



# Attitudes of Patients With Cancer Towards Truth-telling and Self-Determination in Kerman, 2016: A Cross Sectional Study

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## Abstract

**Background:** Regarding the patient autonomy principle, patients have the right to make informed decisions about their medical care. In situations like cancer diagnosis, telling the truth is still a challenge for health care providers, especially in eastern countries.

**Methods:** The present cross sectional study was conducted from March to June 2016, in which the convenience sampling method was used. The questionnaire used to collect data consisted of 3 parts. The first part included demographic characteristics; the second part consisted of 22 items that examined the patients' attitudes towards truth-telling; third part of the questionnaire was Ende (1989) autonomy preference index (API).

**Results:** The overall scores showed that the participants had a positive tendency to truth-telling and self-determination. The majority of participants believed that knowing the truth might make them more cooperative during treatment period, prevent unnecessary treatments, and help them deal better with their difficulties. Participants reported their preferences for decision making as low and seeking information as high. They preferred that leave decisions be made by doctors. However, they reported a positive attitude towards information seeking.

**Conclusions:** The results of this study showed that Iranian patients with cancer had highly positive attitudes towards truth-telling and self-determination. Patients expect that their physician play the main decision maker role. Moreover, the preference for self-decision making is high, correlated with education level.

**Keywords:** Truth-Telling, Autonomy, Attitude, Patient with Cancer

## 1. Background

During the past decades, the ethical and legal analysis of medical decision-making in the world of medicine has evolved around the notion of patient autonomy. Regarding the patient autonomy principle, patients are entitled to be informed of their medical care. Accordingly, patients should be told the truth about the diagnosis and prognosis of their disease as well as the risks and benefits of suggested managements; they should also be allowed to make choices based on given information (1).

Debating confidentiality, fidelity, privacy, and truth-telling, the standard respect for autonomy is also invoked, but it is most intensely associated with the notion that individuals must be allowed or assisted to make decisions about their health care autonomously (2, 3).

In situations such as cancer diagnosis, telling the truth is still a challenge for health care providers, especially in eastern countries (4). Additionally, it should be noted that

the full release of all significant information about cancer, including prognosis, is not still commonly acceptable in many European and North American cultures (5). Studies in Iran have shown that many Iranian patients with cancer are not informed of the diagnosis of their disease and, according to some studies, merely 7% of Iranian patients with cancer were aware of their prognosis (6). Since communication is an extremely essential component in any effective cancer care process and that difficulties with the communication between patients and their health care providers might make a wide variety of problematic effects, and because of cultural differences between patients and health care providers, communication failure can become a real concern (7, 8).

Regarding with the idea that the awareness of diagnosis and prognosis may have potential effects on patients' quality of life and attitudes of patient towards autonomy and truth-telling is different across cultures, (9) and the result of investigation of other cultures may not be at-

tributed to Iranian culture, we decided to investigate the attitudes of Iranian patients with cancer towards truth-telling and self-determination.

## 2. Methods

The present cross sectional study was conducted from March to June 2016 in Javad-al-aemme hospital and outpatient clinic affiliated to Kerman University of Medical Sciences (Kerman, Iran).

The study population included the patients who were referred to the selected hospitals for therapeutic or palliative care through the study. The inclusive criteria included patients who were diagnosed with cancer and were aware of their diagnosis, were at least 18 years, had the ability of communication, and passed at least 1 month from the diagnosis date. Not completing the questionnaire, having other physical diseases, and suffering from severe psychological illnesses that can impair the patients' cooperation were considered exclusion criteria. We conducted a pilot study on 20 samples and the sample size was calculated as 200 patients with indexes of  $\alpha = 0.05$ ,  $d = 1.5$ ,  $SD = 0.21$ . To counteract the possibility of sample loss during the study, 225 patients were requested to participate in the study. Convenience sampling method was used and all patients, who were suitable for this study, were chosen to participate in this study. It should be mentioned that 6 patients quieted the study and 5 participants also left uncompleted questionnaire. Finally, data were collected from 214 patients.

The questionnaire used to collect the data comprised 3 parts. The first part included the demographic characteristics and disease-related features of the patients with cancer; the second part consisted of 22 items examining the patients' attitude towards truth-telling. This part was designed based on Malihe Seyedabadi's dissertation which was conducted previously in Kerman University and was approved by regional ethics committee. Responses to each item were based on a 5-degree Likert scale. The third part of the questionnaire consisted of Ende (1989) Autonomy Preference Index (API). This questionnaire examines the 2 main dimensions of autonomy. It has 14 items; 8 items evaluate the preference for information, and 6 items measure the preference for participation. Each of the 14 items is rated, using a five-point Likert scale with response options ranging from "strongly disagree" to "strongly agree". The agreement is associated with preference for information or involvement, respectively. It should be noted that this scale has never been used in other studies in Iran. Thus, this scale was translated into Persian by an expert English translator, using forward-backward method.

