Assessing the willingness of patients' companions to disclose bad news to cancer patients

Arshia Zardoui¹, Mir Saeed Yekaninejad², Ali Kazemian³, Mojtaba Parsa^{4*}

1. Researcher, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran.

2. Associate Professor, Department of Epidemiology and Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran.

3. Associate Professor, Department of Radiation Oncology, Cancer Institute, Tehran University of Medical Sciences, Tehran, Iran.

4. Assistant Professor, Medical Ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran; Research Center for War-Affected People, Tehran University of Medical Sciences, Tehran, Iran; Department of Medical Ethics, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran.

Abstract

Breaking bad news to patients is an essential aspect of the physician-patient relationship, but in Iran, this relationship is often disrupted by patients' families. This study investigates the views of patients' companions on breaking cancer news.

In this descriptive-analytic cross-sectional study, we conducted research on 170 cancer patients' companions and 170 non-cancer patients' companions. We designed a questionnaire to investigate the subjects' opinions and used CVI, CVR, Cronbach's alpha and ICC for evaluation. In order to compare groups, we used Mann-Whitney, Kruskal-Wallis, Chi-square tests and Spearman's correlation.

Most participants believed that patients should be informed of their diagnosis. Cancer patients' companions were more willing to learn the bad news in case they were diagnosed with cancer and were less likely to choose "despair" as the reason for non-disclosure (71% vs. 44%). There was no difference between the two groups in willingness

44%). There was no difference between the two groups in willingness to break the cancer news to patients, choosing who should be informed first, and the reasons for non-

disclosure. Most participants believed the family should be the first to know the diagnosis.

In this study, most participants believed that patients should be informed of their diagnosis. However, they preferred to learn about the diagnosis before the patient, which confirms the importance of educating the families about autonomy.

Keywords: Bad news; Autonomy; Patients' rights; Cancer.

*Corresponding Author

Mojtaba Parsa

Address: No. 23, 16 Azar St., Keshavarz Blv., Tehran, Iran. *Postal Code*: 1417863181 *Tel:* (+98) 21 66 41 96 61 *Email:* <u>mparsa@tums.ac.ir</u>

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Introduction

Bad news is any information that has a severe and undesirable effect on one's future perspectives (1). According to the principle of autonomy, physicians are legally and ethically required to inform patients of their diagnosis, course of illness, and prognosis (2). Disclosing cancer news to patients is an important example of breaking the bad news. Cancer is one of the leading causes of death, and the 19.3 million cancer cases in 2020 are expected to increase by 47% by 2040. Because of the rising occurrence of cancer due to population growth and lifestyle changes, physicians are increasingly finding themselves in situations where they must give their patients cancer news (3).

In North America and Western Europe, autonomy is of utmost importance, and the patient is directly involved in the diagnosis and treatment of the disease. However, in Eastern countries, a balance of autonomy and the evident influence of families is the most important factor in informing patients of cancer diagnoses (4). Therefore, a significant number of patients do not receive the cancer diagnosis directly from their physician (2, 5, 6). According to some studies, in countries such as Japan, Saudi Arabia and Iran, many cancer patients and even physicians agree that the doctor should inform the family first and let them give the news to the patient. As for patients, they have the right to ask not to be informed. Still, if a physician tells the family without the patient's permission, this act will be in direct violation of the patient's autonomy (6 - 9).

There are several protocols, including SPIKES and PACIENTE, for breaking bad news to patients (10 - 12). Along with the SPIKES protocol, a new scoring system has been established to consider individual preferences (13). However, it has been noticed that sometimes following these guidelines does not result in patient satisfaction (14). Therefore, in addition to reviewing the existing guidelines, cultural differences between communities should be considered as indigenous guidelines are developed.

In Iran, the supportive role of families results in the interference of the patient's companions in the doctor-patient relationship; therefore, to adopt appropriate policies, we must study the perspectives of families and their reasons for being against the disclosure of bad news to patients. There are a few studies on Iranian patients' attitudes toward receiving bad news, but to the authors' knowledge, there are not enough studies on the patient's companions' and family members' attitudes toward this issue.

It is critical to understand the circumstances prior to developing a guideline that is appropriate for our culture and society. As a result of the previously mentioned involvement of patients' families, we believe that investigating the families' opinions is an important step in developing a suitable guideline for breaking bad news in our society. In this study, we assess the willingness of the patients' companions to break the cancer news and its relationship with different variables.

