

# BREAKING BAD NEWS - PERCEPTIONS OF CANCER PATIENTS AND THEIR RELATIVES

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## ABSTRACT

**Objective:** To study the perceptions of cancer patients and their relatives regarding disclosure of cancer related information.

**Methodology:** A cross sectional survey was conducted at Medical Oncology Ward, Hayatabad Medical Complex, Peshawar from September 2009 to January 2011. A total of 114 patients and their relatives were interviewed using a pre-designed questionnaire.

**Results:** Eighty Three (73%) were male while 31 (27%) were female. Median age of cancer patients was 36 (18-70) years. Forty-eight percent (29/60) cancer patients wished for full disclosure of bad news while 39% (21/54) of their relatives wanted full disclosure ( $p = \text{Not Significant}$ ). Sixty two percent (37/60) cancer patients and 74% (40/54) relatives wanted to be informed in case of recurrence ( $p = \text{Not Significant}$ ). Over 90% of patients and relatives wanted bad news to be broken by a senior consultant. Fifty eight percent (35/60) cancer patients and 52% (28/54) relatives wished for their relatives to make treatment decisions for them ( $p = \text{Not Significant}$ ). However, 93% (56/60) of cancer patients and 78% (42/54) of their relatives wanted full information about all side-effects of treatment ( $p < 0.02$ ). Fifty eight percent (35/60) cancer patients and 32% (17/54) relatives wanted their close relatives to be present while bad news was being broken ( $p < 0.007$ ).

**Conclusion:** Almost half of patients wished for full disclosure of information regarding cancer diagnosis. Over 90% patients wanted full information regarding all side-effects of chemotherapy. It is recommended that training regarding how to break bad news be made mandatory part of our medical training both at undergraduate and postgraduate levels.

**Key words:** Breaking bad news, Communication skills, Cancer patient perceptions, Pakistan

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## INTRODUCTION

Doctor-patient communication is a core clinical skill which has been shown to improve health outcomes of patients. Lack of training in this essential skill may result in loss of patient's trust in doctor, poor patient compliance, miscomprehension of treatment plan and its outcome and may even lead to litigation. In contrast, better communication and empathy exhibited by a doctor increases patient satisfaction

while greatly reducing the psychological stress in patients<sup>1</sup>. Thus poor communication with patient or concealment of true diagnosis may become counterproductive in the future doctor-patient relationship. This in itself is a major reason why all accreditation and professional bodies all over the world are laying so much stress in mastering of this skill by all doctors.

Breaking bad news to patients is an essential component of communication skills. Bad news has been defined as "any news that drastically and negatively alters the patient's view of his or her future"<sup>2</sup>. Patient autonomy dictates that patients should be given as much information as they wish. On the other hand, patient beneficence dictates that patient should be protected from potentially harmful news. Different cultures across the globe deal with the issue of full disclosure of information to patients in different ways. This results in a dilemma for the doctor who is not fully conversant with the subject. In the West, there has been a transformation from paternalism to full patient autonomy with the resultant full disclosure of all the information and

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shared decision making<sup>3,4</sup>. However in developing countries, paternalistic model is still prevalent where the doctor and family try to cover up the truth in case of diagnosis of a fatal disease<sup>5-7</sup>.

This tendency to cover up and avoid delivering bad news to cancer patients may be due to factors related to doctors or due to perceptions in the minds of family members. Some of the reasons related to doctors include fear in the mind of the resident that being the bearer of bad news patient will put all the blame on the resident; lack of confidence in the resident regarding how to handle the emotional outburst of the patient; not being able to answer all the questions asked by the patient and the fear of expressing emotions and showing empathy himself<sup>2,8</sup>. On the other hand, cultural norms and insufficient knowledge of family members regarding cancer and its outcome are some of the reasons that have been reported to result in family members insisting on not to disclose the diagnosis of cancer to patients<sup>6,8,9</sup>.

However, many studies have reported that patients do wish to be informed about their diagnosis and also to be involved in decision making regarding their treatment<sup>10-13</sup>. We therefore conducted a survey of cancer patients admitted to Medical Oncology Ward as well as their relatives in order to study their perceptions regarding breaking bad news to cancer patients in order to clarify the situation with regards to our society.

## METHODOLOGY

We conducted a cross-sectional survey of cancer patients as well as their relatives presenting to Medical Oncology Ward at Postgraduate Medical Institute (PGMI), Hayatabad Medical Complex (HMC), Peshawar. Convenience sampling was performed. Study was conducted from September 2009 to January 2011. Patients and their relatives who were above 18 years of age and willing to be interviewed were included in the study. Patients below 18 years of age, those with history of psychiatric illness and patient's with terminal disease were excluded. Informed, understood consent was obtained from all participants. Those who did not give consent were also excluded from the study. Structured interviews using a pre-designed questionnaire were conducted in a private office in order to ensure confidentiality. All the interviewers were given training in filling of the questionnaire and conducting interviews so that uniformity was maintained in filling of the questionnaires and to reduce interviewer's bias. Questionnaires were divided into two main sections. First section asked questions about how the participants felt regarding being told about cancer diagnosis, their chances of a cure, about information regarding side effects of chemotherapy, shared decision making or decision

making by proxy. The second section asked questions regarding how the participants felt regarding their relatives being told about cancer diagnosis if they were diagnosed with cancer and other related questions. They were asked questions regarding who was the best person to provide them the information they required and who they would like to accompany them when this information was being provided. Categorical questions were used in these questionnaires to quantify perceptions of participants regarding breaking bad news.

