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## Cancer Disclosure in Iran: Attitude of Patients and Their Families

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### ABSTRACT

**Background:** The present study aims at determining the proportion of clinical information known by the patients with cancer and their families about diagnosis of their disease as well as investigating the different attitudes of patients and their families towards informing the patients of the malignant nature of the disease.

**Methods:** We designed a structured questionnaire which was completed by patients with cancer who were under follow up in Cancer Institute of Tehran University of Medical Sciences, and one member of their families who accompanied them while being treated. Patients, physicians, and patients' family members were interviewed separately.

**Results:** A total of 250 cancer outpatients and 250 patients' family members were interviewed. Overall, 227 patients (90.8%) desired to be informed of their diagnosis, and 98 patients (38.8%) declared that physicians informed them completely. One hundred fifty-three family members (61.2%) believed that patients are entitled to know the truth. Stepwise multiple logistic regression analysis indicated that patients' educational grade (odds ratio: 6.08; 95% CI, 1.27 to 29.07) and patients' age (odds ratio: 7.97; 95% CI, 1.25 to 50.59) were predictable factors for requesting to know the truth.

**Conclusions:** Findings of the present research indicated that most patients and family members wanted to be informed of the diagnosis; The present study suggests that physicians respect the patients' rights to know the truth and inform them accordingly. This can help them adapt themselves to new condition and manage their own life.

### Introduction

Cancer is the third underlying cause of death worldwide, accounting for about 12% of all recorded deaths.<sup>1</sup> The prognosis of patients with cancer is generally poor if left untreated, and surgery or other invasive interventions have a considerable influence on survival and quality of life of the patients.<sup>2</sup>

Therefore, several studies showed that cancer diagnosis is not routinely disclosed in many cultures, and clinicians prefer to tell the truth about cancer diagnosis to the relatives before the patients.<sup>4,7</sup> However, the majority of physicians and patients have accepted that patients are entitled to know the diagnosis and other necessary information of their disease.<sup>4,8,9</sup> It has been shown that awareness of the patients with cancer about their disease may lead to a more appropriate care via better communication and cooperation between patients and their physicians. In addition, disclosure of the necessary information about cancer diagnosis and prognosis help the patients manage their non-medical issues including personal, familial, and occupational issues, appropriately.<sup>10-12</sup>

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Some studies have shown a strong wish for the disclosure of cancer diagnosis among the patients<sup>13-15</sup>; however, the attitude of relatives of the patients was different and the patients were more eager to know the truth than their family members.<sup>2, 16</sup> Patients and their families may differ in their attitude towards such a disclosure. Relatives of the patients with cancer generally prefer not to disclose the detailed clinical information and not to tell patients the truth in order to protect them from psychological and emotional distress.<sup>17-20</sup>

In this study, we investigated the attitude of the patients with cancer and their family members towards the disclosure of clinical information about the diagnosis, treatment, and prognosis. Moreover, we investigated factors affecting the attitude of patients and their family members towards truth-telling and their satisfaction with the disclosure of clinical information.

### Methods

The present cross-sectional study was conducted in Cancer Institute of Tehran University of Medical Sciences. We interviewed 250 patients and their companions including parents, siblings, spouses, and other relatives or friends who had a close relationship with patients who were treated at the cancer institute under the routine follow-up.

We interviewed only patients who had at least 18 years old and could communicate with the interviewers. The interviewers were physicians and nurses specifically trained for this study.

We used 2 types of questionnaire to collect the data for this the study. The questionnaires were designed based on previous studies, were revised based on the expert opinions of the research team, and were finalized based on a pilot study among a few research subjects.

The questionnaires included demographic information (age, gender, socioeconomic status, habitual history, and relationship between patients and their companions), clinical information (i.e. diagnosis, breast cancer diagnosis and the time duration between the diagnosis and the interview, treatment methods, and complications), attitudes about truth-telling, satisfaction with information provided by the physician, and the patient's desire to participate in truth telling for the other patients with the same diagnosis.<sup>3</sup> Face to face interviews were performed with patients and their companions, separately. Ethics Committee of Tehran University of Medical Sciences approved the present study.

### Statistical Analyses

The questionnaires with incomplete data were excluded from analysis. We performed descriptive analyses to describe the distribution of the studied variables. We used Chi-square and t tests to determine the association between variables. Considering the positive attitude of truth-telling as a dependent

variable, we performed stepwise multiple logistic regression analyses to determine the contributing factors affecting it. SPSS statistic software (Version 11.5) was used for data analysis.

