

# Research Paper: Attitudes of Patients and Their Families Towards Medical Privacy and Competence of Bearer or Receiver of Bad News



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## ABSTRACT

**Background:** Based on the patients' and relatives' views on the level of preservation of privacy rights of individuals, we propose a way to reduce problems and disagreements about the competence of the provider and recipient of bad news.

**Methods:** In the current cross-sectional study, the participants were recruited from the main northwest hospital of Iran. It was also conducted to study the scope of medical privacy and competence of bearers or receivers of bad news. After the literature review, two questionnaires were designed and administered. They contained items pertinent to the scope of medical privacy and competence of bearers and receivers of bad news. Each item of the original questionnaire was scored on a 5-point Likert scale.

**Results:** The model quality and significance level were obtained using KMO and Bartlett tests. The results (patient's attitudes questionnaire: KMO=0.729 and P<0.05 in the Bartlett test; family attitudes questionnaire: KMO=0.764 and P<0.05 in the Bartlett test) confirmed the model efficiency. According to the results from factor variance and their cumulative rate, the predictive power of the model was obtained as 62.019%, based on the overall factor variance rate. The majority of patients wanted to be informed about their disease conditions. They also considered bad news to be medical privacy and disagreed that their medical information should be opened up with others without permission.

**Conclusion:** To preserve medical privacy, it is recommended that a system be designed that allows patients at the admission to the medical center to enlist their eligible family members to whom medical information can be delivered.

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## 1. Introduction

**H**uman beings have always considered themselves bound to follow a set of principles and rules, known as good or ethical relationships. In building up this relationship, it is very important to develop mutual trust in different ways, such as privacy protection, which is an inescapable pillar in the history of the physician-patient relationship. An inaccurate perception of this principle not only can damage the sanctity of the medical profession, but also may affect the quality of therapeutic relationship in particular, and public health in general [1]. According to the medical laws in Iran, physicians and other medical staff should maintain the security and confidentiality of patient's records, even if it is not emphasized by the patient unless they are excepted by certain laws or judicial authorities [1]. However, some physicians tend to inform the patient's family about his or her conditions, rather than the patient, in particular when it comes to breaking bad news. This may be due to their concerns about the negative impacts of patient disappointment or lack of patient cooperation. A similar tendency exists among the patient's family towards withholding medical information [1, 2].

Bad news should be treated as medical privacy; therefore, it is the patient's right to decide whether he or she wants to know or not to know about medical conditions. Some patients might prefer not to receive the bad news, or prefer that the family (not themselves) receive the news. Nevertheless, physicians in many communities are reluctant to break bad news directly to the patients, which is a breach of medical privacy [1, 2]. In Iran, physicians prefer to deliver medical information to family members, instead of the patients [3]. However, today's general consent requires the protection of all patient's rights to enable them to make logical and informed decisions about their present conditions [1-4]. As a result, there are several protocols for breaking bad news such as ABCDE, BREAKS, PACIENTE, and SPIKES protocols [5-9]. In some articles SPIKES protocol has been recommended as a preferred guideline for delivering bad news but based on the cultures, these protocols can be different [5-10].

### Gaps in the research

This study intended to address the important challenges facing physician-patient relationship from two different perspectives: medical privacy and bad news from the standpoint of the patients and their families.

Medical privacy refers to the practice of maintaining the security and confidentiality of the patient's records by the physician to preserve trust in medical relationships [11, 12]. However, the dominant culture and perception of life continue to remain a challenge facing the delivery of medical information in critical cases, such as the disease exacerbation or serious or incurable illnesses [13, 14]. Physicians should be accountable for delivering bad news to patients. Bad news refers to any information that adversely affects an individual's view of his or her future [14]. It is very difficult to deliver bad news to the patients and it may be associated with unpleasant reactions by them [11-14]. On the other hand, withholding the treatment process from the patients may create a sense of mistrust towards the medical team and harm their psychological and physical conditions [14-18]. Patients usually expect physicians to be honest with them and inform them about the curable or incurable nature of the disease, its treatment complexity, and associated medicinal side effects or surgical complications in compliance with their demands, beliefs, and culture [19-21].

Hancock observed that although the majority of physicians contend that the patients should be completely informed about their conditions, they are practically reluctant to deliver bad news [22].

