



# Truth Disclosure to Patients with Poor Prognosis: A Comparison of the Perspectives of Patients, Physicians and Nurses

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## Abstract

**Background:** Truth disclosure to patients is the cornerstone of medical ethics. However, perspectives are variable regarding telling the truth and disclosure of bad news to patients in different communities and cultures. Also, physicians, nurses, and patients have different perspectives in this respect. All these factors are responsible for the ongoing debate regarding the disclosure of truth to patients with poor prognosis.

**Objectives:** This study aimed at assessing the perspectives of patients, physicians, and nurses regarding disclosure of disease status to patients with poor prognosis.

**Methods:** This descriptive cross-sectional study was conducted at Neyshabur University of Medical Sciences, during year 2016. A total of 215 participants, including 105 nurses, 30 physicians, and 80 patients were selected using stratified random sampling. A researcher-designed questionnaire comprised of 3 parts was used to collect the data. It contained 7 questions regarding demographic information, 17 questions regarding the perspective of the participant about telling the truth, and 10 questions on factors affecting the decision of physicians and nurses regarding disclosure of disease information to patients with poor prognosis. The data was analyzed using the SPSS version 20 software, with descriptive indexes and Pearson correlation, chi-square, and one-way analysis of variance (ANOVA) tests;  $P \leq 0.05$  was considered significant.

**Results:** Generally, 100% of physicians, 94.3% of nurses, and 94.3% of patients agreed with the statement "patients have the right to know the truth about their disease". All three groups believed that social and cultural factors are the most important parameters affecting the decision of physicians and nurses, which was statistically significant between the groups ( $P = 0.01$ ).

**Conclusions:** Most participants believed that it is necessary to tell the truth to the patients. Thus, in treatment of patients with poor prognosis, the truth must be told to patients in an appropriate way while the medical team needs to acquire skills in this regard.

**Keywords:** Patient's Rights, Medical Ethics, Truth Disclosure

## 1. Background

Truth disclosure is an important topic in patient-physician relationship (1). Truth disclosure in medicine is defined as disclosing the disease status to patients and providing them with the necessary information regarding their disease to allow them to make informed decisions about seeking medical care with regards to other aspects of life (2).

Autonomy is among the most important issues in medical ethics, yet a highly debated topic worldwide. Autonomy emphasizes on the patients' right to independently make an informed decision about themselves, free from any external control or influence. According to autonomy or self-determination principles, patients have the right to know important medical information regarding their

disease status in order for them to be able to make an informed decision in this regard (3).

In Western countries, disclosing poor prognosis to patients has become a norm since the late 1970s. Telling bad news to patients with poor prognosis has always been a challenge because the existing rules and regulations in this regard are not standardized and a standard protocol does not exist for this purpose (4).

Disclosing or hiding the truth could cause ethical and legal issues, thus, it is a delicate topic, especially in patients with terminal illness. Zamani et al., in 2011, assessed the perspectives of cancer patients and their attending physicians and reported that 88% of patients and 90% of physicians were in favor of telling the truth to cancer patients in the first place; 78% of patients and 72% of physicians believed that the truth must be told to end-stage cancer pa-

tients as well (1). In a study by Erer et al. on cancer patients, conducted during year 2008, 86.5% of participants believed that the patients have the right to know the truth and treatment; 76.9% believed that physicians must disclose the truth to patients (5). These results indicate a great change in professional behavior about disclosing the truth to patients (6). The patient may not adequately follow the treatment course if they do not know the entire truth in this regard. The patient cannot make a correct decision if he/she does not know the whole truth. Also, in case of not disclosing the truth, the patients and the community may lose their trust in physicians and the medical team (7). Many patients and some physicians believe that telling the truth regarding a poor prognosis to patients can cause anxiety and hopelessness and further complicate the course of treatment; however, this theory has been challenged by many studies (8). Bou Khalil et al. stated that in the Middle East, by keeping silent about the truth regarding a poor prognosis, a legitimate conspiracy forms aiming to keep the patient's hopes up (9).

Evidence shows that lack of information can cause loss of confidence, raise concerns, and result in dissatisfaction. Despite all these, physicians and nurses sometimes cover the truth for various reasons. For instance, the medical team may not know the proper skills to break the bad news to patients, they may not want the patients to lose hope or become depressed, the patients, themselves, may not want to hear the truth, cultural or religious beliefs may prevent them from telling the truth to patients, or patient's family may not want the patient to know the truth (7). Previous studies in this regard show that although the medical team has always been willing to tell the truth to patients, some cultural differences exist in this regard. Thus, according to the method, the transmission of bad news depends on socio-cultural factors in the society, and so far, in Iran, there are a few studies on this topic, and considering that findings from one culture cannot be applied to other cultures for making decisions, therefore this study aimed at assessing and comparing the perspectives of physicians, nurses, and patients on how to tell the truth to patients with poor prognosis.

