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SYMPTOMS PROFILE AMONG BREAST CANCER PATIENTS ACCESSING CARE AT UNIVERSITY OF ILORIN TEACHING HOSPITAL

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ABSTRACT

Background: Breast cancer is the leading cause of cancer morbidity and mortality among women in developing countries. Advanced stage disease with limited treatment options implies a significant symptom burden, which poses a challenge to attending health care providers.

Objectives: To determine prevalence and the severity of symptoms among breast cancer patients.

Design of the Study: Descriptive cross-sectional hospital-based study

Study Area and Population: Breast cancer patients attending the University of Ilorin Teaching hospital.

Materials and Methods: Breast cancer patients attending surgical outpatient clinics and those on admission during the study period were recruited. The patients completed an interviewer administered symptom assessment tool consisting of 32 physical and psychological symptoms. Demographics, cancer stages, treatments and referrals for palliative care interventions were obtained from the case notes.

Results: Sixty breast cancer patients were studied, and eighty percent (80%) of the patients had advanced cancer. The number of symptoms ranged from 0-18, and the overall mean number of symptoms was 5.5 ± 4.4 . The top 5 symptoms were; pain (63.3%), worrying (45%), feeling sad (41.7%), weight loss (46.7%) and insomnia (35%). Pain, poor body image, breast swellings were the most distressing symptoms. Five percent (5%) of the patients had referral to palliative care team.

Conclusion. This study showed that breast cancer patients manifest significant physical and psychological symptoms. Pain was the most prevalent and distressing symptom. Systematic symptom assessment and palliative care service provision are recommended for breast cancer patients with advanced disease.

INTRODUCTION

Breast cancer is the most common cancer in women worldwide, accounting for 25% of all cancers in women and also a major cause of cancer deaths¹. In Nigeria, breast cancer is also the commonest cancer in women², having overtaken cervical cancer. Majority of patients with breast cancer in developing countries like Nigeria present with advanced disease, and the requisite specialists and facilities for care are either limited or non-existent³. This results in a large number of breast cancer patients resorting to other forms of care rather than present to the hospital. Late-stage clinical presentation for cancer cases and minimal availability of treatment facilities ^{3,4,} all imply significant discomfort for patients. Symptom's profile would enable detection of burden and attention for remedies particularly in the palliative care settings. Significant symptoms are commonly present whether cancer is amenable to cure or management focus will be palliative care services⁵. However, symptoms are often not explored and may oftentimes go unnoticed by the health care providers ⁶. The need to assess for monitoring and addressing symptoms in life threatening conditions like breast cancer improves quality of life.

In health facilities, symptoms care assessment with the aid symptoms diary is considered the gold standard⁷. The Memorial symptoms assessment scale-short form is one of the available symptom assessment tools that have been validated and used among cancer patients in some studies⁸. It was used in this study because of its broader number of symptoms which cut across both physical and psychological symptoms. In addition, it is applicable in clinical palliative care to improve the quality of lives of patients with life threatening conditions like advanced cancer⁹. In the management of advanced breast cancer,

palliative care is relevant right from the point of making diagnosis and therefore having symptoms profile would be invaluable.

Published studies on symptom burden in breast cancer patients in this environment are scarce. The commonly available studies on the symptom burden in breast cancer patients in the developed countries are mainly on post treatment patients or those on treatments 10,11 The symptom profiles in the developed countries are likely to differ from those of the developing countries. The difference emanates from symptoms related to the effects of chemotherapy and radiotherapy that are rather more prevalent in developed countries while symptoms of treatment naïve disease progression are more common in this environment.

Furthermore, young age, premenopausal states of many women, and late presentations have been reported in studies from Nigeria ^{12,13,14} while treatment challenges such as non-acceptance or non-adherence to treatment have also been described⁴. The aim of this study was to prospectively explore the symptom profiles among breast cancer patients accessing care at a tertiary health care center with the view of identifying symptom burden that would inform and possibly improve early detection and enhance holistic care of patients.

METHODOLOGY

Design: The study was a descriptive prospective cross-sectional hospital-based survey.

Study Population: The study population was adult breast cancer patients admitted into the surgical ward and those patients attending the surgical outpatient clinics of the hospital over a 6-month period from 20th October 2015 to 15th of April 2016.

Selection criteria: Patients with histological confirmed breast cancer and over 18 years of age.

Exclusion criteria:

Being in distress such that communication was not possible

Not able to give consent.

Materials and Methods: The data collection tool was the Memorial Symptoms Assessment Scale-Short Form and a participant data sheet. 1). The participant data sheet was used to record socio-demographic details mainly from the case notes. Information obtained included the age, religion, educational level, ethnicity, occupation and phone numbers. Other information included cancer types, duration of disease, and stage of cancer and referral for palliative care interventions.