### Differences in societies and cultures

Although medical ethics reserve patients' rights, in oriental family-centered communities, the family is accountable for deciding for the patient [13, 14]. This difference between the western and oriental societies has also been reflected in the literature, but it seems that these differences can be overlapped. In western societies, it is important to be open about telling the truth to the patient; whereas, due to the family-centered nature of the oriental societies, families most often withhold medical information from the patients and are reluctant to break the bad news to them [15, 16, 21, 23-29].

### Aim

Considering the limited studies in Iran about the level of preservation of medical and privacy rights of individuals as well as the competence of the provider and recipient of bad news and the religious, cultural, and ethnic differences among various societies and cultures, we cannot use the studies of other countries. Therefore, we have tried to quantitatively evaluate the patients' and relatives views on these issues and, if possible, propose a way to reduce problems and disagreements in this issue.

## 2. Materials and Methods

### Time and Place

In the current cross-sectional study, the participants (n=300) were recruited only from the 7 wards of the Internal Medicine Department of Imam Reza Hospital of Tabriz, Iran from June 21 to September 21, 2016 (1612 patients were hospitalized in 7 wards of the Internal Medicine Department at that time). It was also conducted to study the scope of medical privacy and competence of bearers or receivers of bad news.

### Preparation of a questionnaire: Content validity and face validity of the questionnaire

Based on the problems that the authors experienced in the hospitals (for example failure to keep patients' secrets and privacy, illegal and unethical requests from patients' companions, etc.) and literature review, the authors designed the preliminary questionnaires. After the literature review, two questionnaires were designed and administered, containing items pertinent to the scope of medical privacy and competence of bearer and receivers of bad news. To determine the content validity and face validity of the questionnaires, they were given to an expert panel comprising of 10 specialists in the field of forensic and internal medicine.

The content validity and face validity were qualitatively and quantitatively evaluated. The qualitative modifications were made based on the panel's comments. With respect to quantitative assessment, all items were examined in terms of relevancy, simplicity, and clarity. Besides, the rationale behind each item was evaluated through multiple-choice items. In both questionnaires, the content validity index (CVI) and content validity ratio (CVR) for the first three items, and the current item were respectively obtained as 0.996 and 0.992. Besides, the impact score was calculated to assess face validity. The necessary modifications were made based on the panel's integrative comments and the measures were confirmed.

### Preparation of a questionnaire: Construct validity of the questionnaire

The exploratory factor analysis was used to assess construct validity. Based on the nature of extracted outputs, the principal component analysis and direct oblimin rotation were used. In this analysis, two aspects of the construct validity (convergent and discriminant validity) were examined. The cutoff point of 0.3 was considered

for the factor-item relationship. The model efficiency was evaluated using the KMO index and the Bartlett test.

Each item of the original questionnaire was scored based on a 5-point Likert scale. The scores of each domain, as well as the overall score, were calculated by adding the scores of relevant items. The score range in the patient and family questionnaires were (24-120) and (25-125), respectively.

### Preparation of a questionnaire: Internal consistency and stability reliability

The internal consistency and stability reliability of the questionnaire were also assessed. To obtain the internal consistency, a pilot sample comprising of 30 individuals was examined. The results from the Cronbach alpha for the family and patient questionnaires were obtained as 0.7 and 0.62, respectively. The test-retest with a repetition after 15 days was administered to 30 individuals and the Internal Consistency Calculation (ICC) of 0.74 (0.45-0.88) was obtained.

### Data collection

During the 3-month research period, the researchers attended the Internal Department of Imam Reza Hospital of Tabriz to select among mature and conscious inpatients, as well as their mature family companions. Then, the questionnaires were administered to them after obtaining their informed consent. After attending the Department, the research topic and objectives were explained to the patients and their family companions. Then, the questionnaires were administered among those who tend to participate, and the completed ones were collected.

All patients who were admitted to internal wards during the 3 months, after applying inclusion and exclusion criteria were included in the study.

### The inclusion and exclusion criteria

Eligible participants were mature and conscious patients hospitalized in the internal department, as well as their mature family companions, who completed the consent form.

With respect to the low-literate or illiterate participants (32 patients and 8 family companions), the questionnaire items were read for them and their responses were inserted in the questionnaires. We selected the participants that at least one of them in each group (either patient or family companions) was a literate person and

had educational level. In this study, 150 eligible patients and 150 eligible family companions were included.