The study proposal was approved by the ethics committee of Kerman University of Medical Sciences before collecting the data (the ethical code: IR.KMU.REC.1394.690). Then, the approval for sampling was attained from the executives of selected hospitals and oncologists. At each visit in the centers of the study, the patients who had the study criteria were recognized. The patients were informed of the aim of the study and verbal consent was obtained. The questionnaires were given to the literate patients, and for the illiterate cases or incapable individuals, a secluded interview was conducted.

Statistical analysis was processed, using SPSS for Windows 21.0 (SPSS Inc., Chicago, IL, USA). To describe the characteristics of patients, patients' attitudes towards truth-telling and self-determination, descriptive statistics including frequency, percentage, mean, and standard deviation were used. To investigate the relationship between these 2 attitudes, Pearson correlation test was used, and for correlation between demographic characteristics and patients' attitude, linear regression analysis was used;  $\alpha$  less than 0.05 was considered statistically significant.

## 3. Results

Certain demographic characteristics of the participants are indicated in Table 1. As shown in Table 1, most of the participants were female, married, with a primary level of education; about 34% of them stated family history of cancer.

**Table 1.** Sample Characteristics (n = 214)

Character		No. (%)
Gender	Male	106 (49.5)
	Female	108 (50.5)
Marriage Status	Married	175 (81.8)
	Single	39 (18.2)
Education level	Below high school diploma	87 (40.7)
	High school diploma	68 (31.8)
	University degree	59 (27.6)
Family history	Yes	94 (43.9)
	No	120 (56.1)

The overall score of participants' attitude towards truth-telling and autonomy (self-determination) is shown in Table 2. To facilitate the analysis, we transformed the score of these 2 questionnaires as 0 to 100 that higher score represented more positive attitude. As shown in this Table 2, the participants had a positive tendency to truth-telling

(mean score 63.5 out of 100) and self-determination (mean score 53.1 out of 100).

**Table 2.** Participants' Attitude Towards Truth-Telling and Autonomy (Score from 0 to 100)

	Minimum	Maximum	Mean $\pm$ SD
Attitude to truth-telling	26.14	89.77	63.53 $\pm$ 10.00
Attitude to autonomy	30.36	80.36	53.10 $\pm$ 9.09

The truth-telling scale had 2 dimensions; truth-telling and its effects and the methods of telling the truth. As shown in [Table 3](#), the attitude of patients with cancer in truth-telling effects area is absolutely positive; the mean score of the question "the patient is entitled to know the diagnosis" was 4.18 and about the family knowledge of the diagnosis, the mean score was 3.66. The majority of the participants believed that knowing the truth might make them more cooperative during the treatment period, prevent unnecessary treatments, and help them deal better with their difficulties and problems. They also disagreed with losing hopefulness and fall in quality of life if the truth is told. According to [Table 4](#), many of them considered their physician the best one for telling them the truth (mean score of 4.26 out of 5) and the best place for hearing the truth was the physician office. They thought that psychological condition of patients should be taken into account when the truth was revealed (mean score 3.98). The results of the present study showed that participants thought that the truth should be told in the early stage of cancer diagnosis not at the end of disease.

**Table 3.** The Mean Score of Participants' Attitude Towards Truth-Telling and Its Effects

Question	Mean (SD)
Patient is entitled to know the truth	4.18 (0.89)
Patient's family should know the truth	3.66 (1.21)
Patient is entitled to know all about his/her condition	3.98 (0.98)
Therapeutic team is entitled to start treatment without explanation	3.15 (1.20)
If the truth is told, patient cooperate better with his/her physician	4.20 (0.80)
Truth-telling make patient anxious and have a negative impact on treatment	3.51 (1.01)
Truth telling helps patient deal better with difficulties	3.81 (0.84)
Truth should not be told for keeping patient's quality of life	3.64 (1.01)
Knowing the diagnosis make patient hopeless and facilitate his/her dead	3.71 (0.94)
Knowing the truth prevents unnecessary treatments	3.63 (0.84)

**Table 4.** The Mean Score of Participants' Attitude Towards the Methods of Truth-Telling

Question	Mean (SD)
Physician is the more reliable person for truth-telling	4.26 (0.77)
Nurse who takes care of patient is the best person for telling the truth	3.00 (0.85)
It is the duty of family to tell the truth to patient?	3.02 (1.10)
Truth about diagnosis, prognosis, and condition of illness should be told entirely	3.64 (1.04)
Only some part of truth about illness and diagnosis should be told	2.62 (0.94)
Patient should know the truth in the early phase of cancer	3.71 (1.06)
Patient should know the truth through treatment period	3.42 (0.98)
Patient should know the truth in terminal phase of cancer	2.37 (0.9)
Truth-telling should be done in hospital and at patient's bed	2.72 (1.02)
Truth-telling should be done in physician's office	3.73 (0.91)
Truth-telling should be done in accordance with patient's psychological condition	3.98 (0.88)
Truth-telling should be done by someone who had been trained for truth-telling	3.85 (0.92)