2) The Memorial Symptom Assessment Scale Short Form (MSAS-SF)¹⁵ which is a validated symptom assessment tool that is used to document symptoms experienced in the preceding 7 days prior to interview. MSAS-SF is a 32-item tool containing 28 physical and 4 psychological symptoms. It has provision for additional symptoms that may be present. Participants are required to answer yes to symptoms that are present and then go ahead to describe how distressing the symptoms were.

Data management: Data from the participant data sheet was sorted and manually checked for data clarity and errors before entry. Data were entered into SPSS version 20.0 (Statistical products and services solution formerly called statistical package for social sciences [IBM-SPSS inc. Chicago II USA version 20.0). Tables

and graph were used to report descriptive statistics. Categorical variables such as stage of disease and symptoms documented for the patients were presented as proportions and frequencies. For continuous variables, means, median and standard deviations and interquartile ranges (IQR) were computed. *Ethical considerations:* Ethical approval for the study was obtained from the Human Research Ethics Committee of the University of Cape Town and the ethical committee of University of Ilorin Teaching hospital, Ilorin, Nigeria. In addition, the study involved no direct interventions to the participants and deemed care was provided whether patients signed consent or not.

RESULTS

The study was conducted among 60 breast cancer patients. All were accessing care at the University of Ilorin teaching hospital as either outpatients or inpatients. The age range of the studied population was 25-85 years with a peak range of 40-49 years and a mean of 51.5 years. Over half (51.7%) had attained at least a secondary level of education. Majority (83%) of the patients had at least stage 3 diseases and only 5% of the had palliative care involvement in their management.

Twenty-four patients were on chemotherapy (neo-adjuvant or adjuvant chemotherapy), 21 were on hormonal therapy alone, one patient was seen few days after surgery and 14 patients were not on any cancer specific treatment at the time of the interview.

| Socio-demographic and clinical information of the study population | | | |
|--|----------------------|--|--|
| Factor | N (%) | | |
| Age | | | |
| Mean <u>+</u> standard deviation | 52.68 <u>+</u> 12.82 | | |
| Median | 51.5 | | |
| Range | 25-82 | | |
| | | | |
| | | | |
| Educational level | | | |
| None | 18 (30.0%) | | |
| Primary | 11 (18.3%) | | |
| Secondary | 9 (15.0%) | | |
| Tertiary | 22 (36.7%) | | |
| | | | |
| Stage | | | |
| Ι | 2 (3.3%) | | |
| II | 8 (13.3%) | | |
| III | 38 (63.3%) | | |
| IV | 12 (20.0%) | | |
| | | | |
| Palliative care referral | | | |
| Yes | 3 (5.0%) | | |
| No | 57 (95.0%) | | |
| | | | |
| | | | |
| | | | |

 Table 1

 Socio-demographic and clinical information of the study population

Number of symptoms based on MSAS-SF.

The number of symptoms including additional symptoms ranged from 0-18. The mean number of MSAS-SF symptoms was 5.2 + 4.1 and this increased slightly to 5.5 + 4.4 when the additional symptoms were included.

Symptom's prevalence

The top 5 symptoms (table 2) in the studied patients were pain 38 (63.3%), worrying27 (45.0%), feeling sad 25 (41.7%), weight loss 22

(36.7%) and difficulty sleeping (insomnia) 21 (35.0%). There were a number of additional symptoms which were not listed in the MSAS-SF but frequently described by the patients. These additional symptoms were mainly breast swellings, foul smelling discharge from the breast, chest discomfort, neck/axillary swelling, hoarseness of voice, muscle cramps, bed wounds/sores, immobility and amenorrhea.

| Symptoms preduce in dreast cancer patients | | | | |
|--|------------------------|--|--|--|
| Symptom | breast cancer patients | | | |
| Pain | 38 (63.3%) | | | |
| Worming | 27 (45%) | | | |
| Fooling and | 27(45%) | | | |
| Maight loss | 23(41.7) | | | |
| Diff: It I i | 22 (36.7%) | | | |
| Difficulty sleeping | 21 (35.0%) | | | |
| Lack of energy | 20 (33.3%) | | | |
| Hair loss | 19 (31.7) | | | |
| Numbness | 14 (23.3%) | | | |
| Feeling Nervous | 13 (21.7%) | | | |
| Cough | 13 (21.7%) | | | |
| Don't look like myself | 12 (20.0%) | | | |
| Lack of appetite | 10 (16.7%) | | | |
| Dry mouth | 10 (16.7%) | | | |
| Shortness of breath | 10 (16.7%) | | | |
| Sweats | 9 (15.0%) | | | |
| Swelling arm/legs | 9 (15.0%) | | | |
| Dizziness | 7 (11.7%) | | | |
| Feeling drowsy | 6 (10.0%) | | | |
| Nausea | 4 (6.7%) | | | |
| Change in taste | 4 (6.7%) | | | |
| Irritable | 4 (6.7%) | | | |
| Change in skin | 4 (6.7%) | | | |
| Itching | 3 (5.0%) | | | |
| Difficulty swallowing | 3 (5.0%) | | | |
| *Others | 5 (8.5%), | | | |
| Additional 1 19 (31.1%) | | | | |
| Additional 2 4(6.7%) | | | | |
| | | | | |