## 2. Methods

This cross-sectional analytical research was performed during years 2015 and 2016 at teaching hospitals affiliated to Neyshabur University of Medical Sciences, Neyshabur, Iran (22 Bahman and Hakim hospitals). The studied population consisted of all hospitalized patients, physicians, and nurses at the mentioned hospitals. According to the Krejcie and Morgan table, a sample of 245 was estimated, which was selected by stratified random sampling. At first,

the size of each stratum (physician, nurses, and patients) was determined, and then samples were chosen randomly amongst each group.

The inclusion criterion for physicians was working in radiotherapy, oncology, hematology-oncology, gynecology, or surgery, and for nurses, the criterion was working in chemotherapy, internal medicine, surgical or gynecology and obstetrics wards. The inclusion criteria for patients was the diagnosis of cancer, being literate, conscious, and hospitalized. Participants were excluded from the study due to incomplete or inaccurate data.

### 2.1. Data Collection Tool

Data were collected using a self-reported researcher-designed questionnaire. The first part of the questionnaire contained 7 questions about the demographic information of the subjects. The second part included 17 questions regarding the opinions of the participants about telling the truth, which was based on a Likert scale from strongly agree to strongly disagree. The third part contained 10 questions about factors affecting the decision of physicians and nurses on disclosing the truth to patients with a poor prognosis. These factors included emotional stability, accepting the truth by patients, patient's willingness to know the truth, request of family members, diagnosis and stage (progression) of disease, patient's gender and age, life expectancy/survival rate, risks of therapeutic procedures, and cultural and social factors, and, where appropriate, answers were scored on a Likert scale from 'very important' to 'does not matter'.

To determine the validity of the questionnaire, the content validity method was used. For this purpose, the most recent resources, such as publications and scientific articles, were used for designing the questions and then the questionnaire was revised by a panel of experts comprised of 10 faculty members. The reliability of the questions on truth disclosure was assessed and approved by a Cronbach's alpha of 0.74. This value for assessment of factors was 0.71. Patient's questionnaires were completed by a trained person via an interview and physicians and nurses filled the questionnaires on their own.

### 2.2. Data Analysis

Data were analyzed by Pearson correlation, chi-square, and one-way analysis of variance (ANOVA) tests. Pearson correlation coefficient and chi-square test was used to examine the relationship between patients', physicians' and nurses' opinions regarding the patients' right to know the truth about their disease with gender, age, and marital status. Analysis of variance test was used to compare the 3 groups regarding truth disclosure to patients and factors affecting the decision of physicians and nurses about

telling the truth to the patients. Significance was considered as  $P < 0.05$

### 2.3. Ethics

The study protocol was confirmed by the research committee of Neyshabur University of Medical Sciences with code 28, and researchers adhered to the Helsinki declaration during the study period. It should be emphasized that all participants were briefed about the study and its objectives and willingly signed the written informed consent forms prior to participation in the study. They were ensured about the confidentiality of their information and the questionnaires were filled out anonymously.

## 3. Results

Thirty (14.3%) participants were excluded from the study analysis as they either failed to return the questionnaire or did not complete it; and in total, 215 questionnaires were analyzed (response rate = 85.7%). Physicians: A total of 30 physicians entered the study, out of which, 16 (53.3%) were male and 14 (46.7%) were female. The mean age of physicians was  $39.60 \pm 6.49$  years; 80% were married and 56.7% had a work experience of over 5 years. No significant association was found between the physicians' opinions regarding the patients' right to know the truth about their disease and their gender, age or marital status ( $P > 0.05$ ); 93.3% reported encounters with patients with poor prognosis and 100% agreed that the patients have the right to know the truth about their disease; 53.3% of the physicians believed that clinicians are the best people to break the bad news to patients; 36.7% stated that the truth must be told to patients gradually, and 40% stated that the hospital is the best place to discuss these issues with patients.

### 3.1. Nurses

A total of 105 nurses entered the study, out of which, 30 (28.6%) were male and 75 (71.4%) were female. The mean age of nurses was  $32.49 \pm 7.83$  years; 72.4% were married and 27.6% were single; 58.1% had work experience of over 5 years; 94.3% agreed that patients have the right to know their disease status. No significant association was noted between the perspectives of the nurses regarding the patients' right to know the truth and their age, gender or marital status ( $P = 0.8$ ); 81.9% had previous encounters with patients with poor prognosis; 69.5% of nurses believed that physicians are the best people to disclose the truth to patients; 41% believed that the truth must be told prior to initiation of treatment; 49.5% stated that a quiet room is the best place to break the bad news to patients.