The participants' responses to each item of the API are depicted in [Table 5](#). As shown in [Table 5](#), participants reported their preference for decision making as low and seeking information as high. They preferred that leave decisions be made by doctors even if they disagreed. However, they reported a positive attitude towards information seeking as they had high scores of knowing all therapeutic methods, the purpose of diagnostic examinations, and even unpleasant realities.

Regarding one of the objectives of the study, the relationship between attitude of patients with cancer towards truth-telling and autonomy, Pearson correlation test results showed that there was a statistically significant but weak correlation between these variables ( $P = 0.04$ ,  $r = 0.14$ ).

Correlation between demographic information and attitude towards truth-telling and self-determination were tested, using linear regression. According to [Table 6](#), by treatment duration increase, in average, the score of patients' attitude towards truth telling rises 0.13 and the mean score of patients with lung cancer is 6.2 less than other patients. According to [Table 7](#), the mean score of attitude towards self-determination in patients with university degree is 7.4 more than individuals with high school diploma, and patients with high school diploma have 3.7 more score than less educated participants.

**Table 5.** The Mean Score of Participants' Attitude Towards Autonomy

Question	Mean (SD)
<b>Decision-making sub-scale</b>	
The important medical decisions should be made by your doctor, not by you	1.76 (0.90)
You should go along with your doctor's advice even if you disagree to it	1.78 (0.79)
When hospitalized, you should not make decisions about your own care	2.14 (0.81)
You should feel free to make decisions about everyday medical problems	3.46 (0.89)
If you were sick, as your illness became worse, you would want your doctor to take greater control	1.85 (0.93)
You should decide how frequently you need a check-up	2.67 (1.20)
<b>Information-seeking sub-scale</b>	
As you become sicker, you should be told more and more about your illness	3.92 (0.85)
You should understand completely what is happening inside your body as a result of your illness	3.79 (0.93)
Even if the news is bad, you should be well informed	3.66 (0.87)
Your doctor should explain the purpose of your laboratory tests	3.97 (0.81)
You should be given information only when you ask for it	2.79 (1.07)
It is important for you to know all the side effects of your medication	3.89 (0.83)
Information about your illness is as important as treatment for you	3.95 (0.71)
When there is more than one method to treat a problem, you should be told about each one	4.03 (0.79)

**Table 6.** Correlation Between Demographic Information and Attitude Towards Truth-Telling via Multiple Linear Regressions

Variable	Regression Coefficient (95%CI)	P Value
<b>Cancerous part</b>		
GI system	-	
Lungs	-6.2 (-11.79, -0.6)	0.03
Blood (lochemia)	-3.08 (-6.98, 0.82)	0.12
Breast	-3.8 (-8.00, 0.41)	0.07
Other parts	-2.61(-6.25, 1.02)	0.16
<b>Duration of illness</b>	0.13(0.06, 0.2)	< 0.0001

#### 4. Discussion

Based on the reviewed literature, this study is the first research that investigates the relationship between the attitudes of patients with cancer towards truth-telling and self-determination in Iran. Moreover, very few studies have

**Table 7.** Correlation Between Demographic Information and Attitude Towards Autonomy via Multiple Linear Regressions

Variable	Regression Coefficient (95%CI)	P Value
<b>Education level</b>		
Below diploma	-	-
High school diploma	3.7 (0.1, 6.4)	0.008
University degree	7.44 (4.62, 10.27)	< 0.0001

been conducted in other countries on this subject. The results of this study showed that Iranian patients with cancer had high positive attitudes towards truth-telling and self-determination. Hence, Iranian patients with cancer want to know the truth about their illness, treatment options, and prognosis. These results are in line with the results of other studies in Iran and other eastern countries (10-12). In a study conducted by Zamani et al. 88% of participants agreed on telling the truth to patients with cancer at early stages and 78% agreed on telling the truth in the advance stages of cancer (13). The results of a study performed in Pakistan showed that 76% of patients with cancer want to be told the truth (11).

In this study, patients stated that the truth should be told by doctors. Our finding is matched with other researches that previously conducted (13). In studies in Korea and Taiwan on patients and their families, the majority of them preferred physicians as the source of truth (14).

The outcomes of this study showed that patients prefer that their physician take the responsibility of decision making, meanwhile they had a great tendency towards becoming informed of diagnosis, prognosis, and therapeutic methods; these results are in line with the findings of other related studies (15, 16).