### Results

Five hundred participants including 250 patients with cancer and one of their family members were accrued in this study. Characteristics of the participants are presented in Table 1. Among the patients group, 96 (38.8%) were male and 153 (61.2%) were female and the overall average age was 48 years ( $\pm 15.13$ ).

#### Attitude of the patients

While 17 (6.8%) patients disagreed with the diagnosis disclosure, 233 (93.2%) patients wanted to be informed of the diagnosis. A total of 228 (91.2%) patients preferred full disclosure, 1 (0.4%) partial disclosure, and 21 (8.4%) no disclosure. One hundred fifty-three (61.2%) patients preferred the disclosure of diagnosis, treatment methods, and their effectiveness which as shown in Table 2.

High educated patients were more likely than others believed in full disclosure of the truth ( $p < 0.001$ ). Patients preferred to be informed of their real disease first by their physicians (58.5%). Other preferable ways were: patients in the same situation (20%), press and literature (15%), media (10%), relatives and friends (4%), internet (1.6%), and other patients introduced more than one source for getting informed (17.6%).

The relationship between level of education and using other ways of getting information showed that the way of getting information about the diagnosis is different among different levels of education

**Table 1.** Characteristics of patients and family members

| Variables                | Patient N(%)   | Family members N(%) |
|--------------------------|----------------|---------------------|
| Age $\pm$ SD             | 48 $\pm$ 15.19 | 40 $\pm$ 11.63      |
| Gender                   |                |                     |
| Men                      | 94(37.6%)      | 124(49.6%)          |
| Women                    | 153(61.2%)     | 124(49.6%)          |
| Education*               |                |                     |
| Low educated             | 234(93.6%)     | 205(82%)            |
| High educated            | 16(6.4%)       | 44(17.6%)           |
| Economic status**        |                |                     |
| Good                     | 16(6.4%)       |                     |
| Intermediate             | 158(63.2%)     |                     |
| Poor                     | 64(25.6%)      |                     |
| Relationship to Patients |                |                     |
| Spouse                   |                | 69(27.6%)           |
| Offspring                |                | 90(36%)             |
| Sibling                  |                | 45(18%)             |
| Parents                  |                | 19(7.6%)            |
| Others                   |                | 27(8.1%)            |

\*Education: Low educated: Finished high school and below (first 12 years of education), High educated: University education

\*\* Monthly income: Good >25,000,000 IRR, Intermediate: 10,000,000-25,000,000 IRR, Poor <10,000,000 IRR



( $p=0.001$ ).

Patients with high education level used at least one more route to get information and the most common way for these patients was media.

One hundred fifteen patients (46.5%) from 250 participants were satisfied with information that physicians give them about the diagnosis of their real disease. There was also statistical differences between economic status and satisfaction with being informed of the diagnosis and prognosis; patients with good economic status were more satisfied with

being informed of the diagnosis ( $p=0.01$ ).

There was no significant difference between the proportions of socio-demographic factors in patients who wished to know the truth.

#### *Attitude of the family members*

Among the family members, 25 (10%) accepted partial disclosure and 72 (28.8%) did not desire any disclosure. Attitude of the relatives on the necessity of truth-telling and physicians' authority over disclosure are presented in Table 3 and Table 4.

**Table 2.** Patients preference about the disclosure of diagnosis, treatment methods, and their effectiveness

| Patient questions   | Yes        | General Information | No         |
|---|------------|---------------------|------------|
| Do you know the diagnosis of your disease?                            | 160(64%)   |                     | 90(36%)    |
| Do you want to know about the diagnosis of your disease?              | 233(93.2%) |                     | 17(6.8%)   |
| Are you informed of all the details of your disease?                  | 97(38.8%)  | 91(36.4%)           | 62(24.8%)  |
| Do you wish to be informed of the details of your disease?            | 228(91.2%) | 1(0.4%)             | 21(8.4%)   |
| Are you informed of treatment methods?                                | 163(65.2%) | 48(19.2%)           | 39(15.6%)  |
| Do you wish to be informed of treatment methods?                      | 234(93.6%) | 8(3.2%)             | 8(3.2%)    |
| Are you informed of the effectiveness of treatment methods?           | 71(28.4%)  | 37(14.8%)           | 142(56.8%) |
| Do you wish to be informed of the effectiveness of treatment methods? | 242(96.8%) | 4(1.6%)             | 4(1.6%)    |

One hundred forty-one healthy family members (92.8 % from 153 family members), who thought patients are not entitled to know the truth, would not desire to be informed of the diagnosis if they are affected by cancer in future, while 47 (68.1%) of whom with the same point of view wished to know the truth. One hundred eight (52.7%) family members from low educated group thought that the physicians had to give relatives consent to inform patients and 97 (32.5%) thought that physicians should not follow families request about telling patients the truth ( $p=0.001$ ). A total of 108 relatives (57.7%), who believed their patient consent is necessary to inform the family, thought that if they are affected by cancer in future, physicians should not get patients permission to inform the family.

