

Do Cancer Patients Prefer to Know the Diagnosis? A Descriptive Study Among Iranian Patients

Seyed Mehdi Samimi Ardestani,¹ Farhad Faridhosseini,^{2,*} Fatemeh Shirkhani,¹ Ardeshir Karamad,¹ Layla Farid,³ Mohammad Reza Fayyazi Bordbar,² and Ali Motlagh^{4,5}

¹Behavioral Sciences Research Center, Shahid Beheshti University of Medical Sciences, Tehran, IR Iran

²Psychiatry and Behavioral Sciences Research Center, Mashhad University of Medical Sciences, Mashhad, IR Iran

³School of Pharmacy, Southern Illinois University, Edwardsville, USA

⁴Radiation Oncology Department, Shahid Beheshti University of Medical Sciences, Tehran, IR Iran

⁵Cancer Research Center, Shahid Beheshti University of Medical Sciences Tehran, IR Iran

*Corresponding author: Farhad Faridhosseini, Psychiatry and Behavioral Sciences Research Center, Mashhad University of Medical Sciences, Mashhad, P. O. Box: 9195983134, IR Iran. Tel: +98-5137002309; +98-9155115502, Fax: +98-5137124184, E-mail: faridhosseinif@mums.ac.ir

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Abstract

Background: There are important differences regarding cancer disclosure in various geographical populations (Europeans, Western Asia, Eastern Asia), depending on multiple sociocultural factors, and therefore, there is no standard protocol on this issue, especially in Iran.

Objectives: To evaluate the amount of information that Iranian patients have and their preference for the disclosure of the cancer diagnosis.

Patients and Methods: In this cross sectional descriptive research, patients admitted in the oncology departments of 3 referral medical centers, Imam Hussein, Shohada-e-Tajrish and Modarres, in Tehran, from March 2007 to April 2008, were questioned about their awareness and knowledge regarding their diagnosis. Two different structured questionnaires were designed for the people who know and who didn't know their diagnosis. For the former, the survey concerned their psychological reactions to their situations, whether they would prefer to know about their diagnosis and by whom they are preferred to be informed. For the latter, the questionnaire included their preference whether to know the diagnosis and their current emotional state. Descriptive statistics and chi square test was applied to analyze gathering Data, using SPSS version 14.

Results: 60.3% of the patients knew their diagnosis. Among the subjects who did not know their diagnosis, 88% preferred to be more informed about their diagnosis and 68% had some psychological reaction to their situations. Among the subjects who knew their diagnosis, 92.1% preferred to know their diagnosis, 73.6% preferred to be informed directly by their physicians. Following the diagnostic disclosure, 81.5% reported that they had felt nervous, anxious and worried.

Conclusions: The majority of Iranian patients with malignancy want to know the truth and they prefer to be informed directly by their doctors.

Keywords: Diagnostic, Disclosure, Neoplasms, Doctor-Patient Relations, Patient Preference

1. Background

Diagnostic disclosure has been a challenge for physicians who work with cancer patients, in several regions, especially in the case of Asian and Latin countries (1, 2). For instance, cancer patients in Japan are not informed of their disease diagnosis or prognosis. These patients are even occasionally told they have other diseases. In many cases, important information is given without mentioning the word "cancer" (2, 3). In Saudi Arabia, physician's preference is to discuss diagnosis with patients' families (4). Physicians in Iran, also, traditionally prefer to break bad news to family members, rather than the patient (5-8). According to a cross sectional study, studying Iranian physicians' attitude toward cancer disclosure, 54% of respondents preferred their patients not to know they

had cancer and the most common reason is the family request to conceal the diagnosis by the doctors (9).

Despite the majority of family members preferred non-disclosure of information to cancer patients, paradoxically, most of them (70.3%) want a full disclosure by physicians, if they are diagnosed with a serious incurable disease (10). The issue raised here, however, is whether these approaches (hiding diagnosis from patients or just telling to family members) can meet patients' needs and preferences.