Methods

This descriptive and analytic cross-sectional study was conducted in Imam Khomeini Hospital Complex in Tehran, Iran, from October 2020 to January 2021. We chose this hospital because it is a major referral center in the capital of Iran and patients from all over the country are admitted to this hospital, so our sample could be representative of the whole country. The inclusion criteria consisted of being able to read, consenting to be enrolled in this study, and being older than 18 and a first-degree relative of a patient (parents, siblings, children and spouses).

We conducted search of scientific databases such as PubMed, Google Scholar and SID to develop a questionnaire. Based on the previously published studies (2, 6, 15, 16), we aimed to evaluate three factors among patients' companions: their level of agreement with breaking the cancer news to their patients, their level of agreement with giving the cancer news to themselves if they got diagnosed with cancer, and the reason for their opposition to breaking the cancer news. We used closed questions to obtain clarification and generated a 4item questionnaire. Two questions were based on the Likert scale (participant's willingness to break the cancer news to their patient or to themselves if they get diagnosed with cancer), and each item had five possible responses from 1 (strongly disagree) to 5 (strongly agree). The other two questions were multiple-choice questions: the reasons for opposition to breaking the bad news (with possible responses of "patient's anxiety", "patient's fear", "patient's despair", and "not pursuing the treatment"); and the person who should first get informed of the cancer diagnosis (with possible responses of the patient, family members, and both at the same time).

The sample size of 323 was calculated based on a previous study (15), considering a 5% accuracy rate and a 95% confidence interval. This sample size was expanded into 340 companions of cancer

and non-cancer patients (170 for each group) to achieve better results.

To assess content validity, a panel of 11 physicians who were medical ethics specialists or clinicians was asked to express their views on grammar, phrasing and phrase placements. Based on the method proposed by Lawshe, the panel of experts was asked to examine each question based on essentiality, relevancy, simplicity and clarity. Next, the content validity ratio (CVR) and content validity index (CVI) were calculated. CVIs greater than 0.8 and CVRs greater than 0.59 (based on the number of panelists) were considered valid. Thus, all of the questions were shown to have acceptable levels of CVI and CVR (17).

To investigate the reliability of the questionnaire, 100 participants, 50 companions of cancer patients and 50 companions of non-cancer patients (mean age = 41.95 ± 12.823 years), completed the questionnaire on day 0 (in person) and day 14 (via telephone). For all four items, Cronbach's alpha and intraclass correlation coefficient were greater than 0.8, which shows a high level of internal consistency and test-retest reliability over time.

After assessing the reliability, 120 companions of cancer patients and 120 companions of non-cancer patients completed the questionnaire.

Using the data of 340 participants (the initial 100 participants were also included), we looked for the frequencies and possible relationships.

All statistical analyses were conducted using SPSS software version 22. Mean, standard deviation, median, and interquartile range were used to report quantitative variables, and frequency was used to report qualitative variables.

Prior to data analysis, the Kolmogorov-Smirnov test was used to determine the normality of quantitative variables. Also, the distributions of two rank variables were compared using the Mann-Whitney test, and the correlation of two rank variables was estimated by Spearman correlation coefficient. Kruskal-Wallis was applied to compare the distribution of several groups, and the Chisquare test was run to determine the relationship between categorical variables. *P*-values < 0.05 were considered statistically significant.

Ethical considerations

The ethics committee of Tehran University of Medical Sciences approved the study protocol (IR.TUMS.MEDICINE.REC.1399.840), and all participants were notified about the aim of the study and gave informed consent before completing the questionnaire.

Results

We gave the questionnaire to 340 patients' companions who had agreed to be enrolled in our study. The study population consisted of two groups: 170 companions of cancer patients, and 170 companions of non-cancer patients, including 145 males (42.6%) and 195 females (57.4%) participants. The mean age was 40.58 \pm 10.954, ranging from 18 to 85 years old (Table 1). Out of 170 cancer patients' companions, 138 (81.2%) stated that the patient was aware of the cancer diagnosis. Of these 138, 79 (57.2%) said that the patient had been informed of his/her diagnosis by a physician, 21 (15.3%) said that the patient had been informed by his/her family, and 38 (27.5%) stated that the patients themselves had found out about the diagnosis from their general condition. Nobody said that the patient had been informed of the diagnosis by a nurse.