One hundred forty-six family members (58.4%) believed that informing patients of their real disease may lead to desirable outcome in treatment, 88

(35.2%) thought that the disclosure could reduce the treatment efficacy, and 13 (5.2%) thought the disclosure could not influence the treatment process.

However, 84 (49.7%) low educated family members believed that informing patients of their real disease could hamper treatment, while just 6 (13.33%) from high educated group had the same viewpoint ( $p=0.001$ ).

#### *Multiple Stepwise Logistic Regression Analyses of Influential Factors on Truth-telling*

Four stepwise logistic regression analyses of factors influencing the patients' attitude towards truth-telling were identified by 2 models:

1. The necessity of disclosure from patients' point of view
2. Informing the patients by physicians and 2 other models
3. Patients agreement to physicians' truth-telling

**Table 3.** Attitude of patients' relatives about the necessity of truth-telling

| Relatives questions   | Yes        | General Information | No        |
|---|------------|---------------------|-----------|
| Do you believe that the patients are entitled to know their diagnosis with the details? | 153(61.2%) | 25(10%)             | 72(28.8%) |
| Should the physicians inform the relatives with the details?                            | 222(88.8%) | 20(8%)              | 8(3.2%)   |

**Table 4.** Attitude of patients' relatives about physicians' authority over disclosure

| Relatives questions  | Yes        | Sometimes | No         |
|--|------------|-----------|------------|
| Should the physicians inform the patients according to your consent? | 116(46.4%) | 41(16.4%) | 93(37.2%)  |
| Is the patient consent necessary to inform you?                      | 28(11.2%)  | 35(14%)   | 187(74.8%) |



#### 4. Relatives being informed by the physicians

Unlike gender, economic status, and place of living, the first two models indicated that patients' level of education was likely to influence the attitudes towards truth-telling (Table 5). Other

two models showed the influence of patient educational level on physicians' informing relatives and the influence of relatives' state of living on patients' agreement to physicians' truth-telling (Table 6).

**Table 5.** Odds ratio and 95% CIs from Logistic Regression Analysis of factors influencing patient's attitude towards truth-telling

| Variables   | Should there be disclosure? (Yes) |              | Did the physicians inform you? (Yes) |              |
|---|-----------------------------------|--------------|--------------------------------------|--------------|
|   | Odds Ratio                        | 95% CI       | Odds Ratio                           | 95% CI       |
| Gender  |                                   |              |                                      |              |
| Female  | 0.70                              | 0.25 to 1.98 | 0.91                                 | 0.43- 1.91   |
| Male  | 1                                 |              | 1                                    |              |
| Education***  |                                   |              |                                      |              |
| Without formal education  | 1                                 |              | 1                                    |              |
| Primary school  | 1.92                              | 0.47- 7.77   | 1.71                                 | 0.62- 4.70   |
| Secondary school  | 3.65                              | 0.77- 17.35  | 1.10                                 | 0.39- 3.05   |
| High school   | 6.08*                             | 1.27- 29.07  | 6.19**                               | 1.93- 19.77  |
| Higher educated   | 4.39                              | 0.36- 52.32  | 15.04                                | 1.57- 144.01 |
| Place of Living   |                                   |              |                                      |              |
| Village   | 2.40                              | 0.38- 14.87  | 1.43                                 | 0.48- 4.21   |
| City  | 1                                 |              | 1                                    |              |
| Economic status****   |                                   |              |                                      |              |
| Good  | 1                                 |              | 1                                    |              |
| Intermediate  | 0                                 | 0            | 1.35                                 | 0.25- 7.26   |
| Poor  | 0                                 | 0            | 0.74                                 | 0.11- 4.65   |
| Relatives' attitudes towards truth-telling<br>(Should there be disclosure?) |                                   |              |                                      |              |
| Yes   | 2.22                              | 0.82- 6.02   | 1.51                                 | 0.73- 3.14   |
| No  | 1                                 |              | 1                                    |              |

