Patients’ Preference to Hear Cancer Diagnosis

Mohammad Arbabi, MD1
Ava Rozdar, MD2
Mohammad Taher, MD2
Maryam Shirzad, MD3
Mohsen Arjmand, MD3
Sahar Ansari, MD2
Mohammad Reza Mohammadi, MD1

1 Psychiatry and Psychology research center, Department of psychiatry, Tehran University of Medical sciences, Tehran, Iran
2 Psychiatry and psychology research center, Tehran, Iran
3 Psychiatrist, Tehran, Iran

Corresponding author:
Sahar Ansari,
Psychiatry and psychology Research Center, Roozbeh hospital, South Kargar street, Tehran, Iran
Tel: 0098-21-55413540
Email: saharansari3@gmail.com

Objective: Bad news disclosure is one of the complex communication tasks of the physicians. Bad news is defined as: “any news that adversely and seriously affects an individual's view of his or her future”. Recent studies indicate that the patients’ and physicians’ attitudes toward disclosure of bad news have been changed since few years ago. The evidence of breaking bad news is also different across different cultures. In the present study, we aimed to evaluate the patients’ prospect about breaking bad news and to provide a clinical guidance for Iranian patients and those patients in countries with a similar cultural background.

Methods: A cross sectional descriptive study was conducted on a sample of 200 cancer patients at a cancer institute in Tehran. The patients’ demographic characteristics and their attitudes toward the manner of disclosing the diagnosis were registered in a research based questionnaire.

Results: In this study, 165 patients (82.5%) claimed to be aware of the diagnosis; however, only 121 patients (73%) were aware of the actual diagnosis of their disease. Most patients tended to know the diagnosis (n = 186, 93%) and accepted patient as the first person to be informed (n = 151, 75.5%) by their physician (n = 174, 87%). The preference of being alone or with a family member when exposed to bad news was almost the same.

Most patients (n = 169, 84.5%) believed that physicians should consult the patients to make treatment decisions. Treatment options (n = 140, 70%) and life expectancy (n = 121, 60.5%) were the most desirable topics to be discussed. Most patients (n = 144, 72%) agreed upon allowing them to express their emotional feelings.

Conclusion: According to the patients’ preferences about being fully informed about the diagnosis, it is suggested that the disclosure of cancer diagnosis be done by a physician and in the presence of a family member. It is also recommended that physicians consult the patients about treatment options.

Keywords: Bad news, patients’ request, being aware of diagnosis, life expectancy, treatment options.

Iran J Psychiatry 2013; 9:1: 8-13

Disregarding to teach communication skills, as a fundamental element for establishing a proper patient-physicians relationship, induce physicians feel incapable in certain situations like diagnosis disclosure. However, physicians may show avoiding the situation of imparting diagnosis and ignoring patients' emotional problems, as the consequence (1). Both verbal and nonverbal communication skills play a critical role in improving the quality of patient-physician relationship (2) which leads to better patient care; these skills also help patients to comply with their illness and accept treatments. On the other hand, physicians lacking such skills inspire patients’ resentment and also disrupts physicians’ ability to prevail over pain and symptoms (3).

The most famous and common definition of the bad news has been presented by Robert Buckman: “any news that adversely and seriously affects an individual’s view of his or her future”. A physician is expected to be able to disclose bad news and evaluate patients’ request for it. How the bad news is given to the patients affects their interpretation of the disease (4), their psychological adjustment to the disease (5-7), satisfaction with medical care (8-9) and level of hope (10). The way to impart bad news may also encourage patients to participate in complex decision makings (11).

Today, telling the truth is considered as a doctors’ ethical duty and a patients’ legal right (12-17). Nonetheless, making a decision whether or not to reveal bad news were not the same as contemporary
and had been revolutionized in the last decades of the twentieth century.

The literature on breaking bad news suggests that most patients demanded full disclosure (11,18), and about half of them, mostly those with higher education levels (4), wished to know about their lifetime expectancy although only a few of them were informed about this later issue (9,19).

