Section: Psychiatry

Original Article

ISSN (0): 2347-3398; ISSN (P): 2277-7253

Patient's Experience and Expectations of Breaking Bad News

Anant Kumar Verma[1]

[1]Assistant Professor, Department of Psychiatry, Vardhman Institute of Medical Sciences, Pawapuri, Nalanda-803115, India.

Abstract

Background: To explore patient's perspectives and expectations from physicians with respect to breaking of bad news. **Subjects and Methods:** A cross-sectional survey was carried out in the outpatient department of a tertiary care teaching hospital Vardhman Institute of Medical Sciences, Pawapuri, Nalanda, India. All consenting individuals from 18 to 60 years of age were interviewed on the basis of a structured, pre-tested questionnaire. **Results:** The response rate for this study was 91.3%. A total of 400 respondents completed the full interview. About 60% patients had a fairly accurate idea about the implications of the phrase "bad news". A big proportion (44.1%) of people reported that bad news had been broken to them previously with incomplete details. From their personal experience, most respondents quoted "disease diagnosis" and "chances of survival" as most commonly encountered bad news. Diagnosis of cancer or its recurrence was stated as the most likely example of bad news (35.5%). A significant majority of respondents (40.5%) stated that it's the patient's absolute right to know bad news. A significant association for the relationship between both age as well as the gender of the respondents and type of emotional response expressed on hearing bad news (p=0.000) was observed. **Conclusion:** The response rate for this study was 91.3%. A total of 400 respondents completed the full interview. About 60% patients had a fairly accurate idea about the implications of the phrase "bad news". A big proportion (44.1%) of people reported that bad news had been broken to them previously with incomplete details. From their personal experience, most respondents quoted "disease diagnosis" and "chances of survival" as most commonly encountered bad news. Diagnosis of cancer or its recurrence was stated as the most likely example of bad news (35.5%). A significant majority of respondents (40.5%) stated that it's the patient's absolute right to know bad news. A significant association for the relationship between both age as well as the gender of the respondents and type of emotional response expressed on hearing bad news (p=0.000) was observed.

Keywords: Bad news, patient's perspectives, patient's expectations.

Corresponding Author: Dr. Anant Kumar Verma, Assistant Professor, Department of Psychiatry, Vardhman Institute of Medical Sciences, Pawapuri, Nalanda-803115, India.

Received: January 2019
Accepted: February 2019

Introduction

A bad news can be defined as "any information, which adversely and seriously affects an individual's view of his or her future".[1] In the context of medicine, some examples of bad news situations include disease diagnosis, disease recurrence, failure of treatment, prognostication of outcomes, presence of side-effects of treatment, results of genetic tests, or raising the issue of palliative care and resuscitation.[2] Breaking bad news is a daunting task for the health care professionals. Similarly, receiving bad news is an onerous task for patients because it may drastically cone down options for their future. In every medical specialty, grim information might have to be given to patients and their families at many junctures and it is one aspect of medical care that all the technological advancements have not been able to avert yet. An insensitive approach in this regard serves no purpose but to alienate and distress the recipients of bad news while also engendering feelings of hostility and resentment towards the deliverer of bad news; culminating in an increased risk of litigation as well.[3] Studies have consistently shown that the way a health care professional delivers bad news places an indelible mark on the doctor patient relationship.[2]

Effective communication between the doctor and patient forms an essential crux of breaking bad news. It is central to the delivery of high quality medical care and has been shown to affect patient satisfaction, decrease the use of pain killers, shorten hospital stay and improve recovery from surgery and a variety of other biological, psychological and social outcomes.[4] The increase in human life span has brought a spate of chronic illnesses in its wake. Myriad issues related to quality of life heighten the importance of understanding the mechanism of delivery of bad news.[2,5]

The debate about the amount and levels of truth given to patients about their diagnosis has developed significantly over the last few years. While some health care professionals may now increasingly share information with patients, it had once been the rule rather than the exception to withhold information because it was believed to be in the best interests of the patient.[6] Evidence indicates that patients increasingly want additional information regarding their diagnosis, their chances of cure, the side effects of therapy and a realistic estimate of how long they have to

live.[7,8] Patients want their doctors to be honest and compassionate in this regard. They want to be told about bad news in person, in a private setting, and with adequate time for discussion.[9]

