

1-1-2015

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### Recommended Citation

YALÇIN, ABDUSSAMED; SILAY, KAMİLE; BÜYÜKÇELİK, ABDULLAH; IŞIKDOĞAN, ABDURRAHMAN; TÜRK, HACI MEHMET; COŞKUN, HASAN ŞENOL; ÖZDEMİR, FEYYAZ; UĞURLU, MEHMET; ÜSTÜ, YUSUF; and YALÇIN, BÜLENT (2015) "Opinions of the Turkish population on cancer and being informed of the diagnosis of cancer," *Turkish Journal of Medical Sciences*: Vol. 45: No. 2, Article 20. <https://doi.org/10.3906/sag-1312-72>

Available at: <https://journals.tubitak.gov.tr/medical/vol45/iss2/20>

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## Opinions of the Turkish population on cancer and being informed of the diagnosis of cancer

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## Opinions of the Turkish population on cancer and being informed of the diagnosis of cancer

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Received: 19.12.2013 • Accepted: 08.07.2014 • Published Online: 01.04.2015 • Printed: 30.04.2015

**Background/aim:** An opinion survey was conducted to investigate the opinions and attitudes of the Turkish population regarding cancer if they or one of their family members were to receive a diagnosis of cancer.

**Materials and methods:** The opinion survey was completed by 6566 subjects and consisted of questions about the demographics of the participants and their overall opinions about cancer. The other points of the investigation asked whether they would inform relatives who had cancer about the diagnosis and whether they would prefer to be informed if they were the one with the cancer diagnosis.

**Results:** The median age of the participants was 33 years (range: 18–100) and 53.3% were male. It was found that 57.7% of the participants would prefer not to disclose a cancer diagnosis to their first-degree relatives. The diagnosis had been disclosed to relatives with cancer in 69.9% of cases. When asked about their overall opinion of cancer management, 76.5% of participants were optimistic, 16.3% were pessimistic, and 2.9% had mixed opinions.

**Conclusion:** This study represents one of the largest surveys done in Turkey to identify the thoughts of healthy people about cancer and their opinion on informing their relatives about the diagnosis if the relatives have cancer. It is comparable with reports from East Europe and Asian countries.

**Key words:** Cancer diagnosis, cancer patients' relatives, attitude and behavior, empathic approach, patients' rights, paternalistic approach

### 1. Introduction

Cancer is the second leading cause of death after cardiovascular diseases (1,2). Lung cancer and gastrointestinal cancer are among the most frequent causes of cancer deaths around the world and in Turkey (3,4). The belief that cancer is a terminal disease is still popular in society in spite of rapid development and achievements in oncology (5). It is essential for the patient, family members, and well-disciplined medical personnel to work together, discussing and making decisions at each step of the diagnosis and management for an optimal result (6).

While the paternalistic approach to medicine was at the forefront 2–3 decades ago, a nonpaternalistic approach has now become popular. However, individuals in the East

European countries, Turkey, and other Asian countries are known to hold a more negative attitude since relatives of a cancer patient are overprotective when it comes to informing the patient about the disease and treatment (5,7). On the other hand, the thoughts of healthy people about cancer and their opinions about informing relatives who have cancer about their diagnosis are not exactly known in Turkey.

We designed and conducted an opinion survey to determine the thoughts of healthy Turkish people about cancer and how they would react if one of their relatives were to be diagnosed with cancer. This study aimed to investigate the opinions and attitudes of healthy Turkish population regarding cancer if they or one of their family members were to receive a diagnosis of cancer.

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## 2. Materials and methods

The calculated sample size for this study should have been 9219 to achieve a power of  $\alpha = 0.05$ ,  $d = 0.01$ , and  $P = 0.40$ . However, 6656 people (71%) completed the survey. The people who did not complete the survey indicated that it was too time-consuming. This was a descriptive and cross-sectional study. The selected subjects were over 18 years of age, had a healthy lifestyle, resided in various geographic centers of Turkey, and had the capacity to represent the entire Turkish population. They were randomly selected from among the healthy population without a history of cancer and none of them were medical practitioners.

The questions of the survey were about the demographic characteristics, age, sex, occupation, educational background, and lifestyle of the participating subjects, as well as their family history, their thoughts about cancer, whether they had had a relative with cancer (and whether this relative was informed about the diagnosis, when the information was given, and whether the relative was still alive), and their opinion about informing their relative if the relative were to be diagnosed with cancer in the future. After completing these questions, they were asked whether they would wish relatives to inform them in the event that they were diagnosed with cancer, their reasons for this choice, and what their attitude would be if their relatives preferred not to inform them.

