Divorced	8	8.7
	Widowed	11	12.0
	Separated	7	7.6
Religion	Christian	84	91.3
	Muslim	8	8.7
Stage of the cancer	Stage 1	13	14.1
	Stage 2	42	45.7
	Stage 3	24	26.1
	Stage 4	13	14.1
Duration since diagnosis (in months)	Mean		37.14
	Standard deviation		46.268
	Minimum		3
	Maximum		288
Treatment modality	Immunotherapy	43	46.7
	Chemotherapy	86	93.5
	Radiotherapy	55	59.8
	Surgery	62	67.4
Treatment goal	Palliative	21	22.8
	Curative	71	77.2
Source of support for treatment	Friends and relatives	24	26.1
	NHIF	31	33.7
	Family	37	40.2

A summary of the socio-demographic characteristics of the participants in the focus group discussion is outlined in Table 2.

Table 2: Sociodemographic characteristics of FGD participants

Participant	Age in years	Gender	Marital status	Religion	Disease stage	Treatment modalities given
PPT 1	42	F	Married	Christian	2	Chemotherapy Radiotherapy Surgery
PPT 2	35	F	Married	Muslim	2	Chemotherapy Surgery
PPT 3	38	F	Married	Christian	3	Chemotherapy Radiotherapy Surgery
PPT 4	62	F	Widowed	Christian	4	Chemotherapy Radiotherapy Hormonal therapy
PPT 5	55	F	Married	Christian	3	Chemotherapy Radiotherapy
PPT 6	45	F	Single	Christian	2	Chemotherapy Radiotherapy Surgery

						Hormonal therapy
PPT 7	29	F	Single	Christian	1	Chemotherapy Surgery
PPT 8	32	F	Separated	Muslim	1	Chemotherapy Radiotherapy Hormonal therapy
PPT 9	41	F	Married	Christian	3	Chemotherapy Surgery
PPT 10	37	F	Separated	Christian	2	Chemotherapy Hormonal therapy Surgery Radiotherapy

Distressing Symptoms in Patients with Breast Cancer

The study sought to characterize distressing symptoms among the respondents. The most occurring symptoms included fatigue, pain, lack of appetite, drowsiness, nausea, anxiety, and vomiting while the least experienced symptom was shortness of breath, as illustrated in Table 3.

Table 3: Distressing symptoms experienced by the participants (n = 92)

Symptom experienced	Frequency(n)	Percentage (%)
Fatigue (Lack of energy)	76	82.6
Pain	74	80.4
Lack of appetite	66	71.7
Drowsiness	64	69.6
Nausea	64	69.6
Anxiety (feeling nervous)	62	67.4
Vomiting	46	50.0
Depression (Feeling sad)	42	45.7
Diarrhea	41	44.6
Constipation	24	26.1
Shortness of breath	22	23.9

In addition to the symptoms depicted in Table 3, 52.2% (n = 48) of the respondents experienced other additional symptoms as highlighted in Table 4.

Table 4: Additional distressing symptoms as reported by the respondents (n = 48)

Other symptoms experiencing	Frequency(n)	Percentage (%)
Abdominal pain	11	22.9
Mucositis	10	20.8
Skin changes	10	20.8
Insomnia	8	16.7
Lymphedema	6	12.5
Anger	3	6.3
Weight loss	2	4.2
Confusion	2	4.2
Dizziness	2	4.2
Tingling sensation	2	4.2
Lump in breast	1	2.1
Nipple discharge	1	2.1
Low self esteem	1	2.1
Coughing	1	2.1

The distressing symptoms as expressed by the FGD respondents included nausea, fatigue, hotness of the body especially in head, depression, hair loss, lymphedema, mucositis, lack of appetite, feeling of pins and needles and tingling of sensation on the

fingers and toes, anger, skin changes, vomiting, bone weakness causing pain on the joints, backache and legs.

Some of the respondents' quotes were "*My skin has become very dark and coarse…….".* another explained that *"……the kind of nausea I feel worse than when I was pregnant…."* (PPT 5). And at this point a couple of the participants reported that it was true that the nausea was beyond what they could explain. Another respondent stated that she had sores in the month *"……I could barely put anything in the mouth, even the presence of saliva was painful…."* (PPT 1) and another reported that *"I feel as if my hand is about to burst……". (PPT 8)*

There was a discussion about the top five most common distressing symptoms they experienced and the group agreed them as including nausea, pain, mucositis, fatigue and anxiety. However, they could not agree on the top five worst of the symptoms because everyone described their own symptom as the worst.

Severity of the Distressing Symptoms among the Patients with Breast Cancer

With use of the Edmonton Symptom Assessment Scale (ESAS), anxiety was the most severe symptom among the respondents with a mean of 5.7. This was closely followed by appetite at a mean 5.52, well-being 5.43, fatigue 5.24, nausea 5.14, pain 4.84 and drowsiness at a mean of 4.74. The most common symptom among the respondents was pain (n=80, followed by drowsiness (n=79), drowsiness (n=74), nausea (n=73), well -being at (n=72) and appetite and best sleep at n=66. Results were as shown in Table 5.