### Statistical analysis:

Statistical analysis was done with SPSS v. 17. The obtained data were presented as Mean±SD for the numeric variables and as frequency (percentage) for categorical variables.

## 3. Results

### Overall results

Despite an almost equal number of male and female patients in the internal department, men were more reluctant to participate, so 64% of patients who signed informed consent were female. Concerning the family companions, 64.7% were female and 35.3% male.

The youngest and oldest patients were 19 and 80 years old, respectively. The Mean±SD age of the patients was 43.07±15.48, (Median=43) years.

According to the findings, 110 patients (73.3%) were almost fully aware of their illness and 40 patients (26.7%) were not aware or did not have accurate information.

In terms of severity, their illness was divided into five groups: acute, chronic, benign, malignant, uncertain (under examination). According to this categorization, there were 65 chronic patients (43.3%), 60 acute patients (40%), 14 malignancy-susceptible (9.3%), 6 patients with benign tumors (4%), and 5 patients under examination.

The youngest and oldest participants among family companions were 16 and 61 years old, respectively. The mean age of them was 36.75±12.035 (Median=35) years old.

The participants' level of education ranged from post-graduate study to a primary (elementary) school education (forty participants were illiterate).

Among the patients' group, the most abundance was among uneducated patients (21.3%) and next in line was related to those with higher education degrees (bachelor's degree) (18.7%).

In the group of relatives, the most common were related to patients' companions with diplomas (32%) and afterward were those with a bachelor's degree (17.3%).

About the relations between participating patients and their companions in this project, 79 people (52.7%) were their children (son/daughter) and the rest in decreasing

order were sister/brother, spouse, daughter in law, parents, nephew, cousin, grandson, friends, and sister in law.

### Results of heuristic and confirmatory factor analysis

The model quality and significance level were obtained using KMO and Bartlett tests. Results (patient attitude questionnaire: KMO=0.729 and P<0.05 in the Bartlett test; family attitude questionnaire: KMO=0.764 and P<0.05 in the Bartlett test) confirmed the model efficiency.

According to the results from factor variance and their cumulative rate, the predictive power of the model was obtained as 62.019%, based on the overall factor variance rate.

### The participants' answers

Items and frequency of selection on the attitudes of patients and their family components are presented in [Table 1](#).

## 4. Discussion

According to the results, the majority of the patients wanted to be informed about their disease conditions. They also considered bad news to be medical privacy and disagreed that their medical information should be opened up with others without their permission. The majority of patients also wanted certain family members (specified at admission) to be informed about their disease process and conditions at the same time.

Although the majority of companions considered bad news to be medical privacy and entitled the patient's rights to know their medical information, their responses to detailed items indicated no family involvement limitation. To them, the family should even receive bad news before the patients.

Among the significant skills of physicians in establishing a physician-patient relationship is their ability to inform patients about the medical conditions and their severity. Regarding the sensitivity of this relationship, physicians' knowledge of a patient's attitude can contribute to better protection of a patient's rights and his or her medical privacy.

According to previous studies, the best protocol is to evaluate the patient's knowledge first, and then provide him or her with necessary information based on his or her culture and literacy or knowledge level<sup>3,7,9,30</sup>. In this study, 76.7% of the patients and 86.6% of their family companions believed that breaking bad news should be based on the psychological, family, and knowledge of the

