

PATTERN OF BREAST CANCER REFERRAL TO PALLIATIVE CARE AND THE COMPLIMENTARY ROLE OF A PALLIATIVE CARE UNIT IN A RESOURCE-LIMITED COUNTRY

Agodirin SO¹, Rahman GA¹, Olatoke SA¹, Durojaiye AO²

¹Division of General surgery, University of Ilorin Teaching Hospital, ¹Ilorin, Kwara State, Nigeria, ²Pain and Palliative Unit, University of Ilorin Teaching Hospital, Ilorin, Kwara State.

Abstract

Background: Poor quality of end of life care is an information problem. Information about palliative and end of life care is sparse from developing countries. Only 10 percent of the information in this field of care emanates from developing countries where about 85% of annual deaths due to cancerous diseases occur. We present review of breast cancer patients referred to Palliative unit of our hospital between May 2009 and June 2013. This article demonstrates challenges to palliative care and the complementary role of the palliative unit to palliative care in developing countries

Method: The records of the Palliative unit University of Ilorin Teaching Hospital were reviewed for information about the stage of the disease at referral, performance status of the patients, the support given by the palliative unit and outcome of care.

Result: One hundred and one patients were reviewed for breast cancer by the Palliative unit during the study period. Most of the referrals were from one of a general surgery units in the hospital. The number of referrals per year showed no sustained commitment to referral for palliation.

The palliative unit provided counselling, home visitation and source of psychosocial and financial support. The median survival duration was 3 months. 59 percent of the recorded deaths were at home

Conclusion

This report demonstrated that even though the palliative unit filled a void in the management of breast cancer patients, palliative care is still not widely accepted.

Key Words: palliative care, challenges, breast cancer

INTRODUCTION

Medical management of malignant diseases will consider one of two aims; to cure the early disease or to palliate the late disease. These 2 aims are usually adequately addressed by the system of care in the developed countries. The beneficial role of palliative care such as pain control, treatment of anorexia, insomnia and other symptoms control as recommended by WHO is reported in developed countries and in few developing countries where palliative care is well established^{1,4}. Many centers in the developing countries have no palliative care system, specialized palliative care is virtually non-existent^{2,3,6,7} and cure appears to be the recognized and readily acceptable measure of success¹. A goal which is rarely achievable due to late presentation^{1,4,5}

In many developing centres, once cure is no longer achievable the patient and many care-givers literally “submit to the will of the disease” because of several reasons^{4,5} including of course, “the submission to the will of God”. This “fatalistic acceptance”⁶ deprives

many patients of the active care required towards the end of life.

Breast cancer which is the most common malignancy in women is also a leading cause of death, mutilation and misery. In the developing countries, more than 70% of patients with breast cancer present at a late stage⁷. At this stage the disease brings untold hardship to the afflicted and their relations.

Poor quality of end of life care has been described as an information problem⁶. Information about palliative and end of life care is sparse from developing countries^{6,8}. Only 10 percent of the information in this field of care emanates from developing countries where about 85% of annual deaths due to cancerous diseases are recorded⁶. In our center, there is a budding palliative care unit established in 2009. We present a review of breast cancer patients referred to this center for palliation. This article describes the pattern of referral and the complementary role of palliative care. The article also adds to the information emanating about palliative care for breast cancer patients in developing countries.

Corresponding Author: Agodirin Sulaiman Olayide
University of Ilorin Teaching Hospital, Ilorin,
Kwara state Nigeria.

Email Address: cancer1992@yahoo.com

Conflict of Interest: None Declared

Method and Study Center

Study centre

The pain and palliative unit (PAPU) of our hospital (University of Ilorin Teaching Hospital, Ilorin, Kwara state Nigeria) was established in 2009. At the time of this review, the PAPU was still a relatively small unit for a 650 bedded tertiary care center. It was

manned by 4 doctors two of whom are anesthesiologists, 4 nurses, 1 physiotherapist, 1 social worker, 2 spiritual leaders (a Muslim and a Christian) and 2 other volunteer members. Referrals were initially expected at the time of diagnosis of all terminal illnesses, especially HIV/AIDS and all cancers. At the time of this review, the referral for cancer patients was preferred at stages III and IV because of the limited staff strength and the increasing workload.

