The Impact Of Failed Communication On The Treatment Of Cancer Of The Breast; A Case Series

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Abstract

Breast lumps generate many questions from the bearer to the caregiver. The caregiver's response may determine the decision path taken by the bearer of the lump especially if it is a malignant lump. Communication between the patient and the care giver is as important as early detection. Failure of communication has diverse implications and may lead patients to delay treatment or seek alternative care that may be more persuasive. Our aim is report the effect of communication on treatment of 4 cases of breast cancer and to suggest ways of improving communication

Three patients with delay in commencement of treatment and a control patient were identified. Reasons for representation were noted. The patients, their relations and care givers were interviewed and their case notes were reviewed. The reasons for delays in treatment were noted. The discussion sheds light on the patient's mindset.

One patient delayed because of incomprehensible discrepancies between result of clinical findings and histology. Another delayed because of deflection of communication and fear of breast cancer. The third patient delayed because she failed to cede control to the primary physician. The control patient accepted treatment because of persistent communication and retraction of false proclamation by the primary care physician.

Thus, failure in communication may have more devastating effects than we suspect. In clinical practice acceptance of mastectomy and other medical care requires skillful communication.

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Keywords: breast cancer, delayed treatment, communication failure.

Introduction

The anxiety generated by the presence of a lump in a woman's breast provokes many questions, not in the least the question of loss of breast. This and many more are the questions the patient throws at the caregiver. The caregiver's response, choice of words, organization and presentation of the facts will influence the patient's decision(s), especially if the lump is malignant. Communication is very important[1], perhaps as important if not more important than the time of detection. Because lack of trust ensues from failure of communication, even if it is early disease, the patient may decline the treatment[1,2]. The patient may opt for traditionalists who are often more convincing in providing alternative information, sometimes the only information[3]

Inappropriate communication has wide spread implications[1], ranging from ethical issues and litigations, delay in accepting treatment and outright preference for alternative care[2]. Given the opportunity, the alternatives to Western care may prey on the spiritual and religious beliefs of the already perplexed and clueless patients; they give patients irresistible reasons by using a combination of the traditional folklores about the disease, the art of persuasion, and sometimes deceit[3,4]. The use of alternatives to western medicine in oncology is particularly more in breast cancer compared to other malignancies[3].

This series is not about ethical considerations nor is it about alternative to western care in cancer of the breast. It is solely about the physicians' role in communication or failure of communication leading to decline or delay in treatment of breast cancer. The need for this report became apparent after encountering patients whose delay in treatment appeared to be appreciably hinged on gaps in communication between the patient and the caregiver. We suggest ways of handling some of the difficult situations in communication, including the content of such communications.

Methodology

Three patients with delay in commencement of

management of their breast cancer due to failure in communication were identified and their records were reviewed. A forth case was used as control. Reasons for initial decline of treatment and eventual return back to the hospital were noted. The patients, their relations and family physicians were either invited and interviewed directly or interviewed through mobile telephone conversation via to clarify and augment the available records. The reasons underlying their decisions were sought.

The patients are labeled A, B and C and a comparison patient is labeled "control". The cases were summarized. The discussion sheds light on their mind sets as captured by discussions with the patients, the relations and their family physicians where possible

Case summaries

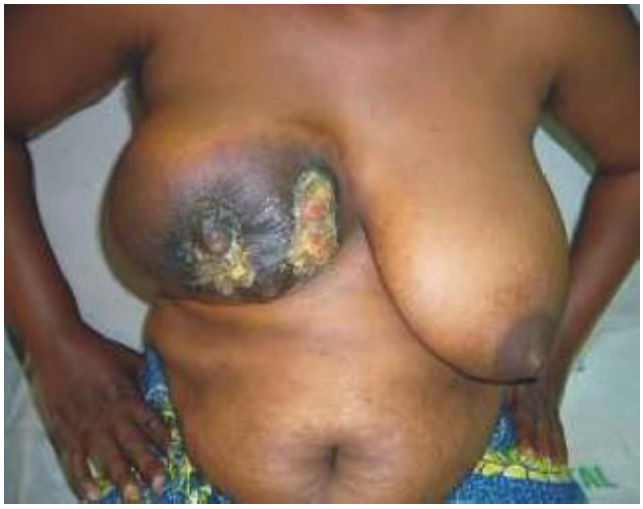
PATIENT A

A 40 year old multiparous accounts clerk in a tertiary institution presented initially with painless lumps in her right breast. She had no identifiable risk factors for cancer of the breast. Examination at that time revealed two mobile lumps in separate quadrants of the right breast. . One was well defined while the other was ill-defined, there was no axillary lymphadenopathy. A clinical diagnosis of mammary dysplasia was communicated to the patient without ano mention of possibility of malignancy. Fine needle aspiration and cytology was inconclusive hence excisional biopsy was done. The excisional biopsy revealed invasive ductal carcinoma leading to the diagnosis of stage I breast cancer.

