

Disclosure of Cancer Diagnosis: Pakistani Patients' Perspective

Masood Jawaid*[♦], Beenish Qamar*, Zubia Masood*, Shaukat Ali Jawaid**

**Surgical Unit, Civil Hospital, Karachi, Pakistan*

***Member of National Bioethics Committee, Government of Pakistan*

Abstract

Objective: To ascertain cancer patients' views regarding disclosure of diagnosis in the Pakistani population, anxiety levels after disclosure of the diagnosis, interest in knowing all the treatment options and desire to inform their families.

Patients and Methods: In this cross-sectional study, 147 cancer patients from different hospitals in Pakistan were asked questions to determine their opinions regarding whether the diagnosis of cancer should be disclosed to patients and their relatives or not. Anxiety after diagnosis disclosure and who should disclose this information were also asked. Patients were also asked about their views regarding whether their families should be informed about the cancer diagnosis without patient's prior consent.

Results: A total of 147 cancer patients completed the questionnaire. Of these, 112 (76.2%) wanted to know about their cancer diagnosis while only 28 (19.0%) patients refused. Anxiety levels were increased in 59 (40.1%) patients, remained the same in 61 (41.5%) and decreased in 27 (18.4%). One hundred and twenty three patients (83.7%), wanted to know the diagnosis from their physicians. Eighty-four (57.1%) patients were interested in all treatment options, while 102 (69.4%) patients wanted to be actively involved in decision making about their treatment. Only 37 (25.2%) patients answered affirmatively to the question which asked if their families were informed about the patient's disease without patient's prior knowledge, while 82 (55.8%) disagreed.

Conclusion: The majority of cancer patients wanted disclosure of their disease by their doctor. The results of this study provide important implications for Pakistani doctors concerning the practice of diagnostic cancer disclosure to the patients.

Keywords: Cancer, Disclosure, Diagnosis, Bad news, Pakistan

[♦]Corresponding Author:

Masood Jawaid, MCPS, MRCS, FCPS, Surgical Unit VI, Civil Hospital, Karachi, Pakistan
Tel: +92-21-9215740
Fax: +92-21-21 5689860
E-mail: masood@masoodjawaid.com

Introduction

The issue of diagnostic and prognostic disclosure to patients diagnosed with cancer has been a

matter of global debate. It is feared that such revelation could accelerate psychological and physical death, thus reflecting the views of Christoph Wilhelm Hufeland, who said that "to

prophesy death is to cause it".¹

Most cultures in the past have refrained from revealing the diagnosis and prognosis directly to cancer patients.²⁻⁷ The first code of ethics (American Medical Association, 1847) advised physicians "not to make gloomy prognostications" but directed them "on proper occasions, to give notice to the friends of the patient timely notice of danger when it really occurs; and even to the patient himself, if absolutely necessary".¹ With changing times, many countries have guidelines in place that advocate directly informing cancer patients.⁸⁻¹⁰ In Pakistan, the age-old practice of informing the patient's family or head of the family is usually followed. A recent survey carried out on the Pakistani general population revealed that most would like to be informed about their diagnosis, if they were to develop cancer.¹¹ It was, however, stated that a person's perceptions could change if he/she had the prospect of suffering from the disease rather than imagining it. It must also be stated that other studies have mostly derived information from physicians or nurses or community group surveys, which have obvious limitations.¹¹⁻¹³ Pakistan also lacks explicit guidelines in this regard. This study was, therefore, undertaken to elicit the views of cancer patients in Pakistani society about direct disclosure of their diagnosis of cancer.

Patients and Methods

This questionnaire-based prospective study was carried out at Jinnah Postgraduate Medical Centre, Civil Hospital Karachi and Pakistan Institute of Medical Sciences, Islamabad, during a four month period from January to April 2007 after receiving ethical approval from the Institutional Review Board. Initially for our study we asked the permission of the family for diagnosis disclosure but because of strong opposition (13 out of 25 patient attendants) we had to change our policy. Therefore, we only interviewed patients who were already aware of their diagnosis. In this study, only cancer patients who already knew their diagnosis and were under treatment were included. All three hospitals are

tertiary care teaching hospitals for Pakistan. Informed consent was taken from all the patients and in some cases (13 patients who did not know the diagnosis during the initial part of the study) from their close family members, after which the diagnosis was disclosed to the patients. These 13 patients were interviewed after one week. All patients who gave consent and were able to understand and reply to the questions were included. Cancer patients who were under the age of 18 years were excluded. A specially designed proforma was used to collect data which included the patient's demography, diagnosis and questions regarding preferences of diagnosis disclosure, change in anxiety level after knowing the diagnosis, how diagnosis was disclosed, and preference as to who should communicate the diagnosis. Information collected also included patient's wishes of knowing all treatment options and their active participation in treatment management. Patients were also asked about their views as to whether their family should be informed about diagnosis without the patient's awareness.