### 3.2. Patients

Eighty subjects entered the study, out of which, 42 (52.5%) were male and 38 (47.5%) were female. The mean age of patients was  $38.08 \pm 11.62$  years; 85% were married; 45% were businessmen. No significant association was found between the patients' opinion regarding truth disclosure and their gender, age or marital status ( $P > 0.05$ ); 94.3% agreed that the patients have the right to know the truth about their disease; 68.8% believed that physicians are the best people to disclose the truth to patients; 40% agreed that the truth must be disclosed to patients immediately after the diagnosis, and 35% believed that the physician's office is the best place to break the bad news.

As indicated by Table 1, Comparison of the 3 groups showed significant differences among them with regards to their opinions about the 2 statements namely "patients have the right to know the truth about specific conditions related to their disease" ( $P = 0.0$ ) and "Physicians and nurses are allowed to talk to patients' family members without the patient knowing" ( $P = 0.05$ ).

Table 2 summarizes the factors affecting the decision of physicians and nurses about truth disclosure to patients, based on the opinions of the 3 groups. The results revealed significant correlations with cultural and social factors in this regard ( $P = 0.01$ ).

## 4. Discussion

The results showed that 95.8% of the participants agreed that the truth must be told to patients; this result is in accordance with the findings of some recent studies. Zamani et al. reported that 90% of physicians and 88% of patients in their study believed that the truth must be told to cancer patients in their primary stage of disease (1). However, Kazemian et al. showed that only 35% of physicians believed that patients have the right to know the truth about their disease (10). Such a controversy in results may be due to the fact that in the study by Kazemian et al., truth disclosure to patients depended on specific conditions determined by attending physicians themselves.

In the current study, all participants stated that the physicians are the best people to disclose the information to patients. In a study by Beyraghi et al., participants reported that physicians are the best people to disclose the truth to patients (11). In a study by Arbabi et al., in Iran during year 2014, patients preferred to hear the truth about their diagnosis from their physicians (12). In another study conducted in China by Jiang et al., in 2006, most oncologists believed that clinicians were the best individuals to inform patients about their diagnosis (13). The main reason behind selection of physicians as the best person to

**Table 1.** Results According to Questions (N = 215)<sup>a</sup>

No.	Question	Physicians	Nurses	Patients	P Value (ANOVA Test)
1	Patients have the right to know the truth about their disease	30 (100)	99 (94.3)	77 (96.3)	0.113
2	Patients have the right to know the truth about specific conditions related to their disease	28 (93.3)	96 (91.5)	62 (77.6)	0.000 <sup>b</sup>
3	Physicians and nurses are obliged to inform the patient about his/her condition	26 (86.7)	87 (82.8)	69 (86.4)	0.747
4	Physicians and nurses should only provide patients with general information regarding the disease	18 (60)	64 (60.9)	57 (71.4)	0.274
5	Physicians and nurses are allowed to talk to patients' family members without the patient knowing	21 (70)	50 (47.6)	54 (67.5)	0.050 <sup>b</sup>
6	Providing the family members with adequate information enhances the process of diagnosis and treatment	26 (86.6)	88 (83.8)	72 (90)	0.643
7	Informing the patient's family members about the disease can decrease the possibility of future complaints and lawsuits	28 (93.3)	68 (64.8)	71 (88.8)	0.132

<sup>a</sup>Values are expressed as No. (%).<sup>b</sup>Statistical significant.**Table 2.** Factors Affecting the Decision of Physicians and Nurses About Telling the Truth to Patients (N = 215)<sup>a</sup>

Variable	Physicians	Nurses	Patients	P Value ANOVA Test
Emotional stability	1.70 ± 0.70	1.66 ± 0.71	1.92 ± 0.77	0.055
Accepting the truth by patients	1.80 ± 0.76	1.65 ± 0.75	1.83 ± 0.77	0.258
Patient's willingness to know the truth	1.96 ± 0.80	1.72 ± 0.74	1.88 ± 0.71	0.166
Request of family members	2.16 ± 0.91	2.35 ± 0.89	2.45 ± 0.93	0.349
Diagnosis and stage (progression) of disease	1.56 ± 0.67	1.60 ± 0.65	1.55 ± 0.69	0.831
Patient's sex	1.76 ± 0.89	2.22 ± 1.05	2.28 ± 1.08	0.059
Patient's age	1.76 ± 0.56	1.81 ± 0.87	1.90 ± 0.92	0.715
Life expectancy/Survival rate	1.76 ± 0.50	1.77 ± 0.77	1.80 ± 0.73	0.959
Risks of therapeutic procedures	1.80 ± 0.66	1.78 ± 0.70	1.82 ± 0.74	0.917
Cultural and social factors	2.26 ± 0.98	2.00 ± 0.98	2.53 ± 1.00	0.001 <sup>b</sup>

<sup>a</sup>Values are expressed as mean ± standard deviation.<sup>b</sup>Statistical significant.

break the news to patients is that physicians are well aware of the nature of diseases and can provide patients with thorough information regarding their disease status. They understand patients' emotional conditions as well. Nurses believe that they are ranked second after physicians with regards to the relationship with patients. Thus, they prefer physicians to be in charge in these situations and they are not interested in dealing with the possible reactions of patients or their companions or the possible legal consequences (14).