Despite several cultural and geographical differences, for physicians' approach, there are similarities between patients' preferences, regardless of cultural and geographical differences. Cancer patients in Western Asia,

including Saudi Arabia (98%) (11), as well as Eastern Asia, such as Malaysia (82%) (12) and Nepal (80%) (13), are even more interested to know their diagnosis than in western countries, like the UK (79%) (14). A study conducted in UK showed that 79 gastric and esophageal cancer patients, out of 100, wished to know the diagnosis, while only five in 100 physicians found it necessary for patients to be informed (14). In a survey undertaken on Kathmandu's general population (in Nepal), 80% of participants preferred to be informed of cancer diagnosis, even if it is an incurable type (13). Based on these studies, there are contradictions between patients' preferences for disclosure of cancer and physicians approach to this issue.

Several physicians believe discussing cancer diagnosis with patients might psychologically influence them in a negative way, making diagnostic disclosure a controversial issue in Iran (9). However, it is demonstrated that social constraints about cancer disclosure have been associated with increasing the level of distress among patients diagnosed with cancer (15). Therefore, knowing a patient's preference for disclosure may help physicians make proper decisions and it can have implications for planning a more supportive care system for cancer patients.

2. Objectives

The objective of this study is to investigate the amount of information that Iranian patients have and their preference for the disclosure of the cancer diagnosis.

3. Patients and Methods

This cross-sectional, descriptive study was conducted on 126 cancer patients, by means of questionnaires, prepared by the researchers. They were selected by convenience sampling, among patients who admitted in the oncology departments of three referral medical centers, Imam Hussein, Shohada-e-Tajrish and Modarres, in Tehran, Iran, from March 2007 to April 2008.

3.1. Questionnaires

First, a preliminary draft was prepared, using a validated questionnaire, applied in previous study (5). We had two types of questionnaire: one for patients who know their own diagnosis (Box 1) and the other, for those who did not (Box 2). Patient information (such as date of birth, duration of hospitalization and type of treatment) was asked at the beginning of each questionnaire. In this study, we assessed patients' attitude toward knowing the diagnosis, as well as subjective psychological reaction (not a definite psychiatric disorder) of patients who were exposed to a major bad news. As our survey did not investigate psychiatric disorders, following this stressful event, we do not check the reliability of the questionnaire.

Box 1. Content of Questionnaires Given to Patients Who Knew the Diagnosis

Contents

Demographic information

Type of disease

Time since patients were informed of diagnosis

Source of diagnosis disclosure

Patient's satisfactory level regarding current disclosure method

Patient's preference for diagnostic disclosure method

Patient's stress level before/after diagnostic disclosure (based on subjective report by patient)

Patient's current stress level (based on his/her own report)

Box 2. Content of Questionnaires Given to Patients Who did not Know the Diagnosis

Contents

Demographic information

Time when symptoms first appeared/type of symptoms

Pre-occupation with symptoms, and patients' emotional state

Patients awareness regarding treatment

How patient was educated about treatment

Patients' preference regarding the methods of being informed

Patients' level of satisfaction regarding current level of being informed

3.2. Patients

In this research, patients in stage 3 or 4 of different types of cancer, who were under chemotherapy or radiation therapy, were included to participate in the research. Patients were asked to sign a consent form. Patients, who are demented or delirious at the time of admission, or did not agree to participate in the study, were excluded. According to a previous similar study (16), in which the level of diagnosis awareness was reported to about 62% and considering 0.05 for alpha and 0.2 for prevalence precision, the sample size was estimated at about 130 individuals.

3.3. Methods

The researchers received approval from the Institutional Review Board and Medical Ethics Committee, in all three centers. A general practitioner was trained to explain the aim of the study, present the consent form, monitor the patients during answering the questionnaire and obtain medical information from their medical record. After the informed consent by each patient, the first question regarded his or her disease and its type. If the answer was known, patients were given the questionnaire prepared

for those aware of their diagnosis. Those who did not know about their disease were given the second questionnaire. Difference in questionnaires helped to avoid unwanted disclosure of cancer to those unaware of their diagnosis. All patients included filled in the questionnaires. The number of patients with diagnosis awareness was found out using descriptive statistics. Chi-square test was also applied to compare the level of distress among patients, with and without diagnosis awareness. The SPSS version 14 (SPSS Inc., Chicago, IL, USA) was used to make a data bank, acquire descriptive information, as well as analyze the data.