Statistical analysis

Data was analyzed with SPSS version 10. The mean and standard deviation were computed for quantitative output response and frequency percentage for qualitative output response.

Results

A total of 147 cancer patients (75 males and 72 females) were successfully interviewed from three centres (Jinnah Postgraduate Medical Centre, Civil Hospital Karachi and Pakistan Institute of Medical Sciences, Islamabad). Most patients (53.7%) were not educated. Patient demographics are shown in Table 1. One hundred and two (69.4%) patients were freely mobile, 36 (24.5%) had limited mobility and 9 patients (6.1%) were bedridden. Diagnoses of all patients are shown in Table 2. One hundred and twelve (76.2%), wanted to know the diagnosis regarding cancer while only 28 (19.0%) refused. Anxiety levels were increased in 59 (40.1%) patients, remained the

Table 1. Demographics of patients.

Factor	n (%)
Age	
Mean±SD	44.3±15.4
Range	18-90 years
Gender	
Male	75 (51)
Female	72 (49)
Education	
Nil	79 (53.7)
Primary	17 (11.6)
Secondary	42 (28.6)
Graduate	9 (6.1)
Mobility	
Freely mobile	102 (69.4)
Restricted	36 (24.5)
Bedridden	9 (6.1)

same in 61 (41.5%) and decreased in 27 (18.4%) patients. One hundred and twenty three patients (83.7%), wanted to be informed about the diagnosis by their doctor and 14 (9.5%) by their family members. Eighty-four (57.1%) patients wanted to know all treatment options, while 102 (69.4%) patients wanted to be actively involved in decision making regarding their treatment. Only 37 (25.2%) patients agreed to the question about informing their families about the cancer diagnosis without informing the patients themselves, while 82 (55.8%) disagreed. Responses to all questions are shown in Table 3.

Discussion

The change of culture in 'disclosure of cancer diagnosis' attitudes suggest a radical change in the practice of delivering information to the patients, but limited research is available from countries known for their policy of non-disclosure, like Pakistan. In contrast to Western cultures, which adhere to more individually oriented philosophies, traditional Pakistani cultures place more value on the collective role of family in decision making. For this reason, initially for our study we asked the permission of family members for the diagnosis disclosure. However, because of strong opposition we had to change our policy and thus we only interviewed patients who already knew their diagnosis.

There are two important findings from this

study. First, most family members of patients did not want the patients to be informed about the diagnosis of cancer and second, the majority of our cancer patients wanted the cancer diagnosis to be told to the patients.

Despite providing some useful information, this study has certain limitations. Apart from retrospective patients' views, samples were selective as only patients already knowing their diagnosis participated, so the results cannot be generalized to patients before disclosure. Anxiety level was assessed retrospectively for the same reason. Only a small number of patients were enrolled in the study. Since the study was conducted at only three centres, there is a need for a much larger, multi-centre study to confirm our findings.

Disclosure of the cancer diagnosis is a difficult task for doctors in developing countries. The majority of doctors both in developed and developing countries tell the truth more often today than in the past, but some, especially in developing countries prefer to disclose this diagnosis to the next of kin.¹⁴ The doctor-patient relationship is a triangle consisting of doctor, the patient and the family. Each part supports the other two and is affected by the cultural background of each.

Family members are often opposed to telling the diagnosis to the patients. In this study, 63 out of 76 (83%) family members of cancer patients did not allow diagnosis disclosure. This was an additional finding, although it was not one of our objectives. This may be due to the fact that most

Table 2. Diagnosis of cancer patients (n=147).

Cancer type	n (%)
Gastrointestinal tract	40 (27.2)
Genitourinary tract	29 (19.7)
Blood	15 (10.2)
Breast	13 (8.8)
Skin	11 (7.5)
Soft tissue	11 (7.5)
Lung	11 (7.5)
Bone	8 (5.4)
Brain	5 (3.4)
Salivary	3 (2.0)
Renal	1 (0.7)

Table 3. Questions asked from cancer patients.

Questions	n (%)
Cancer diagnosis should be told to patients?	
<i>Yes</i>	112 (76.2)
<i>No</i>	28 (19.0)
<i>Indifferent</i>	7 (4.8)
Your anxiety levels after diagnosis disclosure?	
<i>Increase</i>	59 (40.1)
<i>Same</i>	61 (41.5)
<i>Decrease</i>	27 (18.4)
Who disclosed the cancer diagnosis to you?	
<i>Doctor</i>	78 (53.1)
<i>Own judgment</i>	26 (17.7)
<i>During this study</i>	17 (11.6)
<i>During investigations</i>	16 (10.9)
<i>Relatives</i>	8 (5.4)
<i>Friends</i>	2 (1.4)
Preferably who should communicate cancer diagnosis to you?	
<i>Consultant</i>	123 (83.7)
<i>Family members</i>	14 (9.5)
<i>Any one</i>	10 (6.8)
Do you want to know all treatment options?	
<i>Yes</i>	84 (57.1)
<i>No</i>	56 (38.1)
<i>Indifferent</i>	7 (4.8)
Do you wish to be actively involved in your disease management?	
<i>Yes</i>	102 (69.4)
<i>No</i>	13 (8.8)
<i>Indifferent</i>	32 (21.8)
Should your family be informed about your diagnosis without informing you?	
<i>Yes</i>	37 (25.2)
<i>No</i>	82 (55.8)