The records of breast cancer patients referred to the PAPU between May 2009 and June 2014 were reviewed and the Nursing staff of the PAPU were briefly interviewed to shed light on some of the records and clarify the findings. The information sought was the source of referral, the stage at referral, the complications present at the time of referral, performance status of the patients at the time of referral, the treatment and other aids given by the PAPU team and the duration of exposure to palliative care as at the time of this report. Results were presented in descriptive statistics.

Results

The sources of referrals to the PAPU were 3 general surgery units within the hospital, the General outpatient department of the hospital, other adult clinical subspecialties and external sources (private hospitals within the state and neighboring states). Most of the referrals were from one of the general surgery units within the hospital, in this report we refer to this unit as General Surgery unit A (GSA) (Figure 1).

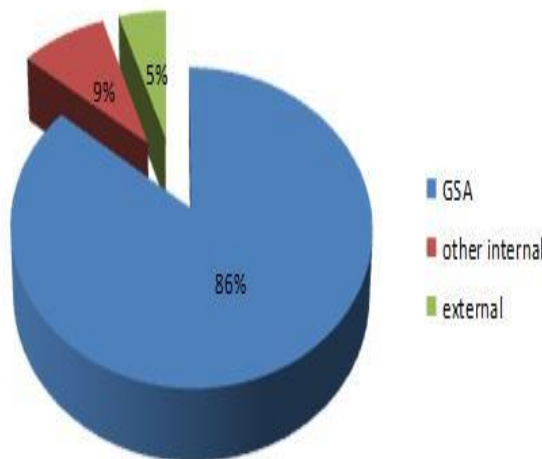


Fig. 1: Sources of referral

One hundred and one patients were reviewed for breast cancer by the PAPU during the study period. Ninety four percent of the patients presented to the PAPU in advanced stage (figure2). The karnofsky performance score was documented in 56 percent. The

median performance score was 50 percent for the available records. The number of yearly referrals

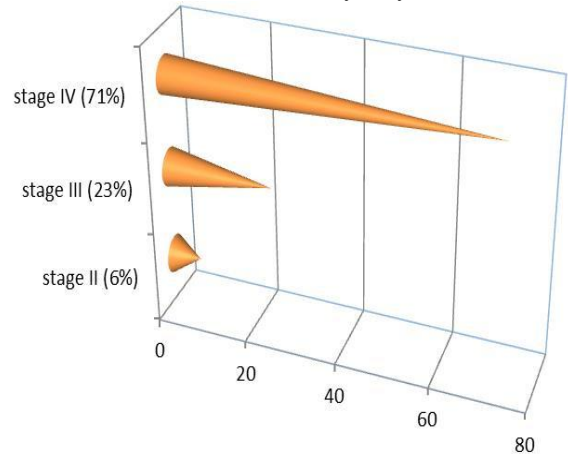


Fig. 2: Stage of presentation to the PAPU

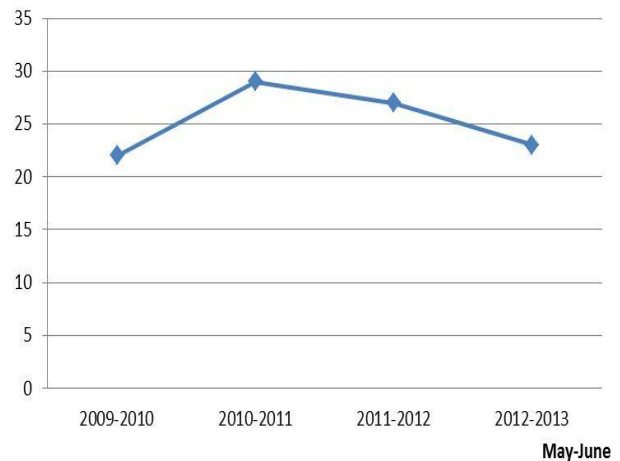


Fig 3: Frequency of referral to the PAPU per year over the four year period

Table 1: Complications present at time of referral to PAPU

Complications	Frequency
Chest Metastasis	24
Fungation	13
Spine Metastasis	11
Brain Metastasis	7
Lymphedema	6
Liver Metastasis	2

revealed a fluctuating trend (Figure3). The most frequent complication present at the time of referral was chest metastasis (Table 1)

Care and aids given by the PAPU were communication and counseling in line with the objectives of orthodox palliative medical care. Some specific aspects of the communication and counseling included establishment of other outcomes different

from cure, tactical provision of information about possible progression, outcomes and realistic goals and expectations. Other supports rendered by our PAPU included pain control, home visitations, telephone contacts and sourcing for financial aids.