Despite growing focus in the developed world on "optimization" of the process of breaking bad news to patients, there is a lack of indigenous guidelines on the subject in our part of the world. In a survey done in various teaching hospital, only 60% doctors thought that they broke bad news properly; 26% out of them had conveyed the news to the families and not to the patients.[10] There has been no study to evaluate patient's perceptions and expectations from doctors with regards to breaking bad news in India to the best of our knowledge. The aim of our study was therefore, to fill the gaps in information that exist with respect to patient's perspective about breaking bad news.

Subjects and Methods

A cross sectional survey was conducted, in order to assess knowledge, attitudes and practices at the psychiatry outpatient department of The Vardhman Institute of Medical Sciences, Pawapuri, Nalanda (India). The study was completed within a time frame of approximately 6 months, from February, 2018 to July, 2018. The psychiatry OPD is attended by a large number of people from various socio-economic backgrounds people of nearby 100 square kM. A sample size of 440 was calculated at a 95% confidence interval and 5% sample error, assuming a 50% variance. Adjustment was made for a 15% refusal rate. Convenience sampling was used in order to draw the sample. All consenting individuals attending the CHC aged between 18 to 60 years were included. An interview was conducted using a structured, pre-tested questionnaire. Ethical considerations, such as informed consent and confidentiality of the subject were ensured.

A total of 482 individuals were approached for this survey. Among them 42/482 (8.7 %) declined to participate. While complete information was missing in 40 participants. In all 400 respondents completed full interviews which was used for primary analysis.

The initial questionnaire was developed based on the prior experience of investigators, input from colleagues, peers as well as patients. The initial framework of the questionnaire was then expanded by incorporation of new aspects encountered during an extensive literature search. The draft so prepared was then pre-tested on 25 respondents and no changes were deemed necessary to be made in the questionnaire based on this pre-testing. The results of the pre-testing were not included in the final analysis of the data. A meeting of the investigators was held prior to the administration of the questionnaire in order to maintain uniformity in its administration; hence reducing chances of interviewer's bias in the study. The questionnaire was divided into three sections. The first section comprised of socio-demographic information of respondents. Section 2 assessed patient knowledge and perspectives regarding breaking bad news. Section 3 comprised of questions assessing the attitudes and expectations of respondents regarding breaking bad news from their physicians.

Data was entered, validated and analyzed using Windows Statistical Package for Social Sciences (SPSS) version 16.0. Descriptive statistics were reported and associations were assessed using Chi -square test. A p-value < 0.05 was considered as significant.

Results

Table 1: Socio Demographic characteristics of Study Population.

Socio-demographic Variables		Frequency (n= 400)	%
Gender	Male	164	41
	Female	236	59
Mean age (years)	Male	36	-
	female	38	-
Marital status	1. Married	214	53.5
	2. Single	118	29.5
	3. Widowed	30	7.5
	4. Separated	20	5.0
	5. Divorced	18	4.5
Income (Indian Rupees)	<5000	74	18.5
	5,000 - 10,000	112	28
	10,001 - 50,000	146	36.5
	50,001—100,000	42	10.5
	>100,000	26	6.5
Occupation	Currently employed	174	43.5
	Currently unemployed	226	56.5
Educational status	Till class 5	14	3.5
	Till class 10	82	20.5
	Till Class 12	136	34.0
	Graduate/post Graduate/Diploma	146	36.5
	Illiterate/can read and write name	22	5.5