Practically, patients prefer being informed by physicians (20), in the presence of family members (11) with acceptable behaviors including honesty, clarity, being simply understood,, responding their patients questions patiently (21) and respecting through nonverbal communications like eye contact (18). However, the some issues like physician-patient physical contact such as taking the patients’ hands were not of significant importance for the patients (21).

Evidence shows that people with different cultural background may show different attitudes toward disclosing bad news. In North America and Europe, most physicians express the diagnosis obviously, but in South and East Europe and China, due to the current paternal view, some patients are excluded to receive information about their disease (22 and 23).

The present study on a sample of Iranian patients intends to explore the patients’ preferences and attitudes toward being informed about the diagnosis and prognosis which may help to

This study may provide a clinical guidance of giving bad news to the Iranian patients and those patients with a similar cultural background.

Materials and Methods

Subjects: Two hundred patients above the age of 15 who referred to the Cancer Institute of Imam Khomeini Hospital with a definite or suspicious diagnosis of cancer (during the previous month) were enrolled in the study. All the subjects consented to join the study and were excluded for cognitive disorders. They were all Persian native speakers.

Instrument: The questionnaire was established based on the literature review and after examining its content validity by a number of psychiatrists. Patients’ view and variables affecting how to break the bad news was discussed in the questionnaire.

Method: A cross-sectional study was done during 2010-2011 in the Cancer Institute of Imam Khomeini Hospital to evaluate the patients’ prospect about disclosing bad news. Informed consent was obtained from all the subjects. Then, they were interviewed and a questionnaire was completed for each of them by the interviewers. The patients’ medical history, final diagnosis of disease, the actual time of diagnosis, treatment options and the frequency of probable relapses were also obtained by referring to the patients’ medical records. Finally, the recorded data were extracted from the questionnaires and analyzed using SPSS, version 16. Pearson and Spearman correlation coefficients, independent sample t tests and Chi-square were used to compare and examine the relationship between the variables.

Ethical Issues: The study was conducted after providing sufficient explanation to the participants and obtaining written informed consent. This study was approved by the Research Ethical Committee of Tehran University of Medical Science. All data will remain confidential.

Results

Two hundred patients participated in this study; of whom, 110 (55%) were male. The mean age was 43.04 +/- 13.07 years. Of the patients, 68.5% (n = 137) were married, 16.5% (n = 33) were single, 12% were widowed (n = 24) and 3% (n = 6) were divorced. Among the patients, 22% (n = 44) had gastrointestinal cancer, 20% (n = 40) hematological malignancies, 15.5% (n = 31) breast cancer, 13% (n = 26) head and neck cancer, 9.5% (n = 19) gynecological and urological cancers and 20% (n = 40) had other types of cancer. It is noteworthy to mention that 23.5% of the patients (n = 47) had a positive family history of cancer.

The chosen treatments for patients were as below: Surgery for 39.5% (n=79), chemotherapy for 29.5% (n=59), radiation therapy for 0.5% (n=1), and a combination of all three methods for the rest 30% (n=60).

Of the subjects 165 claimed that they knew their diagnosis while the rest were not aware of their disease. Among the 165 patients who claimed to know the diagnosis, only 121 cases (73%) had an accurate information about the diagnosis and the rest mentioned their diagnosis with titles other than cancer (mostly benign and treatable ones). Among those who claimed to know the diagnosis, 140 (84%) cases had been informed by their physicians and 4 cases (5.2%) had been informed indirectly. Most patients (n = 172, 86%) believed their disease was treatable.

The majority of the patients (93%) tended to be informed about the diagnosis. Pertaining to the best person to be informed first, 75.5% of the subjects (n = 150) chose the patient, 22% (n = 44) chose one of the family members and only 5.2% (n = 5) chose patients’ close friends as the first to be informed.