Pain control was achieved with combinations of oral or intravenous morphine, oral paracetamol, oral nonsteroidal anti-inflammatory agents and oral amitriptyline. Fifty four patients (53%) had pain at presentation, the median pain score on a numerical rating scale of 0 to 10 was 3. The sites of the pain were the breast, axilla and locations of metastasis (chest, spine, or long bones). Of the 54 patients that presented with pain, total relief or reduction in pain score was achieved in 31 patients, the pain worsened or remained unchanged in 14 patients while the remaining 9 had no repeat documentation of their pain score as at the time of this report

Within the study period, 85(84.2%) of the patients referred to the palliative records had died; the median survival duration was 3 months (Figure 4a and 4b).

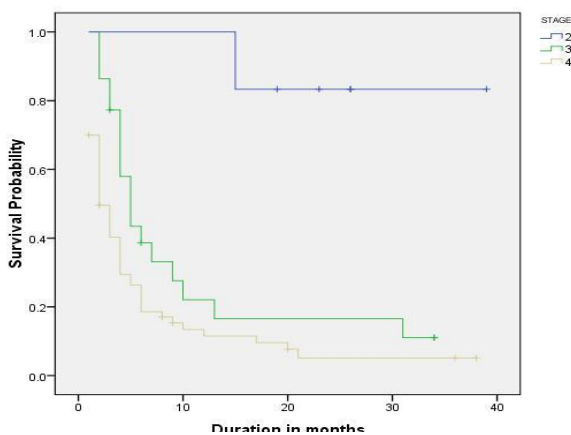


Fig. 4a General survival curve

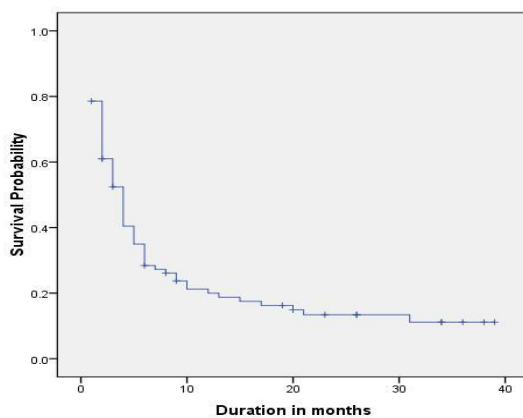


Fig. 4b: Survival curve by stage of presentation

The survival was similar for both stages III and IV diseases. Place of death was recorded for 61 of the 85 patients. 59 percent of the recorded place of death was

home. The others died in the surgical wards or at the accident and emergency unit.

Discussion

The incidence of breast cancer is increasing in developing countries yet the stage of presentation still remains late. At the late stages, the disease may constitute a serious problem; it may be mutilating, destroying the self-esteem of the patients. It may disrupt the family system and lead to social isolation and abandonment because of the physical and socioeconomic demands on the family. The patient in Figure 5 was a victim of such circumstances. She was abandoned in the hospital.



Fig. 5 Advanced breast cancer patient; mutilated and abandoned

The PAPU unit in our center complements the medical management of these patients by offering home visitations, communication and counseling consistent with orthodox care and realistic expectations, sourcing for funds and other psychosocial supports. The effort of the PAPU encourages the relations to sustain the care of the patients and protects the family unit.