Variable Age (Mean ± SD, Min - Max)		Cancer Patients' Companions	Non-Cancer Patients' Companions 40.36 ± 10.8, 18 - 71	
		$40.74 \pm 11.11, 18 - 85$		
Gender	Male	71 (58.2%)	74 (43.5%)	
	Female	99 (58.2%)	96 (56.5%)	
Marital Status	Married	140 (82.4%)	121 (71.2%)	
	Not married	30 (17.6%)	49 (28.8%)	
Residence	Urban	144 (84.7%)	152 (89.4)	
	Rural	26 (15.3%)	18 (10.6%)	
Education	High school and lower	59 (34.7%)	52 (30.6%)	
	High school diploma	50 (29.4%)	55 (32.4%)	
	Associate degree	19 (11.2%)	16 (9.4%)	
	Bachelor's degree	37 (21.8%)	35 (20.6%)	
	Master's degree and higher	5 (2.9%)	12 (7%)	

Table 1. Characteristics of the participants

In total, 129 (75.8%) of cancer patients' companions and 125 (73.6%) of non-cancer patients' companions agreed with breaking the cancer news to the patient. 147 (86.5%) of cancer

patients' companions and 124 (73%) of non-cancer patients' companions said they wished to learn the news if they were diagnosed with cancer (Figure 1). The most reported reason for opposition to breaking the cancer news was "patient's anxiety" among cancer patients' companions' (53.7%), and "patient's despair" (71.1%) among non-cancer

patients' companions. "Not pursuing the treatment", on the other hand, was the least reported reason for both groups (Figure 2).

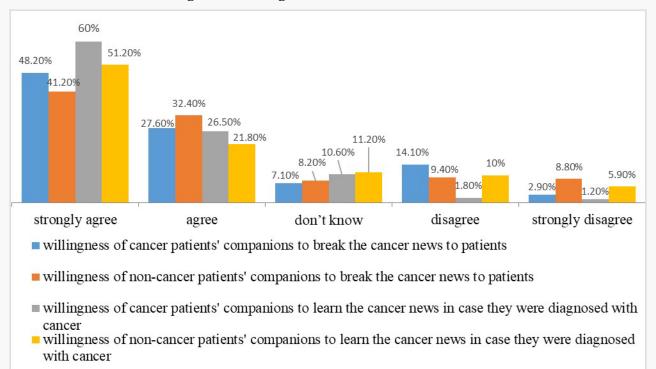


Figure 1. Willingness to break the cancer news

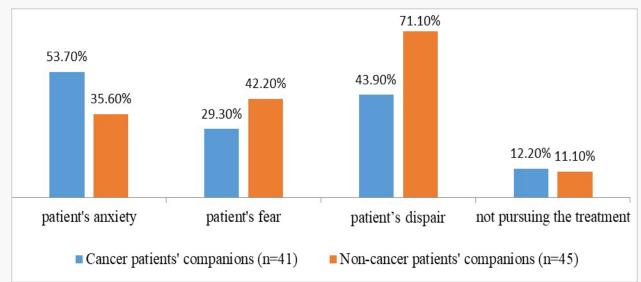
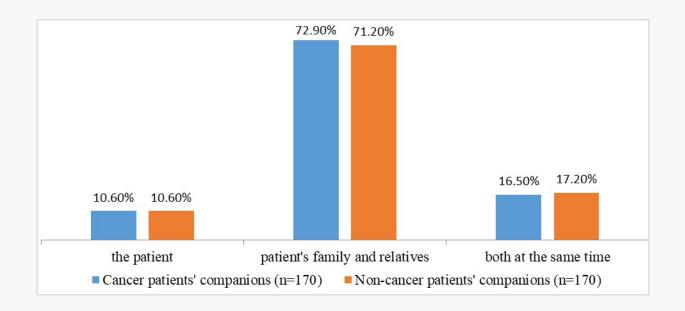


Figure 2. Reasons for opposition to breaking the cancer news to patients

Approximately 70% of the participants in both groups believed that the patient's family and relatives should be informed of the diagnosis first, about 17% believed that the patients and the relatives should be informed at the same time, and nearly 10% believed that the patient should be informed of the diagnosis first (Figure 3).