\* $P < 0.05$

\*\* $P < 0.01$

\*\*\* Primary school: First 5 years of education, Secondary school: Second 3 years, High school: Third 4 years, Higher educated: University education

\*\*\*\* Monthly income: Good >25,000,000 IRR, Intermediate: 10,000,000-25,000,000 IRR, Poor <10,000,000 IRR

**Table 6.** Odds ratio and 95% CIs from Logistic Regression Analysis predicting attitudes towards truth-telling

| Variables                  | Patients' agreement to informing relatives |             | Physicians informed relatives |             |
|----------------------------|--|-------------|-------------------------------|-------------|
|                            | Odds Ratio                                 | 95% CI      | Odds Ratio                    | 95% CI      |
| Gender                     |  |             |                               |             |
| Female                     | 0.82                                       | 0.21- 3.22  | 1.14                          | 0.55- 2.34  |
| Male                       | 1  |             | 1                             |             |
| Place of Living            |  |             |                               |             |
| Village                    | 2.68                                       | 0.28- 25.72 | 0.47                          | 0.15- 1.49  |
| City                       | 1  |             | 1                             |             |
| Education**                |  |             |                               |             |
| Without formal education   | 1  |             | 1                             |             |
| Primary school             | 0.52                                       | 0.09- 2.80  | 1.71                          | 0.62- 4.70  |
| Secondary school           | 1.33                                       | 0.16- 11.13 | 4.08*                         | 0.39- 3.05  |
| High school                | 6.24                                       | 0.42- 91.22 | 2.54                          | 1.93- 19.77 |
| Higher educated            | 1.03                                       | 0.05- 21.57 | 11.27*                        | 1.03-122.98 |
| Relative's Place of Living |  |             |                               |             |
| Village                    | 0.04*                                      | 0.004- 0.52 | 1.41                          | 0.33- 5.95  |
| City                       | 1  |             | 1                             |             |
| Relative's Education**     |  |             |                               |             |
| Without formal education   | 1  |             | 1                             |             |
| Primary school             | 0.36                                       | 0.02- 6.34  | 0.55                          | 0.14- 2.11  |
| Secondary school           | 0.08                                       | 0.005- 1.49 | 0.79                          | 0.21- 3.00  |
| High school                | 0.30                                       | 0.01- 6.63  | 1.14                          | 0.30- 4.28  |
| Higher educated            | 0.02                                       | 0.007- 6.20 | 5.25                          | 0.75-36.40  |

\*  $P < 0.05$

\*\* Primary school: First 5 years of education, Secondary school: Second 3 years, High school: last 4 years of the school, Higher educated: University education



## Discussion

Receiving a diagnosis of cancer is often emotionally traumatic for the patients. Patients who feel they are not being told enough, often suffer from a feeling of insecurity due to a lack of information about what is going to happen in the immediate future.<sup>18</sup>

Recent studies clearly indicate that physicians must be educated to routinely ask the patients about their wishes for knowing the truth, because telling patients the truth may lead to more appropriate care and many physicians believe that disclosure have many advantages; for instance, it enables patients to cooperate with physicians better, to settle the incomplete business, to manage their life better, and to be treated according to their own values and preferences.<sup>10-12,18</sup>

Truth-telling benefits, reported in other studies, are accompanied by less pain, anxiety, and depression as well as less interference in daily lives and higher levels of satisfaction with pain management.<sup>21,22</sup> Higher levels of anxiety, tension, irritability, and suicidal tendency in the patients who did not know their diagnosis were reported in similar studies.<sup>16</sup> Not telling the truth can harm the patients in many ways; patients who remain uninformed of their condition may fail to obtain medical attention when necessary. They may also make decisions affecting their lives that they would not make, if they were aware of their condition.<sup>23</sup>

The attitudes of patients with cancer and their families towards telling the truth about cancer diagnosis and prognosis differs across cultures.<sup>18-20</sup> An international survey reported the different percentage of patients with cancer who were given the truth.<sup>4</sup>

The rate of disclosure may influence the physician and family attitude as well as the hospital policy.<sup>18</sup>

The main finding of the present study was that 90% of patients desired to be informed of their real disease. This finding is in line (83%-96%) with the previous studies.<sup>24,25</sup> However, a study conducted in China reported that 69.3% of patients preferred disclosure, which is significantly less than other studies. The authors found relationship between a number of factors such as type of cancer, etc.<sup>26</sup> Traumatic influences of receiving the diagnosis of cancer as an incurable disease can be the main reason for rejecting disclosure by some patients.