Sample size was calculated using a confidence interval of 95% (precision level 0.05) and margin of error of 5%. The sample size came out to 60 participants in each group. Convenience sampling was performed in our study. To test the significance of difference between the two groups, chi squared test was applied. Level of significance was taken as 0.05 with 95% confidence interval. Approval of Institutional Research and Ethics Board (IREB) of PGMI was taken for the study.

## RESULTS

A total of 120 participants were interviewed during the study period. Questionnaires of six of patients' relatives were not included in the study as they were incomplete. Total numbers of questionnaires found eligible to be included in the study were therefore 114. Among the 114 eligible participants, sixty participants were cancer patients while 54 were their relatives who accompanied them. Amongst patients, thirty seven (62%) were male while twenty three (38%) were female. Median age of patients was 36 years (range 18-70 years, IQR 21). Amongst relatives, forty six (85%) were male while eight (15%) were female. Median age of patients' relatives was 33 years (range 18-60 years, IQR 16). Geographic locations to which these participants belonged is shown in Table 1. Almost all areas of Khyber Pakhtunkhwa province of Pakistan as well as adjoining areas of Afghanistan were represented.

**Perceptions of cancer patients:** Twenty nine out of 60 patients (48%) said that they wished to be informed about cancer diagnosis directly while 31 (52%) did not want to be told about the diagnosis of cancer. However, 37 (62%) patients wished to be informed if they had a recurrence of cancer. Forty four (73%) patients wished to be informed regarding the diagnosis if they had chances of a cure. When asked about the setting in which patients should be told about the bad news, 23 (39%) patients said they would like to be told about cancer diagnosis alone, 35 (58%) preferred their relatives to be present at the time of breaking bad news while 2 (3%) said they would like their friends to be present. Interestingly, 56 (93%) patients said that they wished to be informed fully regarding all the side effects of chemotherapy.

Thirty five (58%) patients opted for their relatives to make treatment decisions for them (treatment decision by proxy). When asked who would the patients want to break the bad news, 54 (90%) opted for a senior consultant, 4 (7%) opted for a trainee doctor while 2 (3%) opted for their relatives to break the bad news to them. When asked, if one of their close relatives is diagnosed with cancer, would you like him or her to be told about the diagnosis, 23 (38%) patients said yes while 37 (62%) said no. When asked, if a close relative of yours has a cancer, would you like him to be fully involved in decision making about his/her treatment, 49 (82%) said yes they should be fully involved in making treatment decisions.

**Perceptions of patients' relatives:** Twenty one out of 54 patients' relatives (39%) said that they wished to be informed about cancer diagnosis directly if they had cancer while 33 (61%) did not want to be told about the diagnosis of cancer. However, 40 (74%) patient's relatives wished to be informed if they had a recurrence of cancer. Forty (78%) patients wished to be informed about the diagnosis if they had chances of a cure. When asked about the setting in which the patients should be told about the bad news, 32 (59%)

patients said they would like to be told about the cancer diagnosis alone, 17 (32%) preferred their relatives to be present at the time of breaking bad news while 5 (9%) said they would like their friends to be present. Forty two (78%) patients said that they wished to be informed fully regarding all the side effects of chemotherapy. Twenty eight (52%) patients opted for their relatives to make treatment decisions for them. When asked who would the patients want to break the bad news, 49 (90%) opted for a senior consultant, 4 (8%) opted for a trainee doctor while 2 (2%) opted for their relatives to break the bad news to them. When asked, if one of their close relatives is diagnosed with cancer, would you like him or her to be told about the diagnosis, 16 (30%) patients said yes while 38 (70%) said no. When asked, if a close relative of yours has a cancer, would you like him to be fully involved in decision making about his/her treatment, 38 (70%) said yes they should be fully involved in making treatment decisions.

Comparison of patients' perceptions and the perceptions of patients' relatives along with statistically significant differences, if any, is shown in Table 2.