**Table 1.** Items and frequency of selection on attitudes of patients and their family components

Row	Items on the Attitudes of Hospitalized Patients and Their Families	Group	No. (%)		
			Agree	Neutral	Disagree
1	All patients should know the truth about their medical conditions	Patients	130 (86.7)	8 (5.3)	12 (8)
		Family companion	104 (69.4)	9 (6)	37 (24.6)
2	Patients should know the truth about their disease conditions, regardless of their psychological state	Patients	66 (44)	26 (17.3)	58 (36.7)
		Family companion	52 (34.7)	14 (9.3)	84 (56)
3	Patients should know the truth about their disease conditions, regardless of their physiological state	Patients	85 (56.7)	21 (14)	44 (29.3)
		Family companion	72 (48)	14 (9.3)	64 (42.7)
4	Incurable patients should know the truth about their chance of cure	Patients	77 (51.3)	27 (18)	46 (30.7)
		Family companion	70 (46.7)	16 (10.7)	64 (42.6)
5	Bad news must be delivered to patients	Patients	55 (36.7)	25 (16.6)	70 (46.7)
		Family companion	37 (24.7)	17 (11.3)	96 (64)
6	Bad news must be delivered to the patient's family companion	Patients	109 (72.7)	21 (14)	20 (13.3)
		Family companion	121 (80.7)	14 (9.3)	15 (10)
7	Bad news is considered a patient's confidentiality	Patients	110 (73.3)	25 (16.7)	15 (10)
		Family companion	99 (66)	26 (17.3)	25 (16.7)
8	Bad news should not be delivered to anyone other than the patients without their permission	Patients	96 (64)	22 (14.7)	32 (21.3)
		Family companion	62 (41.3)	18 (12)	70 (46.7)
9	The act of breaking or withholding bad news should be in favor of patients	Patients	115 (76.7)	14 (9.3)	15 (10)
		Family companion	130 (86.7)	5 (3.3)	15 (10)
10	Breaking bad news to patients is always to their advantage	Patients	49 (32.7)	20 (13.3)	81 (54)
		Family companion	17 (11.3)	21 (14)	112 (74.7)
11	At the admission to the medical center, the patients should provide a list of the people to whom bad news should be delivered	Patients	124 (82.7)	20 (13.3)	15 (10)
		Family companion	118 (78.7)	20 (13.3)	12 (8)
12	Before directly delivering bad news to patients, the information concerning their disease should be evaluated	Patients	135 (90)	5 (3.3)	10 (6.7)
		Family companion	135 (90)	4 (2.7)	11 (7.3)
13	Before directly delivering bad news to patients, their educational attainment should be evaluated	Patients	94 (62.7)	34 (22.6)	22 (14.7)
		Family companion	108 (72)	27 (18)	15 (10)
14	Informing patients about their disease conditions should be proportional to their level of knowledge	Patients	126 (84)	9 (6)	15 (10)
		Family companion	124 (82.7)	16 (10.7)	10 (6.6)
15	Physicians may not withhold medical information even if patients do not ask about it	Patients	109 (72.7)	31 (20.6)	10 (6.7)
		Family companion	96 (64)	10 (6.7)	44 (29.3)

Row	Items on the Attitudes of Hospitalized Patients and Their Families	Group	No. (%)		
			Agree	Neutral	Disagree
16	Physicians may not withhold medical information even if patients' companions do not ask about it	Patients*	-	-	-
		Family companion	136 (90.7)	4 (2.7)	10 (6.6)
17	All information demanded by the patients concerning their medical conditions should be provided	Patients	138 (92)	6 (4)	6 (4)
		Family companion	109 (72.7)	4 (2.7)	37 (24.6)
18	All information demanded by the patients' family companion concerning their medical conditions should be provided	Patients	98 (65.3)	11 (7.4)	41 (27.3)
		Family companion	123 (82)	14 (9.3)	13 (8.7)
19	Bad news should be delivered to the patients by the medical staff	Patients	108 (72)	20 (13.3)	22 (14.7)
		Family companion	81 (54)	15 (10)	54 (36)
20	Bad news should be delivered to patients by their family companion	Patients	47 (31.3)	29 (19.3)	74 (49.4)
		Family companion	71 (47.3)	32 (21.3)	47 (31.4)
21	Bad news, as well as medical information of patients, must be delivered first to their family companion	Patients	87 (58)	23 (15.3)	40 (26.7)
		Family companion	133 (88.7)	4 (2.7)	13 (8.6)
22	Family companions must be informed about patients' conditions, despite the patient's reluctance	Patients	77 (51.3)	13 (8.7)	60 (40)
		Family companion	105 (70)	12 (8)	33 (22)
23	It is the patients' right to specify to whom their medical conditions should be delivered	Patients	108 (72)	21 (14)	21 (14)
		Family companion	60 (40)	23 (15.3)	67 (44.7)
24	It is the right of the patient's family companion to specify to whom the patient's medical conditions should be delivered	Patients	32 (21.3)	24 (16)	94 (62.7)
		Family companion	83 (55.3)	23 (15.3)	44 (29.4)
25	It is the medical staff who should state to whom the patient's medical conditions should be delivered	Patients	52 (34.7)	38 (25.3)	60 (40)
		Family companion	53 (35.3)	44 (29.4)	53 (35.3)

\* According to the experts' opinion, this item was irrelevant and unnecessary.