 Table 2

 Sumptoms prevalence in breast cancer patients

*Others: (vomiting-1, difficulty concentration-1, constipation-1, feeling bloated-1, problem with sex-1, diarrhea-0, problem with urination-0, mouth sores-0)

Additional 1: (breast swelling-7, breast discharge-1, chest discomfort-2, neck/axillary swelling 2, hoarseness of voice-1, muscle cramps-1)

Additional 2: (abdominal discomfort-1, bed sores-1, breast wound-1, immobility-1)

The most distressing symptoms among the patients studied

Table 3 shows the topmost distressing symptoms among the patients. The most distressing symptoms for which >50% of the patients rated as "quite a bit/very much were pain 19 (50.0%) and "I don't look like myself" (75. 0%). The other symptoms rated as highly

distressing are not listed in the MSAS-SF and they included breast swellings or ulcerations, neck swelling and immobility. Most of the psychological symptoms were not considered highly distressing because more than half of the patients rated the symptoms as rarely or occasionally occurring.

| The most distressing symptoms among the breast cancer patients | | | | |
|--|---------------------------|--------------|-----------------------|--|
| Symptom | Not at all/little bit (%) | Somewhat (%) | Quite a bit/Very Much | |
| Pain | 13(34.2) | 6(15.8) | 19(50.0) | |
| Don't look like myself | 1(8.3) | 2(16.7) | 9(75.0) | |
| Additional symptom 1 | 2(10.5) | 7(36.8) | 10(52.6) | |
| Additional symptom 2 | 1(25.0) | 0(0.0) | 3(75.0) | |

 Table 3

 The most distressing symptoms among the breast cancer patients

* Additional symptoms are not in the original MSAS tool

DISCUSSION

This cross-sectional prospective study was carried out in order to document symptom prevalence in breast cancer patients in a tertiary health care institution in North Central Nigeria. To our knowledge this is the first Nigerian study to prospectively survey symptom prevalence among breast cancer patients in this institution.

Demographics

Breast cancer is a disease of younger women in Africa when compared with the Caucasians where it occurs in much older women. This study reported a peak age range of 40-49 years and a mean of 51 years. This age range is similar to that found by Adesunkanmi¹⁶. However, the mean age, although slightly higher than 44 years and 48 years found by Anyanwu and Adesunkanmi 4,16, was still comparable to that found in this study. The consistency in these two studies are the lower mean ages than the 51 years in this our study. The reasons for the lower mean age obtained in those other studies could be because of the larger sample size in those retrospective studies compared to this study.

In this study more than 50% had attained at least a secondary school level of education. The high proportion of breast cancer patients with at least a secondary school level of education was similar to 48.7% found in study by Adesunkanmi et al¹⁶, and high literacy level was also demonstrated among the study population by Anyanwu⁴. This is not surprising since breast cancers occur at a younger age and young patients are more likely to be educated than the older ones. Generally, literacy level is gradually increasing in Nigeria, like in other developing countries. *Stage of Disease*

One-sixth 10/60 (16%) of the patients had early disease (stage 1 or 2) while more than 80% of patients were at stage 3 or 4 of their disease. This conforms to previous studies 4,13 among Africans that have shown that cancer patients present in advanced stages of cancer. More than half (51.7%) of the patients studied had at least secondary level of education while the remaining were less educated, having only primary level of education or none at all. This level of education, however, did not reflect in the stage of the disease found in this study as more than 80% of the patients were with stage 3 or 4 disease. This finding implies that being educated does not necessarily mean that patients will present early for clinical evaluation. This was similar to the findings by Anyanwu⁴ who reported a similarly advanced stage of disease in their population of highly literate patients managed for breast cancer. Poor knowledge about cancer generally and early cancer symptoms, particularly both by the educated and the uneducated people have

been reported by some authors ^{4,12}. Cancer screening centers are also scarce in many African settings, including Nigeria ¹⁷. All these contribute to the late presentation of cancer cases to the hospital. There is need for continuous public education by providing accurate information on early cancer symptoms and embarking on awareness campaigns on cancers, especially that of the breast which is an easily accessible organ. The training on symptoms profile and retraining of health care providers and creating more cancer screening centers as well as renovating the existing centers are needed in order to reduce the number of patients presenting in advanced stage of disease.

