WHY DO BREAST CANCER PATIENTS REPORT LATE OR ABSCOND DURING TREATMENT IN GHANA? A PILOT STUDY

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SUMMARY

Objectives: To determine the causes of delayed presentation in breast cancer patients at Korle Bu Teaching Hospital (KBTH), and reasons for patients absconding before and during treatment.
Design: Questionnaire survey.
Setting: Out patient departments and surgical wards of KBTH.
Participants: Women newly diagnosed with breast cancer and breast cancer patients who previously absconded and were returning for treatment.
Results: Sixty six newly-diagnosed patients aged between 20 and 84 (mean 44.8, median 43) years and 35 previous absconders aged 20 to 74 (mean 44.5, median 44) years were interviewed. The causes of delayed presentation were: previous medical consultations 26(29.4%), ignorance 19(28.8%), fear of mastectomy 16(24.2%), herbal treatment 13(19.7%), prayer/prayer camps 13(19.7%) and financial incapability 12(18.2%). Fear of mastectomy 20(57.1%), herbal treatment 13(37.1%), financial incapability 11(31.4%) and prayers/prayer camps 10(28.6%) which were prominent causes of late presentation, were the main reasons for absconding. Newly diagnosed patients had duration of symptoms one week to five years (mean 46, median 34 weeks). Those whose lumps were found by clinical breast examination in the community presented to hospital between six weeks to two years (mean 47, median 39 weeks). Married women were more likely to abscond (p=0.001).
Conclusions: There are similar reasons for delayed presentation and absconding among Ghanaian patients. These must be addressed in outreach programmes, and patients must be counselled at time of diagnosis. Dealing with the causes of delayed presentation appears more important than attempts to screen for breast cancer, since patients identified through community screening still present late to hospital.

Keywords: Breast cancer, Delayed presentation, Absconding, Screening

INTRODUCTION

About 60% of patients with breast cancer in Ghana report with Stage III and IV disease, and they report with eight to 10 months duration of symptoms.[1,2] This situation is similar to what pertains in other developing countries[3,4] and in Black American women compared to whites.[5] There are possible socio-demographic, clinical and psychosocial risk factors that may be responsible for this state of affairs. These factors have been extensively studied with inconclusive results.[6] However, one of the ways of surmounting the problem of delayed presentation, whatever the cause, is to screen women at risk.

Screening for breast cancer has resulted in early diagnosis and a reduction in mortality.[7] Breast self examination (BSE), clinical breast examination (CBE), screen-film mammography, digital mammography, magnetic resonance imaging and ultrasound have all been used to detect cancers prior to confirmation by pathology. Although there are controversies about the value of each of these screening methods, the weight of evidence favours screening by mammography in women aged 40 years and above. There is an additional incremental benefit from clinical breast examination (CBE), since it detects some cancers missed by mammography; but the additional benefit of CBE with mammography is not known.[7,8] The practice of BSE, however, has not been shown to reduce mortality from breast cancer. It has rather been shown to lead to an increase in the number of biopsies for benign disease.[7-11]

There is no systematic national screening programme that involves mammography to women at risk from breast cancer in Ghana. There are some non-governmental organisations (NGOs) and other well-meaning groups who organise breast cancer awareness talks, teach women BSE and offer CBE as a means of offering 'breast screening'.[2]

Programmes to encourage early detection like mammographic screening, CBE and perhaps BSE, may not achieve the desired aim of achieving early diagnosis in Ghana since our patients do not report to hospital for months after they themselves detect an obvious abnormality in their breasts. Even in the developed countries many breast cancers are identified by the patients themselves incidentally.[12] The difference with them is that they report early to hospital.

In Ghana the interval between detection of a breast lump and presentation to hospital for investigation

and treatment (8 to 10 months)[1] is so long that addressing the causes of delayed presentation is perhaps much more important than promoting early detection.

After presenting late to hospital, many patients in Ghana further abscond during breast cancer treatment. In the Korle Bu Teaching hospital 12.8% abscond after the diagnosis is made, and a further 10% do not complete their treatment.[1] The latter group include patients who start neoadjuvant therapy but stop treatment and do not proceed to have surgery. Some of these absconders later return with more advanced and often inoperable, incurable disease.

It is the view of the authors that the key to early diagnosis of breast cancer in Ghana is not in instituting screening programmes, but in dealing with the causes of delayed presentation (from time of noticing the lump to presentation in hospital). We deemed it essential to carry out a pilot study to find out the causes of delayed presentation and absconding in the Korle Bu Teaching Hospital. Knowledge of the causes of absconding and delayed presentation will go a long way in shaping health education messages, programmes and actions that will achieve the desired result of early presentation and early diagnosis.