Figure 3. Participants' views on the person who should be informed of the cancer diagnosis first



Our findings showed that cancer patients' companions' willingness to break the cancer news to patients was correlated positively with education and negatively with age (correlation coefficient: 0.216 and -0.191, P-value = 0.005 and 0.013, respectively). Non-cancer patients' companions' willingness to break the cancer news was higher in unmarried participants (P-value = 0.007) and was positively correlated with education (correlation coefficient: 0.198, P-value = 0.010) (Table 2).

The participants' willingness to learn the cancer news in case they were diagnosed with cancer was positively correlated with education in both groups (cancer patients' companions: correlation coefficient: 0.157, P-value = 0.041; non-cancer patients' companions: correlation coefficient: 0.296, P-value < 0.001). However, it was negatively correlated with age in companions of the cancer patients (P-value = 0.047) (Table 2)

Table 2. The	e relations	hips between que	estions and v	ariables		
Questions	Cancer Patients' Companions					
	Gender	Marital Status Median (IQR)	Residence	Education	Age	
The willingness to break the cancer news to the patient	0.845	0.253	0.430	0.005* (ρ = 0.216)	0.013* (ρ = -0.191)	
The willingness to learn the cancer news if diagnosed	0.919	0.850	0.539	0.041* ($\rho = 0.157$)	0.047* (ρ = -0.152)	
Who should be informed of the diagnosis first	0.815	0.008*	0.883	0.001*	0.129	
Stating "patient's fear" as the reason for opposition to breaking the cancer news	0.763	1	1	0.006*	0.741	
Stating "patient's anxiety" as the reason for opposition to breaking the cancer news	0.257	1	1	0.893	0.618	
Stating "patient's despair" as the reason for opposition to breaking the cancer news	0.006*	0.573	0.118	0.562	0.304	
Stating "not pursuing the treatment" as the reason for opposition to breaking the cancer news	1	1	1	0.025*	0.217	
Questions	Non-Cancer Patients' Companions					
	Gender	Marital Status Median (IQR)	Residence	Education	Age Median (IQR)	
The willingness to break the cancer news to the patient	0.989	0.007* Married: 2 (2) Not Married: 1 (1)	0.750	0.010* (ρ = 0.198)	0.543	
The willingness to learn the cancer news if diagnosed	0.403	0.227	0.633	< 0.001* ($ ho = 0.296$)	0.128	
Who should be informed of the diagnosis first	0.614	0.900	0.473	0.207	0.024* Patient: 46 (13) Family: 39 (12) Both: 37 (11)	
Stating "patient's fear" as the reason for opposition to breaking the cancer news	0.787	1	1	0.646	0.704	
Stating "patient's anxiety" as the reason for opposition to breaking the cancer news	0.236	0.005*	0.608	0.913	0.331	
Stating "patient's despair" as the reason for	0.141	0.168	0.308	0.700	0.139	
opposition to breaking the cancer news						

Table 2. The relationships between questions and variables

*P-values are significant

 ρ = Spearman's Correlation Coefficient

Preference of cancer patients' companions regarding the first person to be informed of the cancer diagnosis was dependent on two variables: 1) marital status (the patient: 8.6% in married vs. 20% in unmarried; family and relatives: 77.9% in married vs. 50% in unmarried; and both at the same time: 13.6% in married vs. 30% in unmarried, *P*value = 0.008, Table 2), and 2) education (*P*-value = 0.001, respectively, Table 3). There was an association between age and the preferences of non-cancer patients' companions on the first person to be informed of the cancer diagnosis (*P*-value= 0.024). Also, the median age of participants who believed the patients themselves should be informed first was 46 years old (IQR: 13), the median age of participants who believed family and relatives should be informed first was 39 (IQR: 12), and the median age of participants who believed the family and the patient should be informed at the same time was 37 years old (IQR: 11) (Table 2).

Table 3. The views of cancer patients' companions on the first person who should be informed of thecancer diagnosis, according to the level of education

Education	The Patient	Patient's Family and Relatives	Both at the same time
High school	3.4% (2)	83.1% (49)	13.6% (8)
High School Diploma	10% (5)	74% (37)	16% (8)
Associate Degree	0% (0)	89.5% (17)	10.5% (2)
Bachelor's Degree	27% (10)	54.1% (20)	18.9% (7)
Master's Degree	20% (1)	20% (1)	60% (3)
P-Value	0.001		

For cancer patients' companions, choosing "patient's fear" as the reason for non-disclosure was associated with education level (high school: 19%; high school diploma: 45.5%; associate degree: 0%; and bachelor's degree: 100%; *P*-value = 0.006). Choosing "not pursuing the treatment" was also associated with education (high school: 0%; high school diploma: 27.3%; associate degree: 16.7%; and bachelor's degree: 33.3%; *P*-value = 0.025). Finally, choosing "patient's despair" as the reason for non-disclosure was associated with gender (63.6% in female and 21.1% in male participants; *P*-value = 0.006) (Table 2).