When the patient was informed about the histologic diagnosis she rejected the diagnosis and refused mastectomy. She defaulted hospital appointment and her husband allowed her to make her decision. She opted for vitamin supplement from a vendor and herbs from an Islamic cleric. The vendor promised her the tumor will melt away. She returned to the hospital after 3 years and 4 months because of breast ulceration and offensive odor. At this time the tumor was already fixed to the chest wall and she had bilateral matted axillary lymphadenopathy (see figure 1) and her chest radiograph suggested pulmonary metastasis.

PATIENT B

BA 56 year old widow, a School Mistress and an Evangelist, with family history of cancer of the breast in her immediate younger sister. She detected a lump in her right breast hence she presented to her family physician to have the lump excised but with the caveat that she did not want to know the result of histology. Six months later two new lumps were noticed, one on the site of previous excision and the other in the ipsilateral armpit. She returned back to the family physician to retrieve the histology result of the excised lump. the result was her result which was invasive breast tumor hence she presented to us. She accepted mastectomy. At operation she had apical fixed nodes. She did not complete adjuvant chemotherapy because of toxicity. She died of pulmonary complications ten months after presenting to us



PATIENT C

A 60 year old Unschooled Nigerian woman who had migrated because of business demands to Ivory Coast. She noticed a lump in her right breast hence she presented to a public hospital in Ivory Coast. After examination, in her words, the doctor said to her in a dismissive tone "you have cancer of the breast, we will remove this breast". She replied "no, I won't let you" to which the doctor added "then you will die." Angered by the doctor's presentations she left the hospital. To her, it was her prerogative to determine what happens to her breast and her life. She returned to Nigeria after 8month at which time the lump had grown bigger and lump another had appeared in her arm pit. She accepted simple mastectomy and axillary sampling. She completed her adjuvant chemotherapy and continued on hormonal. She died of pulmonary complications 2 years after presenting to us

THE CONTROL CASE

This is a 38 year old married multiparous Estate Manager. She had attended a seminar where she met a man who had lost his wife to breast cancer. She recounted that the man was very regretful about not convincing his wife to accept mastectomy early enough when she had early disease.

She returned home to perform self-breast examination. The examination revealed a tiny lump in her breast which made her to present to a family physician. A Clinical diagnosis of fibroadenoma was made and was re-affirmed by FNAC. She opted for excision of the lump anyway. The histology returned a diagnosis of invasive ductal carcinoma. She rejected the result of the

histology and insisted the result was not hers because she already had clinical diagnosis and FNAC suggesting fibroadenoma. She demanded a second opinion on the histology. The second opinion also returned a diagnosis of malignancy. She declined mastectomy. She asked why she had to lose her breast now that the offending lump was already excised.

After two months of repeated counseling and explanations at frequent clinic appointments and phone discussions by the family physician and with the support of her husband, she accepted modified radical mastectomy a month later because the facilities available could not accommodate breast conserving surgery and because she was found to have a solitary mobile axillary node. The result of the lymph node returned malignant but there was no lesion left in the breast. The final diagnosis was stage II cancer of the breast. She completed adjuvant chemotherapy. She is more than five years post-mastectomy as at the time of this report. She is assumed cured because she has no evidence of recurrence. She is requesting breast reconstruction

Discussion

Sociocultural factors, religious beliefs and cost of treatment greatly affect presentation to the hospital and the acceptance of appropriate medical therapy[4]. Failure of communication is presented in this series as another factor that may lead to dismal outcome.

