SHORT REPORT

Disclosing bad news of cancer diagnosis: Patients' preference for communication

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Abstract

The majority of relatives of cancer patients in Pakistan request their clinicians to adopt a "do not tell approach" while counselling the patients regarding their disease. The current study aimed to assess patients' understanding of their disease and how they would prefer the physicians to deliver news about cancer diagnosis and its management plan. This was a cross-sectional study in which both patients and their immediate relatives were interviewed. The study enrolled 55 patients with six different types of cancers. The study showed that 35 (65.5%) patients did not know the stage of their illness at the time of diagnosis, while 40 (72.7%) patients did not know the current stage of their disease. In 22 (40%) cases, the patient's family knew the diagnosis ahead of the patient, and 19 (86.3%) families asked the clinicians to hide the diagnosis from the patient. This study, which used a scoring questionnaire, demonstrates that specialist oncologists for breaking the bad news, family counselling, helping patients to figure out how to inform others, giving the news directly to the patient and the effects of cancer on daily life are preferred areas to communicate with cancer patients.

Keywords: Breaking news, Cancer, patients' Preference, Communication.

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Introduction

Bad news in medical literature is usually defined as any news which negatively changes or alters the views of a patient, regarding his or her life or future.[1] In the last few decades, there has been a lot of emphasis on patient autonomy, empowerment, and the patient's direct involvement in decision-making regarding the management of their illnesses, especially if they are suffering from cancer.[2] As a result of this, now in most of the developed countries, all information related to health and disease is disclosed first to the patient.[3] However, it is still widely seen in many cultures that breaking bad news of cancer is a disagreeable experience for patients, and most of the time it causes many patients to lose hope. In many instances, the patient's family is conveyed the bad news, while the patient is not present at the time of disclosure of any unfavourable news. This happens mostly because the family wishes or at times the patients' relatives put undue pressure on the clinicians to not to tell the bad news to the patients directly, whether the bad news is about diagnosis, the need for an intense treatment, or poor prognosis. Unfortunately, in these cultures physicians are often seen to follow the family's wishes.[1]

Cancer is currently one of the leading cause of death and prolonged illness; it resulted in 14 million new cases and 8.2 million deaths, worldwide in 2012.[4] On an average, with each passing minute, 16 patients lose their lives in their fight against cancer, while 26 new individuals are informed that they have some form of cancer.[5] Diagnosis of cancer is always perceived as unfavourable news as not only the patients but the whole family is affected. Debilitating and disfiguring treatment, pain, loss of function, costly treatment, indefinite follow-ups, recurrences, and death are the main issues of discussion. Although in every field of medicine, clinicians often have to communicate adverse medical information to the patients, it is particularly common in oncology setting where unfavourable news of life-threatening conditions, unwanted treatment, and often disease recurrence has to be communicated to the patients and their families. This communication often ends up on a very difficult question to an oncologist: how much time do we have? Even the best specialist finds this question very hard to answer.

Pakistan is a developing, low to middle-income country where modern treatment options for treating cancer are either not readily available or they are very costly.[6] Secondly, low literacy rates and myths attached to the disease often make a diagnosis and available treatment options very difficult to understand not only for the patients but also for their families.[7] There are guidelines available which illustrate how unfavourable news should be communicated and unwanted interviews should be conducted. But in countries like Pakistan, where cancer is still considered the biggest taboo, reactions while admitting bad news of cancer can be very unpredictable both for the patient and their families.

Many clinicians, whether they belong to surgical, medical

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or radiation oncology, firmly believe that the patient has every right to know about his or her illness and only this knowledge can help them to sail through the various periods of the difficult journey. Few studies are available which have assessed the patients' reactions to how bad news of cancer was conveyed to them or have analysed the concurrent relationship between physicians and patients, in terms of how both rank the way bad news was delivered.[8-10] Since delivering bad news of cancer is a two-way communication between the physician and the patient, and as the patient is the one whose life is directly affected, it is very important to consider the patient's understanding, fears, and preferences for communication while conducting such interviews in any clinical setting. Thus, our study aimed to assess the patients' preferences regarding how they should be informed not only about the diagnosis of cancer but also about various management options available.