Table 5: Severity of the distressing symptoms among the respondents

Symptom	N	Mean	Std. Deviation	Minimum	Maximum
Fatigue	80	5.24	2.78	0	10
Pain	79	4.84	2.748	0	10
Drowsiness	74	4.74	3.223	0	10
Nausea	73	5.14	2.54	0	10
Wellbeing	72	5.43	2.55	0	10
Appetite	69	5.52	2.253	0	9
Best sleep	69	4.51	2.649	0	10
Anxiety	66	5.7	3.008	0	10
Depression	63	4.6	3.15	0	10
Shortness of breath	59	1.42	2.207	0	9

Association of Socio-Demographic Characteristics on Severity of Distressing Symptoms

Multiple linear regression analysis was conducted to establish the relationship between the independent variables (income, age, marital status and religion) and the dependent variable (severity of the distressing symptoms).

R^2 (coefficient of determination) indicates how much of the variation in the dependent variable was explained by the model. Our model explained 16.1% of the variation in the dependent variable (severity of the distressing symptoms). However, since we had more than one independent variable, the adjusted R^2 was used as it caters for multiplicity of variables and concluded that the model explained 12.2% of the variation in the symptoms' severity. Results were as depicted in Table 6.

Table 6: Model summary

Model Summary				
Model	**R**	**R Square**	**Adjusted R Square**	**Std. Error of the Estimate**
1	.401[a]	.161	.122	1.67624
a. Predictors: (Constant), religion, monthly household income, age, marital status				

Analysis of variance (ANOVA) in a multiple linear regression is meant to indicate if the model is statistically significant. Since the P-value of 0. 004 <0.05, the regression model was deemed to be statistically significant. Results were as shown in Table 7.

Table 7: Analysis of Variance (ANOVA)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	45.895	4	11.474	4.083	.004[b]
	Residual	238.831	87	2.810		
	Total	284.726	91			
a. Dependent Variable: Severity of the distressing symptoms						
b. Predictors: (Constant), religion, monthly house income, age, marital status						

Regression coefficients results indicated that monthly household income level and marital status were the socio-demographic characteristics that had a statistically significant association with the severity of the distressing symptoms among the study respondents as denoted by P-values of 0.05 and 0.013 respectively. The two had a positive relationship with severity of the distressing symptoms as signified by beta coefficient values of 0.587 for the monthly household income and 0.460 for marital status. This implied that being separated, divorced or widowed marital-wise and coming from a poor household correlated with more severe distressing symptoms among patients with breast cancer. Results were as outlined in Table 8.

Table 8: Regression coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	1.936	1.122		1.726	.088
	Monthly Household Income	.587	.295	.204	1.988	.050
	Age	-.012	.015	-.081	-.777	.439
	marital status	.460	.182	.271	2.524	.013
	Religion	1.196	.628	.191	1.903	.060
a. Dependent variable: Severity of the distressing symptoms						

DISCUSSION

Distressing Symptoms in Patients with Breast Cancer

According to study the most occurring distressing symptoms was fatigue, followed by pain, lack of appetite, drowsiness, nausea, anxiety, vomiting, depression, diarrhea, constipation and least symptom experienced was shortness of breath. The outcome from this study shows similar distressing symptoms as those of a study that was done in Norway [14] though the order and percentage of the symptoms is different.

The study found out that anxiety is the most common distressing symptom. This concurs with another study where psychological symptoms in breast cancer patients, was rated at 10 to 30%.[15] Similarly, this study found that anxiety was among the chief distressing symptoms with a percentage of 10.7%. The same study also stated that anxiety has been shown to cause fatigue and poor treatment outcome, have an effect on the quality of life.[15]

In a study done by Sara Francis, there is a significant increase in fatigue and psychological distress from pre-chemotherapy to post-chemotherapy and improvement was observed six months after the completion of chemotherapy. A positive or negative change in fatigue was associated with the same in psychological distress.[16] The above symptoms indicate appearance of distressing symptoms after the start of

treatment thus treatment related distressing symptoms.

Apart from the commonly experienced symptoms, more than half of the participants had other symptoms that included abdominal pains, mucositis, insomnia, skin changes, anger, weight loss, confusion and dizziness. Correspondingly a study by Henson and others indicated that at any particular time patients typically experience more than one symptom and those with metastatic cancer have, on average 14 symptoms and at the least five.[5]

Severity of the Distressing Symptoms among the Patients with Breast Cancer

In this study the Edmonton Symptom Assessment Scale (ESAS), was used to guide in the selection of the distressing symptoms and their severity. Likewise in a study by Henson and others showed different assessment tools that were commonly used for both clinical practice and research were the Edmonton Symptom Assessment System, the Palliative Care Outcome Scale (POS) and the Palliative Performance Scale.[5]

The study established that the distressing symptoms were anxiety, lack of appetite, loss of wellbeing, fatigue, nausea, pain and drowsiness. This was different from a study done in Switzerland that showed the most distressing symptom was fatigue followed by pain, nausea, vomiting, constipation, insomnia and lack of appetite.[17]

CONCLUSION

In Kenya patients diagnosed with breast cancer experienced a wide range of distressing symptoms chief among them being fatigue, pain, lack of appetite, drowsiness, nausea, anxiety, vomiting, depression, diarrhea and constipation. Mucositis, skin changes, insomnia and lymphedema were other additional distressing symptoms experienced by some of these patients. Fewer number also experienced shortness of breath. The most severe of these distressing symptoms were anxiety, fatigue, nausea, poor wellbeing and lack of appetite. Being separated, divorced or widowed marital-wise and coming from a poor household were predictors of more severe distressing symptoms among the patients with breast cancer. Patients with breast cancer should be counseled on various appropriate coping strategies for effective management of the distressing symptoms.

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