Another important finding of the present study was that patients and family members differed in attitudes towards the disclosure of real diagnosis to patients with cancer. Patients were more interested to be informed about the diagnosis and prognosis than their families. Similar results were observed by previous studies.<sup>24,27,28</sup>

The majority of patients wanted to be informed of their real disease; this is significantly different from

the corresponding proportion in the family member group, meaning that we found a great difference in attitudes of patients and family members toward the truth being disclosed to them. Most of the patients were satisfied with the information which they received from their physicians about their disease and treatment protocol; nevertheless, less than 40% of patients were informed of the outcome and complications of treatment. The majority of family members knew the real disease, potential complications, and outcomes. The reason for this difference may be that families believed disclosure could make patient feel hopeless and make her suffer from psychological disorders such as anxiety, appetite loss, and insomnia that can hamper her life quality. Another reason for this difference may be explained by the difference between educational level of patient and families and cancer disclosure. Low educated family members believed that informing patients of their real disease may prohibit treatment improvement, while just a minority of the high educated group had the same idea; more than 80% of family members were low educated.

In some countries, physicians prefer to follow the families' wish on disclosure, so they comply with the request of not telling the truth to the patient; however, they believe that informing the patients of their real illness is beneficial in establishing satisfactory relationship among the physicians, patients, and the family.<sup>18</sup> The family surrounds the patient during difficult time of the disease and, in many societies, the family is still the strongest supporting entity. Families often believe that it is their duty to protect the patient from harm. In Middle East countries, such as Egypt and Saudi Arabia or Eastern Asia, and in Spain and Italy, the physician prefers to tell the truth about the cancer diagnosis to the relatives before the patient. They argue that there are many valid reasons justifying this; they have enough experience about the likely reactions of the patient than the health-care professionals, and at the same time, they usually deliver the necessary support and physical care.<sup>29-35</sup> The present study, like other studies, shows that patients' relatives play an important role in cancer disclosure.

A large proportion of patients (83.6%) wanted family members to know about their disease, but some patients did not agree with informing families without their consent (6%) because, for instance, they did not want their relationships change, miss their jobs, social position, and experience some other.<sup>36</sup> The assessment of these different attitudes indicated the necessity of patients' preferences. Families who resist on the disclosure of truth should be recommended about the importance of truth-telling, much as they might be counseled about the appropriate management of any medical problem; however, it is important to bear in mind that substantial variability exists within cultures and that



cultural values can change.<sup>23</sup>

In the present study, the attitude towards the disclosure was not shown to be related with the patients' socio-demographic factors such as gender, educational degree, and economical status, but in some other studies, unlike the present study, some characteristics influenced the patients' desire to know the truth,<sup>24, 25, 36</sup> however, patients' lack of education and poor economic status have been related to lower rates of truth-telling and the present research showed that the education level of the patients was a significant factor influencing the patients' awareness of the malignant nature of their disease. Some other studies have shown that elderly patients are less likely to be told their diagnosis.<sup>16, 21</sup> Moreover, low level of education and low socioeconomic status were reported as effective factors in concealment of the truth.<sup>21</sup>

In the present study, physician was introduced as an appropriate person to disclose the diagnosis; patients and their relatives had the same idea in other studies.<sup>25, 36, 37</sup> Investigating the relatives attitude towards informing patients showed that a large number of family members (82%) would desire to be informed if they happen to have cancer, in the future; similar results were observed by Gongal *et al.*<sup>38</sup> where 70% of family members who thought patients were not entitled to know the truth, would desire to know the truth, in case that they would have a malignancy, themselves.

Based on the findings of the present study, a large proportion of family members (58.4%) believed that informing patients of their real disease would lead to desirable results of treatment; some other studies from other countries have reported benefits of cancer disclosure.<sup>16, 21, 22</sup>

To sum up, the present study showed that a large number of patients favored full disclosure of the real diagnosis. Physicians and family members should respect the patients' viewpoint, because patients are entitled to know about their own condition and all information should, first, be told to the patient by the physician.

Although there is no legal obligation for cancer disclosure to patients and family members in Iran, it must be defined as a professional policy with enforceable guidelines for physicians and medical staff; they have to be trained specially to get adequate communication skills for effective communication with patients and relatives to prepare the setting for telling patients the truth with the intention of minimizing stress and avoiding sustained harmful loss.

### Conflict of Interest

We have no financial relationship with the organization that sponsored the present research. We have full control of all primary data and we agree to allow the journal to review the data, if requested.

Ethics Committee of Tehran University of Medical Sciences approved the study.

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