Of the subjects 87% (n =174) wanted to be informed about the diagnosis by their doctors and the rest chose the nurses, family members, close friends and a psychiatrist. To the majority of patients, (74%, n = 148) medical staffs’ gender was not important during bad news disclosure; 47% (n = 94) of the patients preferred to be alone during bad news disclosure; 30.5% (n = 61) wanted the presence of their spouse, and only 1% (n = 2) of the participants tended to be informed in the presence of other patients. Most patients (n = 89, 44.5%) chose their physician’s office as the most suitable place for being informed about the
diagnosis: 53% of the patients (n = 106) wanted to be informed immediately after the diagnosis; 13.5% (n=27) wanted to be informed shortly after the treatment had began. We assessed the patients’ attitudes toward the contexts of information about bad news and the ways to deliver it, using 31 statements. The participants were asked to score the statements based on their agreement. The results are listed in Tables 1 and 2. According to Table 2, the encouraging statement of this is a struggle and you should go through the disease was scored the highest and the frustrating statement of sorry, I have got bad news for you was scored the lowest. Concerning the relationship between patients’ age and their information about the disease, younger patients were more willing to be aware of their diagnosis than older ones; however, the difference was not statistically significant (p < 0.307). The younger patients were also more informed about the accurate diagnosis than the older patients (p < 0.001) and were more informed about their diagnosis (p < 0.001).

Compared to the male patients, the female patients, although demanded less to be informed of the diagnosis (p < 0.001), were more aware of the distinct diagnosis (p = 0.057) and insisted more on knowing about the life expectancy (p = 0.605) and participation in decision making for treatment options (p = 0.454). They also accepted the physician’s physical contact (p = 0.427), and hearing supportive (p = 0.377) and encouraging statements (p = 0.297) and opposed to use disappointing sentences (p = 0.114) when they were informed of the diagnosis compared to the male patients. Single patients were more informed of the diagnosis than the married, widowed or divorced patients (p = 0.002). Married patients were more willing to obtain information about their life expectancy compared to single patients (p = 0.702) and they also more open to use accompanying (p = 0.913) and encouraging sentences (p = 0.506) and were more opposed to the use of frustrating statements when they were informed of the diagnosis (p = 0.019). The more educated the patients, the more they were aware of the diagnosis (p < 0.001) and the more willing to be informed about it (p = 0.634). Patients with higher education level had more tendency to be aware of their life expectancy (p = 0.936), to obtain information in detail about treatment options (p = 0.26) and to be informed of the diagnosis immediately after the diagnosis was proved (p < 0.001).

### Table 1: Patients’ attitude toward nonverbal communication during diagnosis disclosure

| Agree (%) | No comment (%) | Disagree (%) | SD* | Mean** |
|-----------|----------------|--------------|-----|--------|
| Letting the patients express their emotional feelings (anger, crying, sadness, and etc.) during diagnosis disclosure. 72 | 15 | 13 | 0.87 | 3.6 |
| Supporting the patients with silent respect, during diagnosis disclosure. 60.5 | 23 | 16.5 | 1.1 | 3.56 |
| Supporting the patients with taking their hands, cuddling, etc., during the diagnosis disclosure. 51 | 15.5 | 33.5 | 1.18 | 3.22 |
| The physician should not express any certain emotional reactions during diagnosis disclosure. 35.5 | 20.5 | 44 | 1.16 | 2.85 |
| Physicians’ clarity affects patients’ trust to them. 87.5 | 9.5 | 3 | 0.71 | 4.16 |
| Treatment options (chemotherapy, radiation therapy and surgery) should be explained to patients. 71.5 | 15 | 13.5 | 0.91 | 3.75 |
| Treatment complications should be explained to patients. 72.5 | 12.5 | 15 | 0.95 | 3.74 |
| Treatment administration route (injection or oral) should be explained to patients. 66.5 | 19 | 14.5 | 0.93 | 3.65 |
| Patients’ chance of recovery should be explained to them. 76 | 11.5 | 12.5 | 0.95 | 3.81 |
| Patients’ life expectancy should be discussed. 60.5 | 8.5 | 31 | 1.26 | 3.36 |
| The patient has got a right to know his situation. 86.5 | 7 | 6.5 | 0.82 | 4.10 |
| Diagnosis disclosure makes patients better accept the treatment and cooperate with physician. 88 | 9 | 3 | 0.7 | 4.16 |
| The patient would understand the diagnosis eventually. 71.5 | 16.5 | 12 | 1 | 3.77 |
| Decision about treatment options must be made due to physicians’ discretion. 59 | 14 | 27 | 0.83 | 3.41 |
| Physician should consult with patients about treatment options. 84.5 | 8.5 | 7 | 0.83 | 4.02 |
| Decision about treatment options must be made according to the patients’ desire. 19 | 21.5 | 59 | 1.08 | 2.52 |
| The patient would be disturbed by understanding the diagnosis. 29 | 10.5 | 60.5 | 1.14 | 2.59 |
| Diagnosis awareness would not help the patient. 19 | 10 | 71 | 1.09 | 2.32 |
| Diagnosis awareness would help patients to finish their incomplete life tasks. 66.5 | 15.5 | 18 | 1.07 | 3.61 |
Patients’ Preference to Hear Cancer Diagnosis