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patients. Moreover, 90% of the patients and their family companions believed that the patient's knowledge about his or her disease should be evaluated before breaking bad news. Then, the required information should be provided based on the patient's knowledge level.

Because of poor psychological state, malignancy of the disease, and the nature of bad news, some physicians may withhold medical information from the patients and open it up to their family to avoid patient disappointment<sup>27</sup>. In this study, 86.7% of the patients and 69.3% of the family companions believed that it is the patient's right to be informed about his or her medical condition.

Previous studies investigated the necessity of delivering bad news to cancer patients and its associated

emotional impact and showed the lack of a distinctive difference between the informed and uninformed patients [27-32]. Breaking bad news to patients resolves their mental challenges that lie in the disease-pertinent uncertainties, provides them with an accurate viewpoint, and promotes their cooperation in the diagnosis process. Besides, greater trust is observed by the medical staff in relationship and cooperation with the patients.

Fifty-eight percent of the patients and 88.7% of their family companions believed that the physician should deliver bad news to the family companions before the patients. Studies suggested that in oriental family-centered societies, the family is accountable for making the decision instead of the patients [24, 25, 28, 30-32]. Comparison of Canadian and Spanish patients showed

that the former group believed that the patients should be informed with complete and detailed information about their disease; whereas, 89% of Spanish families considered it unnecessary [21].

### Limitations and directions for future research

Despite the same number of male and female patients admitted to the hospital (Equal full beds number), the lack of participation of more male patients in this study, studying in a limited time interval, and studying only one department of the hospital, could be considered some limitations of the study. On the other hand, considering that the study was carried out in the largest referral hospital in the northwest region of Iran, the patients and relatives of various academic levels and socioeconomic status from different parts of the northwest of the country participated in this study, so the results of the study can be generalized to the community but further supplementary studies may also be necessary to conduct in other areas and geographical locations, and in different hospitals and surgical departments (other than the internal), to obtain more accurate and comprehensible information. Also, in subsequent studies, considering the influence of inter-family relationships and the degree of dependence of relatives on communication and decision-making for the patient, as well as the role of different personality trait in this field, it seems necessary to determine the effect of these relationships on the performance of relatives and patients.

## 5. Conclusion

Patients tend to know about their disease and pertinent information and consider it among medical privacy, indicating a change in the way of thinking among Iranians. To preserve medical privacy, it is recommended to design a system that allows patients at the admission to the medical center to enlist their eligible family members to whom medical information can be delivered.

Disclosure of the patient's secret by claiming bad news to relatives is a major problem in protecting the privacy of patients, especially sick patients, therefore, in addition to teaching patients and relatives of the patients and medical personnel about the confidentiality of the medical and privacy of individuals, designing a system for identifying the person who is first informed about the patient condition that the patient declares during the first hospital admission will improve the quality of the patient's privacy.

Implementation of the Ministry of Health's training programs for patients, their relatives, and medical personnel can enhance the process of securing patients and reduce the

unwanted and unethical expectations of relatives regarding the confidentiality of the patient's medical condition.

Implementing a system for identifying a person who is informed about the condition of the disease that the patient reports during the initial admission of the hospital can decrease the medical staff's confusion in preserving the medical secret, as well as the diagnosis of the recipient of bad news. Finally, this system will prevent the consequences of the disclosure of the patient's secret.

## Ethical Considerations

### Compliance with ethical guidelines

The project was approved by the Ethics Committee of Tabriz University of Medical Sciences under the codes: 5/4/7825(Oct/19/2015) and 5/4/8499(Nov/4/2015). All ethical principles were considered in this article. All procedures performed in this study involving human participants followed the ethical standards of the Institutional and or National Research Committee and were in compliance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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### Author's contributions

Conceptualization, study design: Maryam Zaare Nahandi, Ali Banagozar Mohammadi; Data analysis: Mohammad Asghari Jafarabadi, Kosar Ashrafrezaei, Marziyeh Shaker Saeedabad; Writing – original draft: Maryam Zaare Nahandi, Mehnoosh Haghightajou, Kosar Ashrafrezaei, Marziyeh Shakeri Saeedabad, Ahad Banagozar Mohammadi; Writing – review & editing, investigation: All authors.

### Conflict of interest

The authors declared no conflict of interest.

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