In this survey 236 females (59%) and 164 males (41%) were interviewed [Table 1]. Majority were married (53%). Almost 70% had twelve years or more of education. More than half of the respondents (60.5%) had a fairly accurate idea of what is "bad news". Fifty-nine percent of the respondents were able to recall an incident in the past where a doctor had broken bad news to them. For most (47.5%) of these people, such an incident had occurred within the last 1 to 3 years. The location where the bad news had been broken varied for different individuals but most [126/236; (53.4%)] reported a hospital setting where this had occurred. Fortyfour percent of the people reported that the bad news had been broken to them verbally with incomplete details. Grief / sorrow (26.3%), guilt (18.6%) and denial (16.1%) were amongst the most intense emotions experienced by them when the bad news was broken to them. Out of the four hundred respondents, 82 (20.5%) people knew someone who had been given bad news by a doctor; mostly the parents (36.6%) of the respondents had was stated as the most likely example of bad news (35.5%),followed by a diagnosis of depression and other psychiatric illnesses (23%) and news of foetal demise (12.5%). Least likely examples of bad news cited by respondents included diagnosis of an upper respiratory tract infection (28.5%), gastroenteritis (24%), diabetes and

hypertension (20.5%). Most of the respondents (44.1%) opined that the bad news was broken verbally to them in the past with incomplete details. [Table 2] details the personal experience of respondents with regards to breaking of bad news.

Table 2: Knowledge and Practice variables regarding Breaking Bad News.

Knowledge and Practice variables	Frequency	%
A.Personal experience with receiving bad news (N= 236)		
-Disease Diagnosis	74	31.4
-Disease Recurrence	16	6.8
-Chance of cure	10	4.2
-Side effects of therapy	24	10.2
-Chance of survival	78	33.1
-Progression of the disease	34	14.4
B. How the news was broken		
-Verbally with complete and clear details	56	23.7
-Verbally with incomplete details	104	44.1
-Verbally with complete details and addressing of emotional response	42	17.8
-Verbally with complete details, addressing of emotional response, summarizing the discussion and provision of outline of future plan	16	6.8
-Via telephone or email	18	7.6

Regarding the attitudinal variables of breaking bad news, 134/400 (33.5%) people expressed the immediate and absolute need to know the bad news, while 190 (47.5%) expressed a desire to know the bad news at a later time. Only, 44 (11%) respondents wished never to know the bad news. For the majority of the respondents [228/400; 57%], their home was the most preferred setting where bad news should be broken to them. While most of the people (51%) favoured verbal route for breaking bad news, others also mentioned a preference for letter/ email (23%) and telephone (15%). Up to 52% of the respondents expressed a desire to know the complete details of the bad news while 32% preferred smaller bits of information disseminated over a longer course of time. Only 16% wanted their physicians to tell them the summary of the bad news. A hundred and sixty-four respondents (41%) believed that receiving bad news is actually more sinister than the disease itself while 110 (27.5%) answered in negative. Breaking bad news was reported to lead to adverse emotions in the patient (39.5%), family of the patient (27.5%) and patient's friends (22%). In this survey about, 232/400 (58%) people preferred the entire patient – doctor interaction in the exercise of breaking bad news to be patient-centered while 26.5% wanted this interaction to be disease-centered. Almost half (56%) of the people expressed confidence in the abilities of a general physician or a family doctor to deliver bad news in an acceptable manner. However, only 17.5% people believed that specialists are as capable in this regard.

More than half of the respondents, 232/400 (58%) strongly negated the idea of breaking bad news to them in front of their family. Among the 18% people who responded positively, spouse (39.5%) and parents (28%) were favoured as confidantes in this process. In all 258/400 (64.5%) people wanted their doctors to address their emotional needs after breaking bad news to them. Also, 254/400 (63.5%) people were of the view that doctors should take explicit permission from the patients before breaking any news to them.

Around a sixty percent of the individuals said that they would like to take a second opinion to confirm the bad news delivered by their primary doctors is accurate. Specialists at the hospital were the most preferred physicians (63%) for taking second opinion in case of bad news broken to patients.

Table 3: Attitudinal variables regarding Breaking Bad News.