Patients and Methods

This was a cross-sectional study, conducted from October 1, 2016 to December 31, 2016 at the outpatient department rooms of Medical and Surgical Oncology, Aga Khan University Hospital, Karachi. All participants in this study were aged 18 or above and they were interviewed during their follow-up appointments in the medical or surgical clinics. We used convenient sampling technique and only those patients were included, who were diagnosed with cancer at least one month earlier to allow them time to adjust to the news of diagnosis and to reflect on their experience. The study was briefly described, and they were asked to participate. The patients who consented to participate were enrolled. All individuals were interviewed in a separate room in their respective clinics and were given a researchers' self-designed simple questionnaire covering different aspects of communication; they were asked to rate the importance of different communicating methods while counselling on cancer in terms of score — score 1 being not at all effective method and score 5 highly important skills. This rating scale questionnaire was available in both Urdu and English languages. Fourteen questionnaire items were selected to assess patients' preference for communication. Score 4 or higher was taken as the best way of communication. Score less than 3 was regarded as a bad way of communication, while score 3-4 was regarded as an intermediate skill of communication, which can be used according to the situation. The confidentiality of all patients was maintained. The primary investigator also asked some questions to assess the patients' understanding regarding their disease; an immediate family member was also questioned regarding their understanding.

Results

Seventy patients were approached to participate in this study. Twelve patients declined to participate as they were already exhausted due to long waiting times in the clinic waiting area. Three patients did not participate in the study because they did not want to recall the bad experience, which they had in the past when they were first told about the disease. Hence, in total 55 patients gave informed consent before participating in the study. The mean interval (SD) between the diagnosis of their disease and interview was 4.7±3.7 months.

In our study, out of 55 patients, 25 (45.5%) were men and 30(54.5%) were women. The mean age of the interviewed population was 53±13 years. Out of the 55 patients, 18(32.7%) were diagnosed with gastrointestinal cancer, 6(10.9%) with urinary tract cancer, 4(7.3%) with lung cancer, 9(16.4%) with gynaecological cancer, 8(14.5%) with breast cancer, and 10(18.2%) with head and neck cancer. On average, three doctors per patient were visited before establishing the actual diagnosis of cancer. Moreover, the mean time from the onset of symptoms to the diagnosis was 4.85±2.5 months (Table-1).

When the patients were asked about their knowledge related to their disease 45(81.8 %) patients could tell the

Table-1: Demographics and medical characteristics of patients.

Gender	Number (%)
Male	25(45.5)
Female	30(54.5)
Mean Age years	53 ± 13
Number of doctors on average visited before diagnosis	3 per patient
Meantime since diagnosis (months)	4.7 ±3.7
Meantime elapsed from the onset of symptoms until the establishment of the diagnosis (months)	4.85 ±2.5
Type of cancer	**Number (%)**
Gastrointestinal cancers	18 (32.7)
Urinary tract cancers	6 (10.9)
Lung cancers	4 (7.3)
Gynaecological cancers	9 (16.4)
Breast cancers	8 (14.5)
Head and neck cancers	10 (18.2)

Table-2: Level of understanding of patients regarding their disease.

	Number (%)
Patients knowing organ name from which cancer originated	45 (81.8)
Patients knowing stage at diagnosis	19 (34.5)
Patients knowing the current stage of cancer	15 (27.3)

Table-3: Highest and lowest ratings of patients' preferences regarding different aspects of cancer news delivery.

Item	Mean	SD ±
Highest rating questions		
The doctor who breaks news should be a specialist of that particular cancer	4.27	0.7
The doctor tells news directly to the patient	4	1
The doctor tells, how cancer can affect my daily living	4.2	0.7
Having a doctor offering me hope	4	0.9
The doctor informs my family about my diagnosis	4.2	0.8
Doctor helps me how to tell others about my diagnosis	4	1
Intermediate rating questions		
The doctor tells all treatment options on the first encounter	3.5	1.5
The doctor tells me, my 5 years survival chance	3	1.4
The doctor should tell diagnosis as soon as biopsy report is available	3	1.6
Doctor asks me to bring close relative before breaking news	3.3	1.2
Lowest rating questions		
Doctor warns me that he has unfavourable news	2.5	1.3
News of cancer should wait till staging workup is available	2.7	2
The doctor is very blunt and not showing empathy	1.7	0.9
Doctor not making eye contact and teaching his or her students	1.6	0.8

Table-4: Response of family members after knowing the diagnosis.