In non-cancer patients' companions, choosing "patient's anxiety" as the reason for non-disclosure was associated with marital status (85.7% in unmarried and 26.3% in married participants, P-value = 0.005) (Table 2).

Cancer patients' companions were more willing to learn the bad news in case they were diagnosed with cancer (*P*-value = 0.011). Also, among the reasons for non-disclosure, choosing "patient's despair" was not independent of the group of participants (43.9% in cancer patients' companions and 71.1% in non-cancer patients' companions, *P*value = 0.011). There was no difference between the two groups of companions in the willingness to give cancer news to the patient, choosing who should be informed of the diagnosis first, and choosing "patient's anxiety", "patient's fear", and "not pursuing the treatment" as the reason for opposition (*P*-values > 0.1).

Discussion

In this study, 81.2% of the cancer patients were aware of their diagnosis according to their companions, similar to Alzahrani et al. (86.27%) (18). Most of these patients had heard the bad news directly from their physicians (57.2%). Our study showed that 75.8% of the cancer patients' companions were in favor of breaking the bad news to their patients. This rate was 64%, 68%, in studies by Alzahrani et al. (18), Zekri and Karim (15), respectively. Jiang et al. showed that about 70% of

early stages of cancer, while only 34% of companions agreed to bad news disclosure in the late stages (16). This difference may be due to cultural differences across communities. Still, the interesting point is that in all these studies, a significant percentage of patients' companions and relatives were willing to inform the patients of the diagnosis. This might be due to increased awareness of patient autonomy, which can act as a positive motive for patients to start or to continue their treatment. We also found that 76.5% of the companions of non-cancer patients were willing to inform the patient of the cancer diagnosis. We think that the reason behind these high rates of disclosure might be the increased awareness of patients' rights in these eastern countries.

companions favoured bad news disclosure in the

We found that the willingness of both groups of companions to break the cancer news to the patients was significantly related to their education level, so that higher education increased the willingness to inform the patient about the cancer diagnosis. This is in agreement with findings of a study in Saudi Arabia (15). This relationship could come from the fact that educated people may have more information about cancer, the importance of early detection, available treatments for cancer, and the principle of autonomy. Previously, Alzahrani et al. had shown that having prior insight about cancer increases the likelihood of being in favor of disclosure (18).

In our study, 86.5 percent of cancer patients' companions wished to know if they were diagnosed with cancer, compared to 73% of non-cancer patients' companions. This significant difference may be because of cancer patients' companions' prior personal experience with cancer in their first-degree relatives. They are more aware of the importance of notifying the patient of the diagnosis and respecting his/her autonomy, and they have prior knowledge of cancer prognosis and possible treatments.

We could not find any article that assessed the relationship between the desire to know the news if diagnosed with cancer, and demographic variables. In our study, the answer was positively correlated to education in both groups and negatively correlated to age in cancer patients' companions.

This association may be due to the awareness of younger and more educated people about cancer, the importance of early detection, available treatments, and the principle of autonomy. Also, the remaining years of life may be one of the reasons for younger people's willingness to know their diagnosis. In our study, most of the cancer patients' companions (72.9%) believed that the patient's family and relatives should be the first to be informed of the cancer diagnosis. In a similar study in Saudi Arabia, this option had the highest prevalence (61%) among cancer patients' companions' preferences (15). Two other studies conducted in Japan/United States and Saudi Arabia asked the same question of cancer patients themselves and physicians (7, 8). In both studies, 65% of the cancer patients in Japan and Saudi Arabia agreed that the doctor should inform the family first and let the family decide about informing the patient; this was the preference of 80% of Japanese physicians and nearly 50% of Saudi physicians (7,8). A study in Iran also showed that 45% of the patients would like to be informed of the cancer diagnosis by their family (6). Ruhnke et al., however, found that patients and physicians in the United States had a different attitude toward this matter. Only 22% of the cancer patients and 6% of the physicians agreed that the patient's family should be the first to know about the diagnosis (7). A systematic review showed that Americans of Latin, Eastern European and Asian descent are more willing to learn the bad news than their counterparts outside the United States (5).