4. Results

Overall, 126 patients were interviewed in our study. Medical and demographic information is listed in Table 1.

Table 1. Demographic and Medical Characteristics of Patients (n = 126)

Characteristics	Number of Patients, %
Gender	
Male	70 (55.5)
Female	56 (44.4)
Age, y	
< 20	8 (6.4)
20 - 40	46 (36.5)
40 - 60	46 (36.5)
> 60	26 (20.6)
Marital status	
Single	26 (20.6)
Married	100 (79.4)
Education	
No education	26 (20.6)
Primary school	70 (55.6)
High school	16 (12.7)
Graduate degree	14 (11.1)
Place of living	
Tehran	68 (54)
Other cities	58 (46)
Types of cancer	
Lymphoma	26 (20.6)
Gastro-intestinal	31 (24.6)
Breast	12 (9.5)
Osteosarcoma	12 (9.5)
Lung	7 (5.6)
Pancreas and liver	4 (3.2)
Prostate	5 (4)
Ovary	4 (3.2)
Other	25 (19.8)
Types of treatment	
Radiotherapy	6 (4.8)
Chemotherapy	82 (65.1)
Combined	38 (30.1)

Out of all patients admitted in our designated oncology departments in that period, 60.3% (76 patients) were aware of their diagnosis, while 39.7% (50 patients) were not. Within patients who knew their diagnosis, 44.7% (34/76) stated that their own physician disclosed the diagnosis, 21% of patients (16/76) insisted on diagnostic disclosure, while their physicians are reluctant to inform them, 21% (16/76) heard about their disease, while their physician was discussing it with others (such as nurse, a family member) (Table 2).

Overall, in 57.9% (44/76) of patients, their physicians discussed in more detail with them; however, 31.6% (24/76) stated that their doctor did not give them detailed information. In addition, 7.9% (6/76) mentioned that, when they asked questions, their physician would answer them. In 2.6% of patients, physicians would give information to their families.

Among patients who knew their diagnosis (n = 76, 92.1% of patients (70/76) preferred to be informed about the cancer diagnosis and prognosis, while only 7.9% (6/76) wished they did not know the diagnosis. Another question asked was regarding the patients' psychological state, if they did not know the diagnosis. It was found that 78.9% (60/76) stated they would be in worse psychological condition if they did not know the diagnosis, while 15.8% (12/76) mentioned otherwise. In addition, for 5.3% (4/76), it did not make any differences.

About the question concerning "by whom they prefer to be informed about their diagnosis", patients who preferred to be informed by their physicians were found to be 73.7% (Table 3).

Table 2. How the Patients Were Informed About Their Diagnosis, Within Patients Who Knew Their Diagnosis (n = 76)

Source of Being Informed	Number of Patients, %
By physician	34 (44.7)
Patient insisted on	16 (21.05)
Accidentally	16 (21.05)
By nurse	2 (2.6)
By family members	8 (10.5)

Table 3. Patients' Preference Regarding the Person That Would Inform Them About Their Diagnosis, Within Patients Who Knew Their Diagnosis (n = 76)

Patient's Preference	Number of Patients, %
Physician	56 (73.7)
Nurse	0
Family members	4 (5.2)
Friends	2 (2.7)
Doesn't make any difference	8 (10.5)
Prefer not to know	6 (7.9)

Table 4. Comparing Presence of Stress and Psychiatric Symptoms (Based on Patients' Own Report) Within Groups Who Knew Their Diagnosis (n = 76) and Patients Who did not Know Their Diagnosis (n = 50)^a

Patient's Current Stress Level	Patients Who Knew Their Diagnosis (n = 76)	Patients Who did not Know Their Diagnosis (n = 50)	P Value
Did not report major psychological symptoms	44 (57.8)	NA	
Mentally preoccupied by their condition	12 (5.7)	34 (68)	< .001
Symptoms of anxiety and depression	20 (26.3)	34 (68)	.007

Abbreviation: NA; not available.