The education levels of the participants were classified into 3 groups: poorly educated (primary school graduates), moderately educated (secondary school graduates), and well educated (high school and university graduates).

The median values of continuous variables were calculated and categorical variables were specified as percentages. The analysis of categorical variables was conducted using the chi-square test, while the Mann-Whitney U test and t-test were used for comparison of the average of independent variables. A logistic regression analysis was conducted for the multivariate analysis. P-values of less than 0.05 were regarded as significant. The statistical analysis was conducted using SPSS 12.0.

The relationships between characteristics of the participants and the following characteristics were examined by logistic regression analyses: 1) preference not to inform relatives/friends who were diagnosed with cancer about the diagnosis (overprotective behavior), 2) preference to be informed if they had cancer, and 3) initial preference not to inform cancer-diagnosed relatives/friends with reversal of that opinion after contrary questions, the behavior pattern thus changing from overprotective to optimal (optimal behavior).

In this study, a "contrary question technique" was utilized to understand the reaction and level of empathy of the participants. While in the first part of the survey, the subjects were questioned about their reactions if their relatives/friends had cancer, in the second part this scenario changed

and they were asked what their reaction would be if they were the one with cancer.

## 3. Results

### 3.1. Characteristics of the participants

The demographic characteristics of the participants and their answers to the questions including opinions on cancer are depicted in Table 1. The median age of the 6566 participants was 33 years (range: 18–100) and 53.3% and 46.7% of the participants were men and women, respectively. In terms of level of education, 1746 (26.6%) were poorly educated, 2009 (30.6%) were moderately educated, and 2811 (42.8%) were well educated.

The number of participants with cancer-diagnosed relatives or friends was 3598 (54.8%) and 2515 (69.9%) of those relatives/friends had been informed about their diagnosis. The timing of the disclosure of the cancer diagnosis were right after diagnosis for 1798 (71.5%), months after diagnosis for 425 (16.9%), and shortly before death for 226 (9.0%). Those with relatives/friends with cancer reported that 2262 (34.4%) of those relatives/friends died of cancer. When asked about attitudes towards cancer and its treatment, 5023 (76.5%) of the participants were optimistic and 1071 (16.3%) were pessimistic (Table 1).

It was found that 3454 (52.6%) of the participants would prefer not to inform their relatives/friends if the relative/friend were to be diagnosed with cancer. However, among this group, 2261 (65.4%) would wish to be informed about the disease if they were the ones diagnosed with cancer, and 1908 (84.3%) of those 2261 would prefer to be informed right after the diagnosis.

The participants who preferred not to inform their relatives about a cancer diagnosis were questioned as to how they would react if they were to develop cancer in the future and their relatives were to ask the doctor to hide bad news from them: 2470 (71.5%) of them objected to this and would wish to be informed by the doctor about the disease and prognosis.

When the 1001 participants who preferred not to be informed about their own cancer diagnosis were questioned about the reason for that wish, 417 (41.6%) stated fear of death, 312 (31.2%) stated fear of a painful life, 239 (23.9%) stated fear of drifting away from their profession and other people, 286 (28.6%) stated fear of being dependent, 166 (16.6%) stated fear of cancellation of preplanned endeavors, and 533 (53.2%) stated fear of separating from their loved ones.

### 3.2. Relationship between demographic features and participants' opinions

#### 3.2.1. Those who prefer not to disclose a diagnosis to relatives/friends who were diagnosed with cancer (overprotective approach)

Demographic features and their effects on participants' decisions regarding not to disclose a diagnosis to relatives/

**Table 1.** Demographic features and opinions on cancer of the healthy participants.

Number of participants (n)	6566
Median age, years (range)	33 (18–100)
Sex, n (%)	
Male	3499 (53.3)
Female	3067 (46.7)
Education level, n (%)	
Poorly educated	1746 (26.6)
Moderately educated	2009 (30.6)
Well educated	2811 (42.8)
Existence of relatives/friends with cancer, n (%)	
Living cancer patient	3598 (54.8)
Awareness of the patient about cancer diagnosis	1338 (37.2)
Timing of the disclosure	2515 (69.9)
Right after diagnosis	1798 (71.5)
Months after diagnosis	425 (16.9)
Shortly before death	226 (9.0)
Thoughts about cancer and medical treatment, n (%)	
Positive (optimistic)	5023 (76.5)
Negative (pessimistic)	1071 (16.3)
Would prefer not to inform relatives diagnosed with cancer, n (%)	3789 (57.7)
Initially would prefer not to disclose the diagnosis to their cancer-diagnosed relatives but after contrary questions approve of disclosure, n (%)	2841 (75.0)

friends with cancer are presented in Table 2. In general, participants who were young ( $P = 0.005$ ), female ( $P = 0.001$ ), or poorly educated ( $P = 0.0001$ ) would prefer not to disclose the diagnosis if close relatives/friends were diagnosed with cancer.