All of the above indicates that education has an essential role in maintaining autonomy in the society. These differences may be because people and physicians in the United States are more aware of autonomy and patients' rights. Also, in Eastern countries, these outcomes may be due to a lack of clear rules regarding patients' rights, the importance of family relationships casting shadows autonomy, and over cancer treatment misconceptions (19).

We found a relationship between participants' preference as to who should be informed of the cancer diagnosis first, and marital status and education level in cancer patients' companions, and age in non-cancer patients' companions. 50% of the unmarried participants believed that the patients themselves should be present in the initial encounter with the cancer news (patient alone 20%, and patient with family 30%), but only 22.1% of the married participants believed so (patient alone 8.6%, and patient with family 13.6%). This difference may be due to the new attachments and family relationships that are formed after marriage. 80% of the participants with a master's degree and about 47% of those with a bachelor's degree believed that the patients themselves should be present in the initial encounter with the cancer news. At the same time, this number does not reason for this observation may be the commitment and belief of most educated people with regard to autonomy, or their previous knowledge about cancer. Older participants were more likely to prefer the patient's presence in the initial encounter with the cancer news, maybe because they rely on their own experience over the years and believe that the patient can handle hearing the cancer news. As mentioned previously, autonomy is the right of all patients, and its implementation is subject to the removal of administrative barriers. Patients' families' opposition to informing the patient can be a significant obstacle in eastern countries, but one that can be eliminated by knowing the reasons for families' opposition to telling patients about their cancer diagnosis.

exceed 26 percent in lower education groups. The

In our study, "patients' anxiety" was the most common reason for opposition to breaking the cancer news among cancer patients' companions at 53.7%, and "patients' despair and hopelessness" was the most common reason for opposition among non-cancer patients' companions at 71.1%. Similar studies in China and Saudi Arabia involving cancer patients only showed that the most common reason for opposition was to prevent the negative impact of bad news on the patient in Saudi Arabia (77%), and in China, psychological anxiety was the most common reason in the early stages of cancer (50.3%). These findings are similar to our study, but in in the final stages, "maintaining the patient's quality of life" was the most common reasons for opposition (16, 18). It can be said that in all these studies, including ours, the concern about the negative effects of disclosure on patients' mental health (for instance anxiety problems) has been the most common reason for refusing to tell patients about the cancer diagnosis. This indicates that in many cases, by educating families, providing psychological support to patients and reassuring families of the patient's psychological support, they may agree with disclosing the diagnosis to the patient.

Among the cancer patients' companions, the female participants mentioned "patient's despair" more than males (63.6% vs. 21.1%); this difference could be due to psychological differences between genders. The non-cancer patients' companions mentioned "patient's despair" more than the cancer patients' companions as the reason for their opposition (71.1% vs. 43.9%). This can be due to the previous experience of cancer patients' companions with cancer, and the lack of experience thereof in non-cancer patients' companions.

There were a few limitations to our study. First, for reliability analysis of our questionnaire, the retest was done over the phone because many of the patients would have been discharged during the two-week period. Second, this project was run during the COVID-19 pandemic in Iran, and there were far fewer non-COVID hospitalized patients at the time.

Conclusion

Few studies have assessed Iranian patients' companions' willingness to break the bad news before. This study provides insight into the patients' companions' views on informing the patient of the cancer diagnosis. We found that most of the patients' companions agreed with telling the patient about the cancer diagnosis, which may not be consistent with some of our previous concepts. This was significantly related to the level of education. However, most participants believed that family and relatives should be informed of the diagnosis before the patient, which is a violation of autonomy if the physician does so without permission from the patient.

This study confirms that people value autonomy more than before, but still the patient may not be the first to learn of the diagnosis in many cases, and a minority of the patients may never know their diagnosis. This problem compromises the credibility of the informed consent forms obtained in medical centers. As a result, the need to pursue this crucial right of patients through newer guidelines is growing in importance, and more effective rules and education are required to solve this problem. In this manner, patients will be the first to learn about the diagnosis, course and prognosis of their disease. The authors declare no funding for this research.

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Conflict of Interests

The authors declare no conflict of interests.

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