Patient A boycotted hospital because she could not comprehend the radical change in her diagnosis. Furthermore, the lumps had been removed anyway so why mastectomy? The degree of certainty placed on the clinical diagnosis in this instance set the stage for the misunderstanding. It was the seed of the failure in communication. The radical change in the diagnosis was not acceptable to her. Inconsistences between clinical diagnosis and investigation results sometimes leads patients to think that perhaps the provision of western care will not take care of their disease[3] especially if an alternative explanation readily provides folklores on the causation and treatment. So it is imperative that the information given to patient at all times be uniform. But because inconsistencies cannot be totally eliminated, clinicians should prepare for this possibility by communicating the limitations of each method of diagnosis early during counselling[1]

If false positive or negative affirmations have been communicated to the patient as occurred in patient A and the control in this series, then the path taken by the patient may be dependent on the subsequent handling of the situation. The primary physician that managed the control ensured regular short interval appointments, frequent telephone calls; repeated explanation of limitations of orthodox diagnosis and retraction of the false proclamations.

One would expect that someone that has information or had a relation that has been treated for breast cancer will present early upon having any breast symptoms as demonstrated by the control patient who met a stranger. Rather, patient B who had a first degree relative with the disease evaded discussion about the lump in her breast. Conversation with her sister revealed that she was invited by the physician but she did not want to know her result because of fear. This evasive behavior is not peculiar to breast cancer[6].

Many women prefer the removal of any lump(s) in their breast irrespective of the presumed diagnosis because of fear of breast cancer. The problems associated with not having an initial firm diagnosis and counseling before excision of breast lumps are well demonstrated by the patients A and B. This is why pre-diagnosis counseling cannot be over emphasized.

Patient B's faith may have contributed to the delay in her treatment. She did not want to talk about the breast lump, this is sometimes borne out of the belief that talking about the disease is an invitation for the disease and what is most important is to cast the possibility out of one's mind. Patients with such faith are difficult to handle by the physician, the spiritual and religious leaders have major roles to play in handling such patient. Patient B's sister never thought her faith was one of the reasons she delayed, but she admitted it was a plausible reason. In the extremes some patients believe that all diseases are from the devil therefore can only be handled spiritually. The beliefs of science and religion are parallel.

Just as the disease is heterogeneous, so are the afflicted patients. How much information should be provided to the patient? Regarding this question, there are two groups of patients: One group wants to know the details while the other does not. One group prefers to be part of the decision making while the other prefers to leave all the decision to the specialist[1,5,6].Even though unschooled, Patient C wanted to know about her disease. She wanted to know why her breast must be removed. She will not cede control of her situation to the doctor. Perhaps the initial doctor did not recognize this. Could her decline be borne initially out of fear of loss of body part? This is a possibility but our interview with her did not suggest this, neither did the discussion with her relations. Her initial decision was apparently based mainly on the manner of communication by the initial caregiver.

Relaying unfortunate news is a difficult task. What is said may be different from what patients understand

and sometimes there is bitterness and resentment against the bearer of the news[7,8]. . Because of these and the fact that even though she appeared fluent in the foreign language, the communication was not in her native tongue, we cannot exclude the possibilities of misconception or misrepresentation of the physician's intent. Unfortunately, her initial records were not available and the physician was unknown. Nonetheless, The importance of tact in relaying unfortunate news must never be forgotten. In a very recent article, Shockney and Back suggested steps to facilitate discussions with patients bearing advanced cancers[6]

We can only speculate about the stage of initial presentations of the patients B and C and it can be argued that the patient's inherent tendencies to delay medical care selected them into a group that will delay treatment. However, with the histories extracted and especially about patient A whose record was available, what is incontrovertible is that there were delays, probably fatal delays, in their management.

Patient A and the control wondered why the whole breast needed to be removed after the offending lump had already been excised. This is a common question usually when a patient has had lumpectomy and the histology returns as malignant. The explanation we give and which we have found sufficient for most patients is that cancer is an area of change and not a point. We then add that the point we have removed is just like a grown up sibling of a large family of many children. All the children will all eventually grow. Other reasons why mastectomy is often offered to patients with early diseases are lack of facilities for breast conservation, poor follow- up culture among patients and inability to sustain treatment due to poverty[4].

Conclusion and Recommendation

Acceptance of mastectomy and other medical care requires skillful communication. In an article titled *Clinician- patient communication : evidence-based recommendations to guide practice in cancer*[1], some of the recommendations included: Communication in understandable lay man language, providing opportunity for patients to seek clarification, providing information about pros and cons of diagnosis and treatment options and determining how much information the patient wants and how they will want to be involved in decision making. These recommendations were flaunted in the cases presented. So again we suggest that in communicating with patients these recommendations should be considered and in addition we suggest measured release of information and the cautious selection of the appropriate words. The presented cases may be extreme examples of gaps in communication, miss communication or no communication at all, however there is no doubt that communication gaps occur and may have more devastating effects than we suspect.

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