METHODS
Between September 2007 and July 2008, questionnaires were administered to two groups of women diagnosed with breast cancer using convenience sampling. In the first study, patients who had been newly diagnosed with breast cancer were questioned with regard to the duration of symptoms at the time they reported to hospital and what accounted for the delay/interval. They were asked whether they had sought previous hospital consultation and if the diagnosis of breast cancer was made. Other questions included the following: what their anxieties and fears were and whether they had had the opportunity to express them; how their breast abnormality was first detected; whether or not they had received counselling; and lastly their knowledge and practice of breast self examination.

The second questionnaire was administered to patients who absconded but had returned after variable periods to continue their treatment. Questions and information recorded included the following: the duration of absence, the reason for absconding, the stage of the disease at the time they absconded and the current stage of the disease.

The questionnaires were administered by two nurses and two medical students on a mentorship programme. The stage of the disease was determined by the corresponding author whenever it was not obvious from the patient's records. Tabulation of data

was by Microsoft Excel and analysis was done using the same software and Epi Info StatCalc.

RESULTS
There were 66 patients newly diagnosed with breast cancer, aged between 20 and 84 (mean 44.8, median 43) years. There were 35 patients who absconded but later returned for treatment; their ages ranged from 20 to 74 (mean 44.5, median 44) years.

Their standard of education and marital status are shown in Tables 1 and 2.

Table 1 Level of Education of Patients

	New Patients		Defaulters	
Status	**n**	**%**	**n**	**%**
Nil	11	16%	5	14.3%
Primary	15	22.7%	5	14.3%
Secondary	18	27.3%	20	57.1%
Tertiary	22	33.3%	5	14.3%
Total	66	100.0%5	35	100.0%

Table 2 Marital status of Patients

	New Patients		Defaulters	
Marital Status	n	%	n	%
Single	13	19%	2	5.7%
Married	38	57.7%	31	88.6%
Divorced/ separated	3	4.2%	2	5.8%
Widowed	22	18.2%	0	0%
Total	66	100.0%	35	100.0%

Delayed presentation
The duration of symptoms of patients reporting for the first time with breast cancer ranged from one week to five years (mean 46, median 34 weeks).

Previous medical consultation 26 (29.4%) and ignorance 19 (28.8%) were the commonest causes of delay in reporting. The others are shown in Table 3. Forty eight of the patients (72.7%) said they had had a previous hospital consultation before reporting at the Korle Bu Teaching hospital. Of this number the diagnosis of breast cancer was made in only 23 (52%) of them.

The major fears harboured by this group of patients were of mastectomy 23 (34.8%), financial incapability 19 (28.8%) and death 17 (25.8%).

Of the 55 who admitted having fears, 21 (38.2%) had not had the opportunity to express their fears at the time of the survey.

Thirty seven (56.1%) of the women had received counselling in the hospital, and 43 (65.2%) said they would like to meet with a breast cancer survivor.

Table 3 Reasons for late reporting (New Patients)

Reason	n	%
Medical consultation	26	39.4%
Ignorance	19	28.8%
Fear of mastectomy	16	24.2%
Herbal treatment	13	19.7%
Prayers and Prayer camps	13	19.7%
Financial incapability	12	18.2%
Fear of diagnosis	7	10.6%
Other spiritual	6	9.1%
Food supplements	6	9.1%
Busy schedule	2	3.0%
Homeopathy	1	1.5%
Chinese/Acupuncture	1	1.5%
Organic foods	1	1.5%
Travelled	1	1.5%

Number of patients interviewed: 66

Only 28 of the 66 women (42.4%) knew how to perform a breast self examination (BSE). Of that number only seven said they practiced BSE. The breast lump or changes in the breast was noticed by the patients themselves 46(69.7%), through 'screening' 14(21.2%), by a spouse/partner 3(4.5%) and by a doctor 3(4.5%). Among patients identified through clinical breast examination ('screening' organised by NGOs and other groups), the duration of their symptoms ranged from six weeks to two years (mean 47, median 39 weeks).

Absconding patients
The absconders stayed away for periods ranging between 13 and 105 (mean 49, median 41) weeks. Fourteen (40%) of them had received no treatment at all, 16 (45.7%) had two or three cycles of neoadjuvant chemotherapy, one had a full course of neoadjuvant chemotherapy, and four (11.4%) had mastectomy but no chemotherapy, hormonal therapy or radiotherapy.

Of the 35 who absconded, 14 had early stage (I and II) disease at the time they absconded; all but two returned with locally advanced disease. Seventeen with advanced disease returned with disease progression. One of the four patients who had mastectomy without adjuvant therapy returned with ulceration of the chest wall and axillary recurrence.

Fear of mastectomy 20 (57.1%) was the leading cause of patients absconding. The other reasons for absconding are shown in Table 4.