**Table 1: Geographic locations of participants**

Peshawar	34	Mardan	7	Kohat	3
Dir	8	Charsada/Shabqadar	7	Swabi	2
Karak	8	Nowshehra	4	Tank/Lakki	2
Swat/Malakand	8	Bannu/DI Khan	4	Kurram/Parachinar	2
Bajawar	8	Bunair	4	Waziristan	1

12 participants were from Afghanistan

**Table 2: Comparisons of perceptions of patients and their relatives**

Attribute	Patients	Relatives	p-value
Yes, I would like to be told about cancer diagnosis	48% (29/60)	39% (21/54)	0.51
Yes, I would like to be informed about recurrence	62% (37/60)	74% (40/54)	0.22
Yes, I would like to be informed about all side effects	93% (56/60)	78% (42/54)	0.02
Yes, I would like my relatives to make treatment decisions for me	58% (35/60)	52% (28/54)	0.36
Yes, if my relative is diagnosed with cancer, I would like him/her to be informed about diagnosis?	38% (23/60)	30% (16/54)	0.12
How would you like to be told about diagnosis?			
Alone	39%	59%	0.04
In presence of relatives	58%	32%	0.007
In presence of friends	03%	09%	0.35

## DISCUSSION

Patient autonomy has not been accepted as yet by most physicians in developing countries including Pakistan. To further complicate the matter, patients' relatives also insist on not talking directly to the patients and insist on avoiding full disclosure to the patients<sup>14</sup>. A study in Turkey revealed that lack of knowledge of patients' relatives regarding cancer was an important factor that led to their insistence not to break bad news to the patients<sup>9</sup>. Local cultural norms and lack of training of doctors in breaking bad news were some other important factors cited in this regard<sup>8,9,14</sup>. However, many studies from the Western countries to more traditional Eastern countries have shown that 40-96% patients do want full disclosure<sup>10,15-17</sup>. Cancer patients in South Korea were found to believe more than their relatives that patients need to be fully informed regarding diagnosis of a fatal illness<sup>16</sup>. In another study conducted in Pakistan, 40% patients wished for full information regarding their diagnosis and prognosis and considered this as fundamental right of a patient<sup>18</sup>. Lower levels of anxiety and depression were found even in children who were given basic information about their diagnosis and treatment plan<sup>19</sup>. A Japanese study reported that patients preferred for bad news to be broken by a doctor, they wished for emotional support and empathy while breaking bad news, they wanted their near relatives or friends to be present during the interaction with doctor and a proper setting for breaking bad news<sup>20</sup>. This study also reported that patients of younger age group and those with higher levels of education were more likely to expect detailed discussion about their disease and prognosis<sup>20</sup>.

Our results from this study concur with most of the results described in the above mentioned studies. Half of our patients (48%) wished to be informed fully about the diagnosis and prognosis of cancer. This is in line with the results published from most of the developing countries where 40-60% patients wanted full disclosure<sup>16-18</sup>. Over 70% of our participants showed their willingness to be informed about the diagnosis of cancer if they had a chance of a cure. Two thirds of our participants also expressed their desire to be informed in case they had a recurrence of the disease. Thus half of patients wish for full disclosure whatever the prognosis may be where as over 2/3<sup>rd</sup> of patients wish for full disclosure in case of curable cancer.

Although half of our participants opted for treatment decision to be made for them by their relatives (decision by proxy), a positive message from our study is that ninety percent of patients

wanted to be fully informed about side effects of chemotherapy (a step towards shared decision making). Another interesting observation in our study was that majority of patients who wanted to be informed fully regarding their cancer diagnosis opted for the news to be broken to them alone in a private setting. This desire by the patient for bad news to be broken alone was also reported by another study conducted in Pakistan where 58% of patients did not want the news to be broken in front of family members<sup>18</sup>. Our results also show that majority (>90%) of our patients wanted bad news to be broken by a senior consultant which again is in line with reports of other studies<sup>16,18,20</sup>. Studies have also shown that involvement of patient's family physicians in the process can be extremely beneficial for the psychological well-being of the patients. A study conducted in Austria showed that a significantly higher number of patients stated that their family physicians broke bad news to them empathetically or very empathetically compared to their treating oncologists (81% vs 41%)<sup>21</sup>. Thus by including family physicians in the process of delivering bad news as well as decision making for future, patient satisfaction and emotional well being can be improved further.

A limitation of our study is the relatively low number of participants. Main reason for this was the fact that some patients refused to consent to participate in the study that had a title of "bad news" while in some instances patient's relatives insisted on not to include their relatives (patients) in the study. However we did meet the criteria of our sample size required for this study. A larger, multi-center study all over the country shall help clarify the situation even further.

Our study and other studies conducted on the topic calls for a change in attitude of doctors towards breaking bad news and shared decision making as almost half of patients do want full disclosure whereas over half of patients wish for shared decision making. Intensive training of doctors in the skills of breaking bad news therefore should now be an essential part of our curriculum at undergraduate and postgraduate levels since our doctors will have to be prepared for this important role in future. Fortunately, many studies have shown that the art of breaking bad news can be taught and learnt<sup>22,23</sup>.

## CONCLUSION

In conclusion, almost half of patients even in traditional societies such as ours wish for full disclosure of bad news. It is therefore important for our educational system to train doctors in the skills of communicating bad news and expressing empathy both at undergraduate and postgraduate

levels. Using the SPIKES protocol<sup>22</sup> to break bad news will make it easier for doctors to find which patient wants full disclosure and which patient does not wish for it and the doctor can then deal with the situation as required.

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### CONTRIBUTORS

AJ conceived the research proposal and wrote the manuscript. MF did literature search, collected and analyzed the data. SU collected and analyzed the data. All the authors approved the manuscript and its revisions.

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