Considering the delicacy of this issue, proper location for truth disclosure was also evaluated in this study. Physicians, nurses, and patients reported that the best place for telling the truth to patients was the hospital, quiet room, and physician's office, respectively. Monagheb et al., in

their study in 2013, on how to break bad news to patients reported that 63.2% of patients emphasized on disclosing the truth in a private and quiet room (15). Tsoussis et al. reported that the office was considered as the best place for informing the patient (4). Shamsanaie et al., in 2011 showed that most patients believed that physician's office was the best place to hear the news about their diagnosis; a high percentage of participants reported that the location of hearing the truth did not matter to them. Physicians mostly preferred a quiet private room to break the news of cancer diagnosis to patient (16). Thus, special attention must be paid to the place of truth disclosure and quiet private rooms must be chosen for this purpose.

With regards to the time of telling the truth to patients with poor prognosis, most physicians reported that the

truth must be told to patients gradually and over time. Most nurses preferred telling the truth prior to the onset of therapeutic procedures while most patients believed the proper time to be immediately after the diagnosis. In a study by Jiang et al., in 2007 in China, the best time for telling the truth was reported by patients to be immediately after the diagnosis (17).

Most participants in the current study stated that the truth must be told to patients gradually and within a couple of sessions. Sereshti et al., in 2013 assessed the attitude of personnel regarding breaking bad news in obstetrics and neonatal wards and showed that more than half the participants were against quick disclosure of bad news to mothers (18). Beyraghi, in 2011 assessed the attitude of family members of patients and concluded that family members believed that the truth must be told gradually to patients (11).

Participants in our study believed that the medical team must provide patients with general information about the disease. However, in the study of Monagheb et al., 91.6% of patients wanted to know all the details (whether good or bad) about their disease (15). Such differences in results may be due to cultural and social differences. A significant difference was found between groups regarding the statement that states “physicians and nurses are allowed to talk to patients’ family members without the patients knowing”, which is in conflict with the confidentiality and truth principals in medicine. Also, there was a significant difference between groups regarding the statement that states “patients have the right to know the truth about specific conditions related to their disease”. Kazemian et al. showed that 59% of physicians believed that the patients have the right to know about their disease but in certain conditions, which are determined by physicians. Emotional disability, accepting the truth by patients, patient interest to know the truth, disease diagnosis and progression, request of family members, patients’ gender and age, survival rate, risk of therapeutic procedures, and cultural and social factors are important factors mentioned by most participants (80%) (10).

These findings revealed that most physicians believed the patients interest was not enough for telling the truth and it depends on factors, which are determined by physicians themselves.

The current study showed that the participants had significant differences in cultural and social factors affecting the decision of physicians and nurses on disclosing the truth. This result is in accordance with that of other studies. Kazemi et al. evaluated 200 physicians and reported that participants stated that their decision would be dependent on the patient’s condition and cultural and social issues (19). The results indicate that truth disclosure

varies in different cultures and the extent of information provided to patients is also different depending on their gender, age, cultural and social background and a number of specific factors that are different for each person (20). Thus, when disclosing the truth, personality, culture, religious beliefs, and ethnicity of patients must be taken into account (21).

Not having a standard questionnaire custom-made for the Iranian culture and difficulty persuading the patients to fill out the questionnaire (since it was time consuming) were among the limitations of the current study. Considering social and cultural diversities of patients, a scientific protocol is required on how to break bad news to patients by physicians and nurses since this is a commonly encountered situation for them.

#### 4.1. Conclusion

The results showed that most participants agreed that the truth must be told to patients. The medical team must always tell the truth, however, they need to acquire some skills in this regard. This study examined the attitude of patients, physicians, and nurses about truth disclosure and this may differ from their actions. This study only assessed the factors used in previous studies, yet other factors may be effective due to the effect of socio-cultural matters on perspectives of patients, physicians, and nurses.

#### 4.2. Implications of the Manuscript

The results showed that most participants agreed that the truth must be told to patients. Therefore, physicians and Nurses should certainly have and employ skills in the areas of cultural sensitivity, and the decisions should be shaped by the patients’ values and preferences.

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