Table 2: Patients’ attitudes toward verbal communication during diagnosis disclosure

| Accompanist Statements                          | Agree (%) | No comment (%) | Disagree (%) | SD*  | Mean** |
|------------------------------------------------|-----------|----------------|--------------|------|--------|
| I'm accompanying you.                          | 73        | 18             | 9            | 0.75 | 3.9    |
| I admire your courage.                         | 76        | 15             | 9            | 0.90 | 3.93   |
| I can understand how you feel.                | 77.5      | 13             | 9.5          | 0.92 | 3.97   |

**Encouraging Statements**

| There have been patients like you who bounced back. | 87 | 6.5 | 11 | 0.83 | 4.16 |
| Things will go well.                                | 43 | 9.5 | 11 | 0.84 | 4.10 |
| This is a struggle; you should go through the disease. | 86 | 8.5 | 5.5 | 0.88 | 4.25 |

**Disappointing Statements**

I wish I had better news for you.  | 13 | 20.5 | 66.5 | 0.94 | 2.33 |
You couldn’t be helped more.      | 11 | 16.5 | 72.5 | 0.95 | 2.10 |
No worse situation is possible.    | 13.5| 14.5 | 73   | 1.05 | 2.11 |
We all will die one day.           | 28.5| 18   | 53.5 | 1.20 | 2.9   |
I’m sorry I’ve got a bad news for you. | 13.5| 9    | 77.5 | 1.01 | 2.07 |
You will face some discomfort.     | 17  | 8.5  | 74.5 | 1.05 | 2.13 |

*** The range of scores is from 1(disagree) to 5(agree)

Table 3: Correlation between demographic variables and knowing of accurate diagnosis

| Variable                  | Mean                | P-value |
|---------------------------|---------------------|---------|
| age                       | Young/old: 52%/41%  | 0.001<  |
| sex                       | Male/female: 81%/84%| 0.507   |
| education                 | Higher/lower: 92%/73%| 0.001< |
| Family History            | Positive/negative: 98%/78%| 0.002 |
| Marriage                  | Single/married: 97%/63%| 0.002 |
| Type of Cancer            | Hematologic/nonhematologic: 92%/76%| 0.007 |

Table 4: Correlation between demographic variables and tendency to know accurate diagnosis

| Variable                  | Mean                | P-value |
|---------------------------|---------------------|---------|
| age                       | Young/old: 42%/46%  | 0.307   |
| sex                       | Male/female: 93%/92%| 0.697   |
| education                 | Higher/lower: 94%/92%| 0.634 |
| Family History            | Positive/negative:89%/94%| 0.325 |
| Marriage                  | Single/married: 93%/88%| 0.702 |
| Type of Cancer            | Hematologic/nonhematologic: 95%/92%| 0.384 |

In contrast to less educated patients, they also demanded more for participation in decision making for treatment options (p=0.003) as well as malignancies were more aware of their accurate diagnosis (p=0.007) and tended more to be informed of it immediately after the diagnosis was definitely proved (p=0.384).

Patients with a family history of cancer were more informed of the diagnosis (p=0.002), although they tended to be aware of it less than other patients (p=0.325).

Patients who had not experienced cancer relapse wanted to be aware of the diagnosis more than other groups; however, the difference was not statistically significant (p=0.179).

Correlations between demographic variables and knowing accurate diagnosis and tendency to know the diagnosis were mentioned in table 3 and 4.