Symptom Prevalence

The prevalence of symptoms in this study ranged from 0 - 18. This was lower than a range of 0.25 reported by Portenoy et al ¹⁸ and 1.27 symptoms reported by Declan Walsh ¹⁹. Both of these studies involved a wider range of cancer types unlike this study population of breast cancer only. About 20% of patients in this study had 0 or 1 symptom only. The heterogeneity of patients in terms of stages of disease and treatment statuses could explain the widely differing symptom prevalence.

The mean number of symptoms in this study was based on the Memorial Symptom Assessment Scale Short Form that was used. One or two additional symptoms were accommodated if present. The mean number of symptoms was 5.2<u>+</u>4.1 and the median was 5 symptoms in this study. The result is comparable with that obtained for a cancer population studied in Jordan(20) but it was much lower than that reported in a similar group of patients studied in Africa ⁸. Making allowance for the additional symptoms was essential for some patients because the additional symptoms alone were present in them. In considering the additional symptoms, the mean number of symptom for breast cancer patients was 5.5+ 4.4. This mean number of symptoms was much lower than 14.5 \pm 6.4 reported by Muthukkumaran²¹ and also 8 reported by Victor et al²². It was however similar to the overall mean of 6 symptoms reported by Alaweh²⁰. Harding et al ⁸ study was conducted among patients already referred for palliative care intervention, signifying advanced cancer in all of their patients, and this alone may explain the higher mean number of symptoms. The lower mean number of symptoms obtained in this study compared to that of Harding et al ⁸ may also be due to additional symptoms which were eight in number, incorporated into the MSAS-SF used in that study compared the optional one or two additional symptoms that was added if present in this study.

The overall ten most frequent symptoms for breast cancer patients in this study were pain, worrying, feeling sad, weight loss, difficulty in sleeping, energy, lack of hair loss, numbness/tingling in hand and feet, nervousness and cough. Comparing these with the top 10 most prevalent symptoms in a systematic review by Kim et al 23 and Reily et al ²⁴, 6-8 of these symptoms were replicated in this study. Also, Teunissen et al's ²⁵ top five symptoms of fatigue, pain, lack of appetite, weakness and anorexia are similarly found in this study. The symptoms reported in this study correlated well with finding from other studies that have used similar symptom assessment tool. This is because cancer symptoms in advanced stages commonly have similar constitutional symptoms asides the location specific symptoms.

Most Distressing symptoms

The most distressing symptoms for breast cancer patients were "don't look like myself" and pain. Other symptoms rated as most distressing were not listed in the MSAS tool and included presence of breast swellings, neck swelling and immobility. "Don't look like myself" which connotes a body image issue was identified in this study population as most distressing. Pain has similarly been reported in many studies to be very distressing and results in aggravation of other symptoms. Any mutilating surgery is also likely to result in a sense of poor body image in any patient. For the breast cancer patients in this study, mastectomy and the presence of huge breast swellings constituted disfigurement which resulted in poor body image in these patients. A sense of poor body image negatively affects sexuality and sexual function ^{26,27}. For many women, the breast is considered an important component of womanhood and loss of it negatively affects the physical appearance as well as the psyche of most women 27,28. Chemotherapy also contributes to reduction of sexual function by inducing menopause or worsening menopausal symptoms for those already menopausal²⁶.Although that are almost all the patients in this study reported not having any problem with sexual relation or interest as it was stated in the MSAS-SF, majority of them actually do not consider sexual relationship a priority in their present predicaments of battling with cancer diagnosis. Despite asking with much sensitivity and caution, some of them were still offended and other embarrassed by the questioning. It may be more appropriate to find ways to identify patients that will be willing to discuss sexual issues and who may then require advice in this regards other than asking very patient this sensitive question.

All the psychological symptoms were not considered distressing by the breast cancer patients. The low distress caused by the psychological symptoms may be responsible for the non-treatment in spite of the high prevalence. The possibility of under-reporting of the distress caused by psychological symptoms may be due to more focus on physical symptoms, especially if they are severe. The low scores for psychological symptoms reported in this study may also be attributed to poor understanding of cancer as a disease among the populace²⁹. Other studies have highlighted that poor cancer knowledge is common to both literates and the nonliterates⁴. The high prevalence of psychological symptom though with low level of distress is a pointer to the need for repeated or close psychological monitoring as the disease progresses or as the patients understand their illness better.

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