However, there was no significant difference between the existence or lack of relatives/friends with cancer in the past in terms of not disclosing the diagnosis. Participants who were taking care of family members with cancer preferred to inform the patient about the diagnosis later in the course of the disease ( $P = 0.0002$ ). In addition, if the cancer-diagnosed relatives/friends were still alive, participants preferred not to inform the patient about the diagnosis ( $P = 0.003$ ).

Those who were negative about cancer treatment and did not have faith in medical treatment preferred not to inform the patients ( $P = 0.0001$ ).

### 3.2.2. Those who would prefer to be informed if they had cancer

Demographic features and their effects on participants' opinions of whether they would prefer to be informed if they developed cancer are presented in Table 3. Statistically

significant relationships existed between those who would prefer to be informed about the disease if they had cancer and parameters such as younger participants ( $P = 0.0001$ ), well-educated subjects ( $P = 0.0001$ ), lack of a cancer-diagnosed relative/friend ( $P = 0.001$ ), having a cancer-diagnosed relative/friend who was informed at an early stage ( $0.001$ ), having a cancer-diagnosed relative/friend who had died ( $P = 0.003$ ), and being optimistic about cancer management ( $P = 0.001$ ). On the other hand, there were no significant differences for the parameters of sex, existence of relatives/friends with cancer, and information about the disease (Table 3).

### 3.2.3. Those who initially preferred not to inform their cancer-diagnosed relatives/friends but after contrary questions changed their opinion and approved of informing them (optimal behavior)

Demographic features and their effects on participants' opinions regarding changing their mind from negative to positive after answering contrary questions are presented in Table 4. We found statistically significant relationships between the changing of participants' opinions from negative to positive and the variables of younger

**Table 2.** Relationships between demographic features and the opinions of participants who preferred not to disclose the diagnosis to cancer-diagnosed relatives/friends.

Parameter	Definition	P-value
Age	Young	0.005
Sex	Female	0.001
Education	Poorly educated	0.0001
A relative/friend with cancer	No impact	0.322
Timing of informing a cancer-diagnosed relative/friend	Prefer to inform the patient about diagnosis later in the course of disease	0.0002
Survival of a cancer-diagnosed relative/friend	Those who had lost relatives/friends due to cancer prefer not to inform	0.003
Thoughts about cancer	Those who are pessimistic about cancer and medical treatment	0.0001

**Table 3.** Relationships between demographic features and the opinions of participants who would prefer to be informed if they had cancer.

Parameter	Definition	P-value
Age	Young	0.0001
Sex	No impact	0.384
Education	Well educated	0.0001
A relative with cancer	No impact	0.322
Informing relatives/friends with cancer about the disease	Those without cancer-diagnosed relatives/friends	0.001
Timing of informing cancer-diagnosed relatives/friends	Those with cancer-diagnosed relatives/friends who were informed about the disease at an early stage	0.001
Survival of cancer-diagnosed relatives/friends	If the cancer-diagnosed relatives/friends were dead	0.003
Thoughts about cancer	Those who are optimistic about cancer and medical treatment	0.001

participants ( $P = 0.005$ ), female subjects ( $P = 0.038$ ), poorly educated participants ( $P = 0.044$ ), and being optimistic about cancer management ( $P = 0.003$ ). However, there were no significant differences for changing participants' opinions from negative to positive and the variables of the existence of relatives/friends with cancer, having a cancer-diagnosed relative/friend who was informed, the timing of the information, and the survival status of cancer-diagnosed relatives/friends (Table 4).

#### 4. Discussion

In Turkey, similar to other Eastern countries, it is almost a natural process for patients' relatives to exhibit overprotective behaviors such as not disclosing bad news to their relatives. This relatively large survey is one of the first of its kind in Turkey. The participants were analyzed both in regards to informing relatives who were hypothetically diagnosed with cancer and, more importantly, some of

the major reasons behind this fundamental dilemma were revealed. This large-scale survey aimed to collect data and provide insight as well as educate the participants. In addition, the most distinguished part of the study was in the utilization of the contrary question technique to understand the reaction and level of empathy of the participants. Through this technique, we demonstrated that overprotective behavior could be changed to a respectful approach to patients' autonomy.