**Discussion**

In the present study, 82.5% of the patients stated that they were aware of their diagnosis although 73% had correct information about it; 93% of the patients tended to know the diagnosis, and this tendency was seen more in men and in more educated patients. Most patients preferred to be the first to be informed (n = 151,75.5%) by their physicians (87%).
Preferring to be alone (n = 94, 47%) or being with a family member (n=96, 48%) while receiving the distinct diagnosis was almost the same among the subjects. Our finding that most patients (82.5%) claimed to know the diagnosis is consistent with the results of Ferraz (22).

In both studies, some of the patients were not aware of the accurate diagnosis. Only 73 % of our patients were aware of the distinct diagnosis of cancer while others mentioned their diagnosis with titles other than cancer. Similar results are reported in Samimi’s research (6).

The finding of this study about most patients (n=186 , 93%) preferring to be informed of their diagnosis is similar to other studies: Datson (11), Kaufman (18), Parker (8) and Fujimori (4); and this suggests union trends of patients preference over the world , from middle and far East to America and Europe.

The results of this study is supported by the findings of Parker study (8) that revealed female patients as well as patients with higher education levels demanded more information. In the Shofield study (24), 69% of the patients wanted to learn about the bad news and 26% sought moderate amount of information about it.

Of the subjects, 87% wanted to be informed of their diagnosis by their physicians. The data confirmed the results of many previous studies including Ferraz (22), Symond (5) and Samimi (6). Patients’ trust in physicians, physicians being conversant with patients’ medical conditions and emotional feelings might be the probable reasons for such tendency.

Furthermore, 75.5% of the patients preferred to be the first person to be told about their diagnosis. This finding was in accordance with previous studies which were done in Israel (22, 16) and differs from a study in Japan (4).

During diagnosis disclosure, preference for being alone (47%) or with a family member (48%) was approximately the same. The Literature has raised miscellaneous and contradictory results on this matter. In the course of receiving information on the diagnosis, most of the participants of Ferraz (22) and Rassin study (10) preferred being with a family member; adversely, Kaufman (18) and Kim study demonstrated patients inclination to be alone. The small sample size in Kim study (16 patients) or the role of cultural variants could explain these discrepancies.

Among the behaviors during diagnosis disclosure, most patients (n = 144, 72%) voted for the desire to freely express their emotions (mean score 3.65 and standard deviation 0.87) and not making any physical contacts with the physicians (n = 65, 32.5%, the mean score = 3.22 and standard deviation = 1.18) which is in accordance with the results of Fujimori study (4).

Confirming our results, 85% of the patients of Kim study (7), were opposed to physicians touching them or taking their hands. Otherwise supporting through touch is highly respected in some other studies such as Ptecek and Eberhardt (12) and Rassin study (10). Cultural and religious differences could interpret these contradictions.

Similar to Fujimori and (4) and Butow studies (16), 60.5% of the patients, mostly married people and those with higher education levels tended to be informed about life expectancy. Demonstrated by Butow in 1996, only 25% of the physicians expressed information about life longevity (16).

Pursuant to Samimi (6), Fujimori (4) and Rassin (10) 70% of the patients (n = 140), mostly people with higher education levels demanded for more information about their treatment options. Most patients (n = 169, 84.5%) believed that the physicians should consult patients for making treatment decisions; and this corresponds to Ferraz (22) and disputes the findings of Fujimori (4). The current paternal background in the countries of East Asia could elucidate the divergence.

While receiving information on diagnosis, the use of encouraging statements were scored the highest (mean score = 4.17 and standard deviation = 0.68) and disappointing statements were scored the lowest (mean score = 2.22 and standard deviation = 0.69). In the Rassin study (10), using the encouraging (mean score = 2.86 and standard deviation = 0.73) and participatory statements (mean score = 2.97 and standard deviation = 0.81) were also more popular among the patients, and all the participants agreed with avoiding disappointing statements during diagnosis disclosure (mean score = 1.79 and standard deviation = 0.80).

Conclusion

In the present study, most patients preferred to be informed about their diagnosis, while some had not received the correct information about their disease diagnosis. Considering patients’ demands and the proper use of professional communication methods by physicians may help to improve the physician-patient relationship. Obviously, further education in this field is felt to be necessary for physicians.