^aData are presented as No. %.

Following the diagnostic disclosure, 81.6% (62/76) of patients reported that they had felt nervous, anxious and worried. However, at the time of the interview, 57.9% (44/76) did not report major psychological symptoms, 15.8% (12/76) were preoccupied by their disease and its prognosis and 26.3% (20/76) reported to be still anxious, nervous and/or depressed (Table 4).

There were 50 out of 126 patients who were not told about their diagnosis. Among them, 68% (34/50) were found to be mentally preoccupied by their condition. Symptoms of anxiety and depression were seen in 68% (34/50) (Table 4). These patients stated that their excitement level was influenced by their being unaware of their diagnosis. Moreover, 92% (46/50) of patients were informed of their therapy plan, while 8% (4/50) were not. Finally, 80% (40/50) of these patients received this information from their own physician, while 12% were informed by family members and 4% by nurses. However, 4% of patients mentioned that no information was given to them by any of these sources. Also, it was found that 88% (44/50) preferred to be further informed by physicians, about their disease.

5. Discussion

When we are talking about breaking bad news, we need to consider these factors: 1. What percentage of cancer patients know their diagnosis and what is the source of information? 2. What percentage of cancer patients preferred to know and what was their preferred source? 3. What percentage of oncologists tries to disclose the diagnosis and what is their preference? 4. What is the impact of diagnosis disclosure on patients?

Regarding the first question, it seems that, in several countries, physicians approaches are more towards breaking bad news to their patients, due to an increased emphasis on respecting patients' rights and sense of autonomy, while in several other countries, physicians hesitate to inform their patients about the diagnosis of cancer (1, 16-18). In our study, we found that 60.3% of patients under different types of cancer treatment, in designated hospitals, were aware of the diagnosis, while, depending on the culture, this percentile could be different in various countries (18, 19). For instance, a study conducted in

Thailand showed 63.2% of patients under radiotherapy treatment knew about their disease diagnosis, which is a close percentile to our results in Tehran, Iran. Overall, patients' awareness of cancer varied from 38% to 98%, in various countries (16). For example, a study performed in Taiwan, in 1996, indicated that only 37.2% of patients were informed of their diagnosis (20). Another study, undertaken on 96 patients, in 2006 in Nepal, showed that 20% were informed about both diagnosis and prognosis of their disease, while only 17% only knew the diagnosis and 63% were not aware of their disease (13). Also, in Portugal, 68.9% of patients were told about their cancer diagnosis (17). In a study conducted in Riyadh, Saudi Arabia, Bedikian et al. found that only 16% of patients were told they have "cancer" and 34% were told to have "tumors" (21). A research done in Tehran Cancer Institute, Tehran, Iran, on gastrointestinal cancer patients under treatment, showed that 52% knew the diagnosis (22).

Cancer treatments, such as radiotherapy and chemotherapy, require patients to be informed of the procedures and continuous follow-up sessions to be continued. Therefore, it was expected to have more patients aware of their diagnosis. In this study, the necessary information regarding treatments was given to 92% of patients, unaware of their diagnosis, without mentioning the word "cancer". According to a study conducted by Rodriguez et al. many physicians employ implicit language when discussing cancer diagnosis and prognosis with patients (23).

In this study, only 60.7% of patients aware of diagnosis were informed by their physicians and other patients found out by other means, such as family members or hospital staff. Another descriptive study in Iran indicated that 66% of cancer patients were informed about the diagnosis by their physicians, while others got the news from relatives. According to this research, cancer patient education, prior to treatment, was poor in Iran (6). In our study 65.6% (57.8% + 7.8%) of informed patients stated that their physician gave them related information. Therefore, based on these two studies, on Iranian cancer patients, there is still a group of Iranian physicians who refuse to provide information regarding malignancy for their patients.