Although our finding matches other studies on different populations and other illnesses which some are mentioned above, the discussion of patients' attitude and preference to truth-telling and self-determination may not be ended, because the amount of information and participation needed by patients have not been measured. Patients expect that their physician play the main decision maker role. Moreover, the preference for self-decision making is high, correlated with education level. The findings of this study suggest that decision making and information seeking are not concomitant. Patients want to be informed; they do not, however, necessarily want to be main decision maker. Thus, health care policy makers are advised to notice that patients are entitled to make decision; it is advisable that before information disclosure, just like consent before surgery, health care professionals ask them to in-

dicating their preference about information disclosure and participation in decision-making.

The ethical issues of truth-telling and shared-decision making are matters of all health care professionals, including physicians and nurses who work in oncology settings. They should be aware of the amount of information that their patients need and their desire to participate in medical decisions. More investigations are needed on this subject to identify how and to what extent patients desire for information and decision making. Regarding the outcomes of this study and other similar investigations in eastern countries, we can suggest oncology doctors and nurses in Iran to be more agreeable to answer patients' questions honestly when they show a preference to know, even if they do not express it verbally. To achieve this, they should enhance their communication skills and inducing some guidelines might be necessary.

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### Footnotes

**Authors' Contribution:** Hakime Hoseynrezaee design the study, wrote the paper. Javad Kordi Karimabadi contributed to the data entry, literature review, and writing-up process. Yunes Jahani contributed to study design and data analysis. All authors read and approved the final manuscript.

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### References

1. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA*. 1995;**274**(10):820-5. [PubMed: 7650806].
2. Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. *J Gen Intern Med*. 2010;**25**(7):741-5. doi: 10.1007/s11606-010-1292-2. [PubMed: 20213206].
3. Beauchamp TL, Childress JF. Principles of biomedical ethics. Oxford University Press, USA; 2001.
4. Beyraghi N, Mottaghipour Y, Mehraban A, Eslamian E, Esfahani F. Disclosure of Cancer Information in Iran: a Perspective of Patients, Family Members, and Health Professionals. *Iran J Cancer Prev*. 2011;**4**(3):130-4. [PubMed: 26328052].
5. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med*. 2001;**134**(12):1096-105. [PubMed: 11412049].
6. Larizadeh MH, Malekpour-Afshar R. Knowledge of patients with cancer towards their disease status. *Res Med*. 2007;**31**(1):85-90.
7. Oliffe J, Thorne S, Hislop TG, Armstrong EA. "Truth telling" and cultural assumptions in an era of informed consent. *Fam Community Health*. 2007;**30**(1):5-15. [PubMed: 17149028].
8. Baljani E, Khashabi J, Amanpour E, Azimi N. Relationship between spiritual well-being, religion, and hope among patients with cancer. *J Hayat*. 2011;**17**(3):27-37.
9. Kagawa-Singer M. Socioeconomic and cultural influences on cancer care of women. *Semin Oncol Nurs*. 1995;**11**(2):109-19. [PubMed: 7604189].
10. Jiang Y, Liu C, Li JY, Huang MJ, Yao WX, Zhang R, et al. Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. *Psychooncology*. 2007;**16**(10):928-36. doi: 10.1002/pon.1156. [PubMed: 17285684].
11. Jawaid M, Qamar B, Masood Z, Jawaid SA. Disclosure of cancer diagnosis: Pakistani patients' perspective. *Middle East J Cancer*. 2010;**1**(2):89-94.
12. Aghahosseini SS, Rahmani A, Abdollahzadeh F, Kermani IA. The relation between awareness of cancer diagnosis and spiritual health among cancer patients. *J Caring Sci*. 2012;**1**(2):67.
13. Zamani A, Shahsanai A, Kivan S, Hematti S, Mokarian F. Iranian Physicians and Patients Attitude toward Truth Telling of Cancer. *J Isfahan Med School*. 2011;**29**(143).
14. Kazemi A, Pursoleimani A, Fakhari A, Madaen K. Truth telling in medicine: views of Tabriz University of Medical Sciences. *Iran J Med Ethics History Med*. 2010;**3**(2):54-63.
15. Mo HN, Shin DW, Woo JH, Choi JY, Kang J, Baik Y, et al. Is patient autonomy a critical determinant of quality of life in Korea? End-of-life decision making from the perspective of the patient. *Palliat Med*. 2012;**26**(3):222-31. doi: 10.1177/0269216311405089. [PubMed: 21562031].
16. Hari D, Mark Z, Bharati D, Khadka P. Patients' attitude towards concept of right to know. *Kathmandu Univ Med J (KUMJ)*. 2007;**5**(4):591-5. [PubMed: 18604101].