As is known, the right to be informed is specified in Article 7 of the International Patient's Bill of Rights of the World Medical Association (8). Thus, the ethical liability of a doctor to enable a patient to take part in the decision-making process and thereby provide the patient an opportunity to make his/her own decisions is based on informed consent (9). However, opinions about whether to inform a patient about bad news, as well as the problems that are brought along with that, vary by society (5). For instance, doctors

**Table 4.** Relationships between demographic features and the opinions of participants who changed their mind from negative to positive after contrary questions (\*).

Parameter	Definition	P-value
Age	Young	0.005
Sex	Female	0.038
Education	Poorly educated	0.044
Relatives/friends with cancer	No impact	0.345
Informing relatives/friends with cancer about the disease	No impact	0.222
Timing of informing cancer-diagnosed relatives/friends	No impact	0.763
Survival of cancer-diagnosed relatives/friends	No impact	0.707
Thoughts about cancer	Those who are positive and optimistic about cancer and medical treatment	0.003

\*: "Changing their mind from negative to positive" means that the participants initially preferred not to inform their cancer-diagnosed relatives/friends, but then after contrary questions they changed their opinion and approved of informing them.

in the United States inform a patient about a diagnosis, grounded on the right of a patient to have control over his/her own life. Overall, the approach used in West and North Europe has been similar to that of the United States and Japan (10,11). However, it is not customary to inform a patient about a diagnosis in South and East European countries such as Spain, Italy, and Greece, as well as in Central Asia and Africa (7). A similar approach is popular in Turkey, as well. The percentage of patients not informed about their own cancer diagnosis, according to previous studies, ranges from 20% to 54% in Turkey (12–14). Ozdogan et al. pointed out in their studies conducted with patients' relatives that 66% of them do not wish the patient to be informed about the diagnosis (15). Even though the difference of our study was that it targeted a healthy population, our finding seems similar to that of Ozdogan et al., as the rate of overprotective approach was 57.7%.

There are many underlying reasons behind the overprotective approach. In Eastern countries, there is a perception that an individual belongs to a family, and the power and liability for decision-making processes are a family issue. Among the factors that urge people to hide the diagnosis are being male, the cancer being at an advanced stage, the cancer being of a type that makes the lifespan shorter or impairs the quality of life, having a lack of information about cancer, and having strong religious beliefs (15–18). In another study, elderly, female, and poorly educated or unemployed people preferred not to inform the patient (19). In this study, younger, female, and poorly educated participants were found to be associated with overprotective behavior. The rate of well-educated people was higher in this study

than in the general Turkish population. This discrepancy might be due to a high survey participation rate among well-educated participants. The reasons for the different findings might be socioeconomic, cultural, or religious factors.

While the rate of overprotective behavior was approximately 58%, the percentage of participants who would prefer not to be informed if they had cancer was 28.5%. Interestingly, we found that establishing empathy improved participants' behavior. As can be seen, the overprotective behavior rate decreased by 50%.

In our study, the most important reasons for the preference to not be informed about one's own cancer diagnosis were fear of separating from their loved ones (53.2%), fear of death (41.6%), fear of a painful life (31.2%), fear of being dependent (28.6%), and fear of cancellation of preplanned endeavors (16.6%). These findings have not been studied before in Turkey.

Unlike in previous studies, the participants were posed counter questions in order to see if they would change their minds regarding informing their relatives about a cancer diagnosis. After completing the survey, 75% of those who had preferred that doctors not inform their relative with cancer about the diagnosis changed their minds in a positive fashion. It has been demonstrated that establishing empathy via contrary questions improved this behavior pattern from overprotective to optimal by approximately 50%. This improvement was seen especially in association with being young, female, poorly educated, and optimistic about cancer management. This shows that educating people might alter attitudes and behaviors. Training and enlightening people through visual and

written publications will lessen the number of cases where the disease is not disclosed to the patient. Therefore, we think that this type of study can help to establish empathic behavior and educate the public about patients' rights.

In conclusion, more studies are required in an effort to pioneer a movement for people to comprehend and

build upon the concept of "optimistic behavior and human rights" in Eastern countries. We think that analytical studies are crucial to raise awareness and eliminate overprotective behavior for the benefit of patients, families, caregivers, and doctors in terms of optimal cancer management.

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