What percentage of cancer patients prefer to know and

how much and which is their preferred source? In our study, we found that 92% of patients, with whom the diagnosis was discussed, preferred to know the diagnosis and 88% hoped to be given more information about their disease by physicians. Most patients (73.7%) would rather hear the bad news from their own physician (see Table 5). Based on these results, it seems that most Iranian cancer patients would rather know the diagnosis of cancer. Moreover, it seems patients' preference in Iran differs from what doctors might think about patients' preference and their psychological reaction, following the disclosure. These results are close to what researchers have found in Iran and other countries. In a study conducted on 167 Iranian cancer patients and 143 family members, 97% stated they would like to have more information on cancer and possible treatments (22). In a study conducted in Portugal, 74% of patients wished to know everything regarding their disease, in detail, and 85% preferred to be informed about the diagnosis, in case they had cancer. Also, 95% stated they would want to be told the best and worst circumstances of their disease and 92.7% wanted their physician to disclose the diagnosis (17). Similarly, in a country with a completely different culture, such as Nepal, 80% of the general population preferred to be informed about their disease in, case of having cancer (13). Moreover, even among the terminally ill, as well as poor prognosis cancer patients, it was found that they significantly preferred disclosure (directly by a physician) and they preferred to choose palliative care options (24).

What percentage of oncologists tries to disclose the diagnosis and what is their preference? Physicians' preference on diagnostic disclosure and providing necessary information to patients has been found to be different, in various countries. In Northern Europe and America, most doctors prefer to disclose diagnosis and this approach is seen mostly during the past three decades (19). Nonetheless, in several countries, physicians still do not follow this approach. In a survey done in 1987 on oncologists in Iran, Hungary, Panama, Portugal, France, Spain and African countries, only 40% would discuss the diagnosis with their patients and most physicians prefer to tell the diagnosis of malignancy to patients' families (25). In another survey done in 1998 in Japan, 40% of physicians reported to disclose diagnosis with patients, which had an uprising trend compared with several previous decades. However, this percentage is still much lower than United States and Northern European countries (26). In a study conducted in 1998, in Lebanon, 47% of physicians were found to discuss patients' diagnosis with them (27).

Regarding the fact that there was a small percentage of patients, in our study, who did not wish to know the diagnosis, it seems necessary that, prior to having the precise results, physicians ask patients about their preferred method for discussing the diagnosis and to what extent they would like to know the diagnosis and its prognosis. This is one of the main principles of most proposed methods for breaking bad news (28, 29). In other words,

individualization or tailoring communication, according to each patient's own personality characteristics, as well as his/her coping style, is necessary.

What is the impact of diagnosis disclosure on patients? Most physicians refuse to give bad news, to avoid psychological damage to their patients (22). However, several studies indicated otherwise. A study performed in Japan, by Horikawa et al. on patients who were not aware of diagnosis and referred to psychiatrics, indicated a higher level of anxiety, irritability and suicidal ideations (30). According to a research conducted by Hosaka et al. the occurrence of psychiatric disorders, found in patients aware of diagnosis, was not much different (42.9%) than in those who were not informed (48.3%) (31). In a study from 2010, Jackson et al. showed that, following diagnostic disclosure, patients with prostate cancer had higher motivation for finding social support resources, which both ultimately led to an increase in positive emotions (32). In addition, Lin et al. reported that Taiwanese patients, who were aware of their cancer, were more satisfied of their therapy sessions and pain control and had better quality of life (33). Based on these results, it seems that hiding information from patients will not psychologically help them.

In this research, psychiatric assessment was not performed on patients and only subjective sense of suffering, reported by patients, was studied. The results indicate that, in 81.6% of cases reported, they had felt nervous, anxious and depressed, following being informed about their diagnosis. However, 57.9% reported that they could finally adjust with the new situation and seek help and treatment. In addition, 78.9% of patients mentioned that they would have been in bad psychological mental state, if they had not known about their diagnosis. However, following the diagnostic disclosure, 15.8% of patients were still found worried and preoccupied about their condition, at the time of interview, and 26.3% reported psychiatric symptoms, such as anxiety and depression. The prevalence of depression, anxiety and other psychiatric morbidity is found to be high among cancer patients (34, 35). This is also the case in Iran and, in a research conducted by means of Hospital Anxiety and Depression Scale on gastrointestinal cancer patients, 47.2% reported high score for anxiety and 57% for depression. The scores were higher among patients who knew their diagnosis (36).