The late presentations to the PAPU is a reflection of the overall late presentation to the hospital and also late referral for palliative care, it has been shown that it is possible to improve the number of patients presenting to the hospital at early stages with sustained campaign and enlightenment programs^{9, 10}. The declining number of referrals to our PAPU demonstrates the flinching commitment to referral of patients for palliative care. A large percentage of the referrals were from one of the three general surgery units. A brief interview of the nursing staff of the PAPU revealed information that shed a little light on what the members of the PAPU perceived as possible reasons for the skewed and fluctuating pattern of referral. Firstly, the PAPU had permission to review patients being managed for terminal diseases by the GSA while awaiting a formal referral or invitation which may be delayed, but was always eventually done. The PAPU did not have the same from the other units. The express permission given by the GSA

limited the logistics of inter-unit referral. Secondly, some primary care physicians insisted that PAPU team will be invited when and only when no other active treatment can be offered to the patient. And lastly, the PAPU nurses were referred to as “idle workers” by some colleagues. These perceptions of the PAPU nurses were not confirmed by interviewing other nurses and physicians in the hospital. Late referral to palliative unit is not new to Nigeria². In other places, previously documented reasons that dissuade active palliative care and lead to poor volume of referral to palliative units include fear of loss of patient to another unit, non-acceptance of the benefit of specialized palliative care; active palliative treatment is considered not cost effective hence undeserving of a share of the limited resources^{7,9,14}

In our review, the most frequent clinically evident complications at the time of referral to the PAPU were fungation and chest metastasis. In the presence of an active metastatic lesion or complications, the lifespan of the patient is significantly shortened as supported by the median survival of 3 months in this report. The lifespan has been estimated, though with wide variations, to be about 24 months in patients with bone metastasis and 10, 8 and 3 months in patients with lung, liver and brain metastasis respectively¹⁵. In the shortened period of survival following progression of the disease the hardship and pain endured by the patient is unquantifiable, it may be worse than the demise of the patient; this is when palliation becomes of utmost importance. As noted by Merriman⁴ this is when the patients should be supported to live until they die. In this report pain relief was achieved in more than 50% of patients who had documentation of pain, this is higher than the pain relief rate of about 13% recently documented in Nigeria for a combination of various types of cancer where breast and prostate accounted for about 21% of patients reviewed⁵

Many clinicians do not pay adequate attention to palliative care and some even opine that offering active treatment may be overly burdensome and are of unproven effect^{4,9,14}. These postures which significantly hinder active palliative care in developing countries are compounded because the care of advanced cases is totally undertaken by relatively few specialists in the respective fields¹⁶. Hence the time and patience for devoted palliative care is regrettably lacking⁹.

Specialists in many developing centers are already saddled with excess clinical activity hence it is difficult to spare the time required to “sit and chat”. This leaves a gap in communication. The gap is filled with conflicting, misleading and anxiety provoking information from the community: friends, relations, neighbors and news media. Fortunately in our center, the PAPU shouldered the burden of sustained counseling. Because the information provided by the PAPU aligns with the specialist’s consultation contrary

to what is circulated in the community, the effort of our PAPU is additive to the specialist’s consultation.

It is reported that more than 50% of terminally ill patients prefer to die at home but only about 30% or less eventually die at home. Home-based palliative care is relatively new to Nigeria². In this study recorded place of death was home for about 60 of the patients. Even though we have no prior records of the number of patients dying at home because they have previously been labeled as lost to follow-up or absconders and we did not enquire why they died at home or in the hospital, we are of the opinion that the relatively higher percentage of deaths occurring at home may be linked to the interaction between the patient/relations and PAPU team because the interaction attempted to help the patients and relations to understand and accept the transition among other plausible reasons.

The intervention of our palliative team also attempted to help patients and relations to set realistic goals or expectations of their treatment and to accept successful palliation as a form of successful treatment that is different from cure. The home visitations provided the patients with medical care at their doorsteps thus relieved them of the financial and other costs of transportation, hospital admissions and terminal nursing services. The home visitation also significantly reduced the number of patients labeled as lost to follow up and assisted in collection of complete records of patient management and transition. The relevance of home-based palliative care has been previously noted in Nigeria^{1,2}

Conclusion

There is a need to generate more information and interest in palliative care from developing countries. Other measures of successful treatment of advanced breast cancer besides cure should be promoted. This review also adds to documentation about palliative care in advanced breast cancer emanating from developing countries and it highlights the complimentary role of a specialized palliative care unit in a developing center.

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