Most important thing a doctor should do at follow up visit (n=400)		
-Enquire how I am feeling about the news	134	33.5
-Assure me that I will not be abandoned	36	9.0
-Give me more information related to the bad news	30	7.5
-Talk more about the consequences of this news on my life	30	7.5
-Help me identify my support systems	68	17
- Doesn't rush me to treatment; gives me ample time to adjust	102	25.5
Most important reason for breaking bad news to a patient (n= 400)		
- Helps improve coping strategies	98	24.5
-Doctors are being paid to tell the patient	60	15.0
-It is the patient's absolute right to know	162	40.5
- There is always the possibility of sudden/unexpected death	42	10.5
- It is unethical to keep the truth from patients	38	9.5
Most important reason for not breaking bad news to a patient (n=400)		
- Possible worsening effect on people with depression / cancer / heart failure	142	35.5
- Patient's refusal is of paramount importance	62	15.5
- Its agonizing and distressing to the patient, proving to be counterproductive	92	23
- A patient has a right but not a duty to hear bad news	38	9.5
- When the family will ask you not to disclose it to the patient	26	6.5
- When the patient is a minor	40	10
Suggestions on how doctors can improve breaking bad news (n=400)		
- Should warn me earlier that I have some serious news	46	11.5
- Should be simple and clear in delivering the news	94	23.5
- Should check if the message has been understood	84	21
- Should pause to let it sink in, then respond to my reaction and questions	34	8.5
-Summarize and establish a plan for how to move on	62	15.5
- Should never tell me about this news in the first place	24	6
- Should ask me to bring a family member with me	18	4.5
- Should give me his focused, undivided attention	38	9.5

Majority of the participants (42.5%) were unsure about the importance of age in the reception of bad news. Among those who considered age an important factor, 71.1%

believed that this is because young people are able to withstand bad news better than older individuals. With regards to gender; majority (66.5%) felt that gender makes a difference when it comes to breaking bad news. A consensus was expressed by 68.4% participants that this was due to greater emotional expressivity of females than males. Enquiring about how the patient felt about the bad news was stated as the most important thing that a doctor should do at a follow up visit, followed by him giving the patient ample time to adjust and hence, not being rushed into treatment. The most commonly stated reason deterring the doctor from not revealing the bad news was the possible worsening effect on people with depression / cancer / heart failure, as stated by almost one-third of our respondents. About, forty eight percent respondents supported the notion that a doctor should try to ascertain the patient's level of understanding with regards to the disease. [Table 3] details the attitudinal variables regarding breaking bad news.

It was found a significant association in the relationship between both age as well as gender of the respondents and type of emotional response expressed on hearing bad news (p=0.000). Also, the association between age and opinion (that age makes a difference in the reception of bad news) was found to be significant (p=0.000). The association between gender and opinion was also significant (p=0.000).

Discussion

This study provides a valuable local perspective about the patient's expectations and perceptions with regards to the bad news broken to them by their health care providers. Patients today expect their physicians to deliver medical care at a better standard than before. This study is therefore important in our pursuit of better standard of care and higher level of patient satisfaction.

A significant majority (60.5%) had a fairly accurate idea about the connotations and implications symbolized by the term "bad news". Almost one third of the respondents (33.5%) expressed the immediate desire to know bad news in our survey. This is comparable to the results of a study conducted in a regional hospital in Ireland, where most patients (84%) wished to be fully informed about bad news.[11]

Most of the respondents wanted the news to be broken to them verbally in the setting of their homes. Literature review suggested that an ideal location for a physician to break bad news is one that is comfortable, to accommodate multiple staff and family members, if they are present.[9,12,13] According to a study, almost all patients wanted honest information about their health status.[14] Sixty-three percent of the people in our survey wanted doctors to take explicit permission from them before breaking any news to them. In another study, dying patients identified the need to achieve a balance between being honest and straightforward and not discouraging hope.[15] In our study, 44.1% reported that incomplete details regarding bad news were conveyed to them, despite the fact that almost half of the respondents (52%) wanted to know the complete details of the news.

Addressing the patient's emotional response is one of the issues that needs to be addressed with regards to conveying the message (bad news). It is also an important component of the 6 step SPIKES protocol.[16] In our survey 64.5% people wanted their doctors to address their emotional reaction after breaking bad news to them.

An interesting fact to note was that about 56% had more confidence in their family physicians with respect to the issue of delivering bad news. This aspect is supported by a study that revealed that doctors in surgical specialties were significantly more likely to be rated poorly by patients than to this particular aspect of patient care. Surgeons were the group of doctors most likely to break bad news, but nonsurgical doctors were rated more positively in performance of the task.[17]

Fifty-eight percent of the respondents preferred a patient-centered meeting between the doctor and themselves. Previous data show that participants exposed to the patient-centered communication perceived the physician as least dominant, most available, most expressive of hope and most appropriate when it comes to conveying information. Also, they reported to be most satisfied with the visit and they showed the least increase in negative emotions.[18] Therefore, a patient-centered communication style has the most positive outcome for recipients of bad news on a cognitive, evaluative, and emotional level.