In this study, we found that several patients are not able to cope with their illness, following the disclosure, and several require psychological and psychiatric support. For instance, participation in group therapy can reduce patients' anxiety level to a great extent (37). Therefore, it is important to monitor patients' mental state, during specific cancer treatments and, if necessary, provide them with psychiatric help. On the other hand, we found that 68% of patients, who were not told the diagnosis, were still preoccupied by their disease and stated that they were in different emotional state, compared to the time

prior to sickness. Also, 88% of these patients preferred to be informed about their disease by physicians. These results not only show that withholding cancer diagnosis, by physicians, does not necessarily decrease patients' stress and anxiety, whereas most of them stated to be still under stress (31). In any case, when it comes to disclose a terminal illness, patients should be psychologically prepared to hear about it. Otherwise, their psychological discomfort would be at high and intolerable level. This research suggests that it may be better to train physicians with proper communication and disclosure skills. Education about how to give bad news is not common in Iran and Middle Eastern countries (18). Moreover, the other common problem is the lack of professional codes, as well as legislations, regarding the patients' rights in an informed consent (18). Current legal norms, towards cancer disclosure, are also vague, even in several developed far eastern countries (38). Considering rules and legislations about patients' autonomy and providing training programs for physicians are needed in our society.

In this study, we were unable to employ cancer patients from total population; instead, patients were chosen from those under radiotherapy or chemotherapy treatment, in university hospitals. Tendency in knowing the diagnosis may be higher in patients under treatment (16). Also, this study was conducted on patients with cancer, and, therefore, it may not be true for overall healthy population. The rate of preference for diagnostic disclosure, among Iranian patients in early stage of cancer, is unknown and could be the subject of future studies. To find out if Iranian healthy individuals would still prefer to know the diagnosis, if faced with cancer, more surveys among general population will be required. In addition, patients living in the capital city, Tehran, may differ in preference from those from other cities; however, 44% of our patients were living in cities other than the capital. We proposed further investigations in other cities and different cultural backgrounds. Moreover, our patients vary in type of cancer and its stage and we did not consider staging of cancer, as an important variable. It is found that the type of cancer and cancer stage could affect patients' preference in knowing the diagnosis, as well as physicians approach to disclosure (16, 19). Comparing attitudes toward disclosure, as well as psychological reactions, among different types of cancer, could be investigated in the future studies.

The results of this study indicated that Iranian patients undergoing radiotherapy or/and chemotherapy, like patients in most countries, prefer to be informed about their disease. Most of them would like their physicians to perform the diagnostic disclosure. However, despite this preference, several patients receiving therapy may never know the diagnosis. This shows that certain Iranian physicians would not like to give bad news directly to their patients. It seems that diagnostic disclosure may result in more pain and suffering, for a short period of time. Nevertheless, more patients prefer to know the diagnosis,

despite their stress. Regarding patients who were aware of diagnosis, several of them can adapt themselves with the new condition. However, others may need psychiatric evaluation and psychological assistance.

Authors' Contributions

Seyed Mehdi Samimi Ardestani conceived and designed the evaluation, interpreted the clinical data and revised the draft critically, for important intellectual content. Farhad Faridhosseini interpreted the clinical and statistical data and drafted the manuscript. Fatemeh Shirkhani collected the clinical data and helped to draft the manuscript. Ardeshtir Karamad helped to collect the clinical data and to analyze the clinical and statistical data. Layla Farid helped to collect the data and grammatically revised the manuscript. Mohammad Reza Fayyazi Bordbar and Ali Motlagh also revised the draft critically for important intellectual content. All authors read and approved the final manuscript.

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