Limitations and suggestions

This study has got some limitations including small sample size of the patients with cancer, selection of patients only from one medical center and conducting the review only on patients with cancer. Therefore, it is difficult to generalize the results to all patients who have experienced receiving bad news. Also, we did not assess the individual factors affecting the patients’ reaction in stress conditions such as patients’ personality type, race, career family and their supporting systems.

References

1. VandeKieft GK, Breaking bad news. Am Fam Physician 2001; 64: 1975-1978.
2. Dias L, Chabner BA, Lynch TJ, Jr., Penson RT. Breaking bad news: a patient's perspective. Oncologist 2003; 8: 587-596.
3. Farrell M. The challenge of breaking bad news. Intensive Crit Care Nurs 1999; 15: 101-110.
4. Fujimori M, Akechi T, Morita T, Inagaki M, Akizuki N, Sakano Y, et al. Preferences of cancer patients regarding the disclosure of bad news. Psychooncology 2007; 16: 573-581.
5. 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 patients' views. BMJ 1996; 313: 724-726.
6. Valizadeh L, Zamanzadeh V, Rahmani A, Howard F, Nikanfar AR, and Ferguson C. Cancer disclosure: Experiences of Iranian cancer patients. Nursing and Health Sciences, 2012; 14: 250-256.
7. Yun YH, Lee CG, Kim SY, Lee SW, Heo DS, Kim JS, et al. The attitudes of cancer patients and their families toward the disclosure of terminal illness. J Clin Oncol 2004; 22: 307-314.
8. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L. Breaking bad news: patients' preferences for communication. J Clin Oncol 2001; 19: 2049-2056.
9. Butow PN, Dunn SM, Tattersall MH. Communication with cancer patients: does it matter? J Palliat Care 1995; 11: 34-38.
10. Rassin M, Levy O, Schwartz T, Silner D. Caregivers' role in breaking bad news: patients, doctors, and nurses' points of view. Cancer Nurs 2006; 29: 302-308.
11. Manwit SJ, Datson SL. Disclosure preferences about terminal illness: an examination of decision-related factors. Death Stud 2002; 26: 1-20.
12. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. JAMA 1996; 276: 496-502.
13. Lind SE, DelVecchio Good MJ, Seidel S, Csordas T, Good BJ. Telling the diagnosis of cancer. J Clin Oncol 1989; 7: 583-589.
14. Taylor KM. 'Telling bad news': physicians and the disclosure of undesirable information. Socio Health Illn 1988; 10: 109-132.
15. Miyaji NT. The power of compassion: truth-telling among American doctors in the care of dying patients. Soc Sci Med 1993; 36: 249-264.
16. Schofield PE, Butow PN, Thompson JF, Tattersall MH, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. Ann Oncol 2003; 14: 48-56.
17. Buckman RA. Breaking bad news: the S-P-I-K-E-S strategy. Commun Oncology 2005; 2: 138-142.
18. Sapir R, Catane R, Kaufman B, Isaacson R, Segal A, Wein S, et al. Cancer patient expectations of and communication with oncologists and oncology nurses: the experience of an integrated oncology and palliative care service. Support Care Cancer 2000; 8: 458-463.
19. Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. J Am Geriatr Soc 2003; 51: 1398-1403.
20. Kaplowitz SA, Osuch JR, Safran DSC. Physician communication with seriously ill cancer patients: Result of a survey of physicians. End of Life Issues: Interdisciplinary and Multi-dimensional Perspectives. New York: Springer Publishing Company; 1999.
21. Mueller PS. Breaking bad news to patients. The SPIKES approach can make this difficult task easier. Postgrad Med 2002; 112: 15-16, 18.
22. Goncalves F, Marques A, Rocha S, Leitao P, Mesquita T, Moutinho S. Breaking bad news: experiences and preferences of advanced cancer patients at a Portuguese oncology centre. Palliat Med 2005; 19: 526-531.
23. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. Palliat Med 2003; 17: 339-343.
24. Schofield PE, Beeney LJ, Thompson JF, Butow PN, Tattersall MH, Dunn SM. Hearing the bad news of a cancer diagnosis: the Australian melanoma patient's perspective. Ann Oncol 2001; 12: 365-371.