This study has certain limitations which should be kept in mind. This was convenience sampling, drawn from only one locale, therefore cannot be deemed representative of the general population. Maintaining candid and upfront communication with the patients and their families regarding all dimensions of disease lays an enduring foundation of confidence and reliance between the patient and the health care team The research findings of this survey could therefore bridge the gap between patient's expectations and caregiver's practices; providing significant information with respect to patient's perspective about bad news and how it can be optimally broken.

Conclusion

This study provides an insight into the knowledge, perceptions and expectations of patients from their physicians with regards to the process of breaking bad news. It is clear that patients want bad news to be broken to them in an honest and compassionate manner by their physicians.

References

1. Buckman R. How to Break Bad News: A guide for healthcare professionals. New England J Med 1992; 329: 223.
2. Breaking Bad News: Regional Guidelines. Developed from Partnerships in Caring, Department of Health Social Services and Public Safety HMSO Belfast 2003. (Online) Cited 2008 September 14. Available from URL: http://www.dhsspsni.gov.uk/breaking_bad_news.pdf.
3. Fallowfield L, Jenkins V. Communicating Sad, Bad, and Difficult News in Medicine. Lancet 2004; 363: 312
4. Tavakol M, Torabi S, Lyne OD, Zeinaloo AA. A Quantitative Survey

of Intern's Knowledge of Communication Skills: an Iranian Exploration. BMC Med Educ 2005;
5. Taylor SE. Health psychology. The science and the field. Am Psychol 1990; 45: 40-50.
6. Holland JC. Now We Tell - But How Well. J Clin Oncol 1989; 7: 557-9.
7. Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, et al Information Needs of Cancer Patients in West Scotland: Cross Sectional Survey of Patient's Views. BMJ 1996; 313: 724-6.
8. Ley P. Giving information to patients. Chapt 14. Eiser JR (ed). Social Psychology and Behaviour Science 14th ed. New York: Wiley and Sons Ltd,1982; pp 353.
9. Peteet J, Abrams H, Ross DM, Stearns NM. Presenting a Diagnosis of Cancer Patients' Views. J Fam Pract 1991; 32: 577-81.
10. Abbas SQ, Muhammad SR, Mubeen SM, Abbas SZ. Awareness of palliative medicine among Pakistani doctors: a survey. J Pak Med Assoc 2004; 54: 195-9.
11. Keating DT, Nayeem K, Gilmartin JJ, O'Keeffe ST. Advance directives for truth disclosure. Chest 2005; 128: 1037-9.
12. Quill TE, Townsend P. Bad news: delivery, dialogue, and dilemmas. Arch Intern Med 1991; 151: 463-8.
13. Ptacek JT, Eberhardt TL. Breaking bad news: a review of literature. JAMA 1996; 14: 276: 496-502.
14. Langewitz W, Nübling M, Weber H. Hospital patients' preferences for involvement in decision-making: a questionnaire survey of 1040 patients from a Swiss university hospital. Swiss Med Wkly 2006; 136: 59-64.
15. Wenrich MD, Curtis JR, Shannon SE, Carline JD, Ambrozy DM, Ramsey PG. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death, Arch Intern Med 2001; 161: 868-74.
16. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKESA six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000; 5: 302-11.
17. Barnett MM. Effect of breaking bad news on patients' perceptions of doctors, J R Soc Med 2002; 95: 343-7
18. Schmid Mast M, Kindlimann A, Langewitz W. Recipients' perspective on breaking bad news: how you put it really makes a difference, Patient Educ Couns 2005; 58: 244-51.

How to cite this article: Verma AK. Patient's Experience and Expectations of Breaking Bad News. Asian J. Med. Res. 2019;8(1):PY05-PY09. DOI: dx.doi.org/10.21276/ajmr.2019.8.1.PY2

Source of Support: Nil, **Conflict of Interest:** None declared.