of the patients' families, in an effort to protect them from depression and a feeling of hopelessness, exclude the patient from the process of information exchange. A study from Turkey about family members of cancer patients showed that more than half of the accompanying persons did not agree with disclosing a cancer diagnosis to patients, whereas the majority agreed with disclosing it to the relatives.¹⁵ In a recent study of a Southeast Asian population, Back et al. showed that 17.6% of patients reviewed as new consultations had no direct discussion of diagnosis of their malignancy.¹⁶ This was predominantly a family initiated response with specific advance directions to avoid disclosure.

Many doctors preferring to respect the wishes of the family often face the ethical dilemma of whether or not to inform patients of a diagnosis.

Family physicians surveyed in 2006 from Croatia showed that 51.5% told the truth about the cancer diagnosis to the family without the patient's permission.¹⁷ Contrary to this trend, studies have shown that cancer patients wanted to know the diagnosis against their family's opinion. A study from Taiwan showed that cancer patients strongly proclaimed their superior rights to be informed about their disease over their family and preferred their doctor to inform themselves before releasing any information to their family caregivers.¹⁸ In another study, patients have expressed regret that illness-related information had been withheld from them, preventing them from taking timely action to prepare for death and organize their affairs.¹⁹ A study from Saudi Arabia reported that, in case of a patient with incurable cancer, 67% of doctors said that they would inform the patient in

preference to the family of the diagnosis. Assuming the family already knew, 56% of doctors would tell the patient even if the family objected.²⁰

In our study, the majority (76.2%) of our cancer patients preferred that the cancer diagnosis be told to the patients. This high figure contrasts the general belief that our population is not yet ready for the truth in terms of cancer diagnosis. Recent studies are also suggestive of a trend demonstrating more patient disclosure and information provision.^{21,22} Fujimori et al., while surveying cancer outpatients, reported that more than 90% of the patients strongly preferred to discuss their current medical condition and treatment options.²³ A study from Taiwan showed that informed cancer patients reported significantly higher levels of hope than those who were not informed.²⁴

It is interesting to note that 28% of our patients came to know the cancer diagnosis by their own judgment or during investigations without formal disclosure by the doctor or their family members. A survey from Calicut, India, showed that 62% of oncological patients were aware of their disease and 45% of all patients had been told by their doctors.²⁵ Another Indian study from the same city reported that 81% of the 850 respondents (200 pre-clinical students, 300 clinical students, 100 interns, 150 postgraduate registrars and 100 faculties) were of the opinion that the cancer diagnosis should be revealed to the patient.²⁶ Costantini et al.²⁷ in an Italian mortality follow-back survey showed that 37% of people who died of cancer had received information about their diagnosis and 13% about poor prognosis. Interestingly a consistent proportion, although non-informed, knew the diagnosis (29%) and the poor prognosis (50%). Although radiotherapy usually implies a cancer diagnosis, Phungrassami et al.²⁸ reported from Thailand that 37.8% patient treated by radiotherapy did not know the diagnosis.

A question is often asked as to who should communicate the bad news of cancer diagnosis to the patient. A study from Scotland reported that most patients desire to be informed about their

cancer diagnosis by the consultants.²⁹ Our study has also reported similar findings.

Doctors need to respect patients' preferences rather than routinely taking the family's opinions into consideration. In a family centered setup such as ours, we recommend that the doctor makes a formal request to the patient in front of family members if he/she desires further information about their illness, whether they wish to make decisions or whether they prefer that their families should handle such matters. This process gives an opportunity for the patient to ask questions in the presence of family members or to address questions to the family. At times the decision by the family members is directed by their own vested interests, which may vary (e.g. inheritance of property, etc). As such it will be much better if the patients are well informed so that they can take such important decisions on their free will during their lifetimes.

It is essential that we should formulate national guidelines about the disclosure of a cancer diagnosis in our country while keeping in view our cultural beliefs and family environment. This study may prove to be the first step in this direction. Further studies with larger numbers of patients will be needed to confirm our findings. However, the findings of this study may help to prepare guidelines for cancer diagnosis disclosure practices for Pakistani doctors and families.

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