Table 4 Reasons for absconding (Defaulters)

Reason	n	%
Fear of mastectomy	20	57.1%
Herbal treatment	13	37.1%
Financial incapability	11	31.4%
Prayers and Prayer camps	10	28.6%
Chinese medication	5	14.3%
Observing	3	8.6%
Ulcer healed. Thought disease was healed	2	5.7%
Had complete clinical response	2	5.7%
Food supplements	2	5.7%
Exercising faith	2	5.7%
Side effects of drugs	1	2.9%
Pressure from in-laws to refuse mastectomy	1	2.9%
Father refused treatment	1	2.9%
Family commitments	1	2.9%
Acupuncture treatment	1	2.9%

Number of patients interviewed: 35

DISCUSSION
The two sets of patients had similar levels of education. Although fewer of the absconding patients had tertiary education compared with newly-diagnosed patients, this was not significant (p=0.06). With regard to marital status, there was a significantly greater chance of married women absconding compared to those reporting for the first time (p=0.001).

The main reasons given for delayed reporting were previous hospital consultation and ignorance. It is significant that of the 48 women who sought previous consultation, the diagnosis was made in only 23 (52%) of them. This is an issue that requires further investigation. Ignorance has been previously recognised as a cause of delayed presentation of breast cancer in Ghana.[13]

The four main causes of patients absconding are the same as the next common causes of delayed presentation: fear of mastectomy, the use of herbal treatment, resort to prayers and prayer camps, and financial incapability. This shows that after many women finally report at the Korle Bu Teaching hospital with breast cancer, the reasons for delayed reporting are not addressed. They therefore later abscond for the same reasons, mainly to avoid mastectomy.

The fear of mastectomy can possibly be addressed by a number of measures. These include trying to dispel the misconceptions that link mastectomy to death, giving opportunity to patients to express their fears,

offering counselling, and exposing newly-diagnosed patients to healthy breast cancer survivors. As the study shows, the main fear of newly-diagnosed patients was the fear of mastectomy; many did not receive counselling or have the opportunity to express their fears. The patients were therefore at risk of absconding when mastectomy was due. The wish of many newly diagnosed patients to meet with a survivor shows that they wanted to know more about breast cancer and have their questions answered. The resorts to herbal treatment and prayer/prayer camps are other significant causes of delayed reporting and absconding that need to be addressed.

Not many of the women knew or practised BSE. The usefulness of BSE has been questioned and is currently considered optional by the American Cancer Society.[14] It has not been shown to cause any decrease in mortality from breast cancer.[9,10,11] However, these studies have been done in countries where there are screening programmes and women are breast cancer aware. In Ghana, as in many developing countries, the usefulness of BSE has not been shown to be ineffective. In the absence of screening mammography it is perhaps useful to continue to teach BSE.

This study brings up interesting results about the limited usefulness of present efforts by NGOs and other groups performing community-based clinical breast examination. That 14 (21.2%) of the breast cancers were discovered through these 'screening' programmes shows that these programmes are probably reaching a large number of people. However, the duration of symptoms in these 'screen-detected' cancers is worrying: it is as long as for other patients who detected their lumps by other means. These 'screened' patients were examined in the community and informed they had a problem with their breasts; yet they waited for periods between six weeks to two years (mean 47, median 39 weeks) before reporting to the Korle Bu Teaching Hospital. The limited usefulness of these extension programmes is also demonstrated by a previous study in Ghana where a surgical team toured the country and detected suspected breast cancer in some communities: most of the women were already aware of the lump, some refused biopsies and others refused treatment.[13]

A previous study in this hospital showed that 12.8% of breast cancer patients abscond after diagnosis and do not even start treatment.[2] Those that returned usually had more advanced disease. This study shows the same trend. The fear of mastectomy, resort to herbal treatment and prayer camps, and the lack of funds are the main reasons for absconding given by the returnees. Clearly these need to be addressed at the time of diagnosis. Among the women who started neoadjuvant chemotherapy before absconding, many

reported a downsizing of their tumours, and absconded only when they were advised to have surgery. A few stopped treatment because they were out of funds.

The resort to herbs and prayer camps indicate that patients, irrespective of their level of education, have deeply held beliefs and they resort to these other measures in their time of vulnerability.[15]

It appears from this study that dealing with the issues that make patients present late to hospital is much more important than offering community-based CBE or screening; the patients still present late. Educative measures include making patients aware of the dangers of breast cancer, the importance of early diagnosis, and dispelling the fears and misconceptions that keep women with suspected breast cancer from reporting to hospital. Also, dealing with the main fears and misconceptions of patients at the time of diagnosis is likely to reduce the number of patients who subsequently abscond.

ACKNOWLEDGEMENTS

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