The response of family members	Number (%)
Number of families knew diagnosis before the patient	20(36%)
Number of families requested the doctor to hide the news from the patient	19(34.5%)
The reason behind hiding news from the patient	
News will cause anxiety to the patient	8(42%)
Cancer news is a fearful news	8(42%)
The patient is not mentally prepared	3(16%)

name of the organ which had developed cancer. Only 19(34.5%) patients knew the stage of cancer at the time of diagnosis, while only 15(27.3 %) patients were aware of their current stage of cancer (Table-2). Around 40 out of 55(73%) patients never thought that their symptoms might be because of cancer. When patients were first told regarding their disease, 20(36%) patients completely rejected this diagnosis, 13(24%) started thinking about living, 6(11%) thought about family, 6(11%) thought they should have been told much earlier, while only 10(18%) patients were optimistic to take treatment.

In our study, the approach that only cancer specialist should break the news of cancer (mean score 4.2 ± 0.7) news should be told directly to the patient first (e 4 ± 1), clinicians should offer some hope to the patients (mean score 4±0.9), a patient's family should be informed simultaneously (mean score 4.2 ±0.8), educating patients about how cancer affects daily living and how patients can talk to others regarding their disease (mean score 4 ±1), were regarded as the best skill of communication and every clinician should approach cancer patients in this manner. Our survey results completely rejected the approach of warning the patients first before breaking the news (mean score 2.5 ±1.3), waiting to disclose cancer news till all staging workup is available (mean score 2.7 ±1.2), blunt behaviour of doctor (mean score 1.7 ±0.9) and a crowded room with some teaching for students, while communicating with cancer patients (mean score 1.6 ±0.8). (Table-3). We also interviewed the patient's next of kin and the results showed that in 20 out of 55 cases (36%) patient's family knew the diagnosis ahead of patient and 19 (34.5%) families requested their clinicians to hide the news of cancer from the patients. Out of these 19 families 8(42%) thought that it will add anxiety, another 8(42%) families thought that cancer news is itself fearful news, while 3(16%) families believed that the patient was not ready for this news (Table-4).

Discussion

The results of our study showed that in our population a significant amount of time is spent on establishing the diagnosis of cancer. Besides, lack of screening, fear, and poor communication are the other factors of delay, which result in a change of multiple doctors. This study showed the preferences of patients for communication, based on their experience, when they were first told about cancer. The results of our survey demonstrate that there is certain information which the cancer patients want to be given directly to them at a certain point and also some recommendations for clinicians for improving communication with cancer patients. A study done by Sardell and Trierweiler highlighted the importance of hopefulness in the course of cancer treatment.[11] The patients in our study showed their personal preferences regarding how they would like the news conveyed to them, and their ratings showed that content of the message, setting where the news is communicated and core knowledge of a clinician is all-important, and their rating for communication of cancer news is almost similar to the study by Parker et al which highlighted the importance of these fundamentals of good communication.[12] Gebhardt et al13, in their study, concluded that physicians should disclose bad news in a patient-centered way to reduce mismatch with patients' preferences and help them in reducing the anxiety and stress associated with unfavourable news of cancer. Our study also disregards the preference of family members to hide the news of cancer from the patients and concluded that communication regarding disease and disclosure of any news should be patient-centred.

Our study had some limitations, i.e. it was done in a tertiary care hospital with advanced oncology units and skilled professionals, hence it does not take into account those patients who are seen for cancer in small hospitals of our country. Although the study had a small sample size, it had a diverse group of patients, not only from the disease point of view but also from their socio-economic background, which gives a good foundation to conduct a study with a large sample size prospectively.

Conclusion

Our study concluded that the patients have specific preferences for communication at the time of diclosure of bad news of cancer and the clinician must take into acount such considerations. As clinicans, we should not use those communication tools which were highly disregarded by the patients based on their personnel expereiences.

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