

Saudi Cancer Patients' Attitudes towards Disclosure of Cancer Information

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Abstract

Background: The aim of this study was to explore Saudi cancer patients' views regarding cancer information disclosure and whether differences existed between regions or gender.

Methods: In this cross-sectional questionnaire-based prospective survey, we interviewed 332 Saudi cancer patients who received oncological care at King Fahd University Hospital, Al-Khobar, Saudi Arabia from July 2002 to July 2009 to explore their attitudes regarding disclosure of cancer information.

Results: The vast majority of Saudi cancer patients wanted to know the diagnosis of cancer (98%) and only 2% wanted the information to remain undisclosed. Seventy percent of the women wanted family members to know compared to only 39% of the men ($P<0.001$). Only 10% of the patients wanted their friends to know. In this study, 99% and 98%, respectively, wanted to know about the benefits of therapy and about their diagnosis of cancer. Of both genders, 98% also wanted to know the side effects of therapy and the prognosis. The attitudes of Saudi men and women with cancer were almost identical apart from sharing information with their family members. 99% of eastern region cancer patients wanted the diagnosis of cancer disclosed compared to 74% of those from other regions ($P=0.04$).

Conclusion: The findings of this study indicated that most Saudi cancer patients wanted disclosure of cancer information. Significantly more women than men wanted to share information with their family. More Eastern region patients wanted to know about their diagnosis of cancer compared to patients from other regions.

Keywords: Cancer, Patients, Truth, Information, Saudi

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Introduction

Cancer is a major life-threatening disease, affecting a patient's mental adjustment, which can evoke deep-rooted fears of death and a sense of loss of hope. The word cancer is

much feared and is associated with tremendous anxiety, pain and sufferings in both healthy and ill Saudis.¹⁻³

Truth-telling in medicine is a broad area that often encompasses

Table 1. Questions of attitude toward disclosure of cancer information.

Questions to be asked	Yes / No
1- Do you want to know all of the information about your illness?	
2- Do you want to know only partial information?	
3- Should we withhold all the information?	
4- Should we tell your family?	
5- Should we tell your friends?	
6- Should we treat you without telling you about the effect of the treatment?	
7- Should we treat you without telling you about your disease if it proves to be cancer?	
8- Do you want to know all side effects of the treatment?	
9- Do you want to know about the prognosis of the disease?	

several issues. 1) Patients have the right to know the truth and to receive information about their diagnosis and illness (autonomy).⁴⁻¹⁰ 2) Family members are more reluctant than patients to disclose the truth.¹⁰⁻¹³ 3) Most ethicists defend the right not to know. 4) The physician must balance his or her obligation to tell the truth against the imperative to do no harm,¹⁴⁻¹⁷ or justify withholding information which could mean deception or lying.

The majority of both healthy adults and cancer patients from many countries prefer to know their diagnosis, prognosis, treatment options and the success of therapy.^{1-9,18-28} Nowadays, in Western and Eastern countries including Japan, attitudes of physicians towards informing cancer patients about their diagnosis have changed to truth telling and disclosure of all important facts related to the disease.^{21,26-27,29,30}

Religiously and socially among Saudi individuals, lying is unwise and when a lie is told, people lose trust in the individual, particularly if lying occurs in the medical field. On the other hand, relatives of cancer patients defend the right of the patients not to know about their diagnosis and prognosis, and insist that patients receive treatment without being informed or do not allow patients to sign consents for treatment. Therefore, patients will question their diagnosis during diagnostic tests or when receiving chemotherapy.

In view of the dilemma between local culture and autonomy of our patients, we conducted this study to elicit the views and opinions of Saudi cancer patients towards disclosure of cancer information regarding their diagnosis, prognosis,

treatment benefits and the adverse effects of therapy.

Materials and Methods

For the purpose of this study, the author constructed a questionnaire of nine items (modified from Meredith et al.,²⁴ Jawaid et al.,²⁷ Yun et al.³⁰ and Fallowfield et al.³¹) that examined attitudes of Saudi cancer patients towards their views on how much information they wished to know about the diagnosis, prognosis, benefits and side effects of chemotherapy, if the disease proved malignant. The interviews were conducted after the diagnosis was confirmed at our hospital but patients had not yet been informed of their illness. After verbal consent, patients underwent face-to-face interviews. The interviewers explained in detail the objectives and aim of the study and addressed questions raised by the patients. Interviewers asked the participants to think of the answers and respond according to their points of view. All patients were Saudis diagnosed with malignant disease at King Fahd Hospital of the University-Al-Khobar between July 2002 and July 2009. Both men and women were included in this study and all patients were >18 years of age. Patients answered the questions without assistance after the questions were translated into their local language when needed. Respondents replied "Yes" or "No" to the questions, as appropriate (Table 1).

Statistical analysis

Data was analyzed with SPSS for Windows v. 13.0 (SPSS Inc., Chicago, IL). The results were cross-tabulated to examine the relationships between the variables. Statistical analysis was

performed using the chi-squared test for associations and the Fisher exact test. Frequency tables were generated to report descriptive statistics. A *P* value of less than 0.05 was considered significant in all statistical analyses.

Results

Demographic characteristics

From January 2002 to December 2009, 332 Saudi cancer patients were approached and interviewed face-to-face. All patients seen during the survey period agreed to participate. Table 2 shows the patients' characteristics. All patients were Saudis and 60% were from the eastern region. Fifty-eight percent were illiterate (less than primary school) and 42% were literate (more than intermediate school).

Attitudes toward disclosure of cancer information

Out of 332 Saudi cancer patients, 98% wanted to know all information about their malignant disease and 2% wanted either partial or no information about their condition. Saudi women with cancer wanted family members to know significantly more frequently (70%) than men (39%, $P < 0.001$). Only 7% of the women and 14% of the men wanted friends to know ($P = 0.547$). Almost all men (99%) wanted disclosure of benefits and adverse effects of therapy, compared to 98% of the women ($P = 0.547$ for benefits, $P = 0.682$ for adverse effects), and 98% of the entire study sample wanted disclosure of the prognosis with no significant difference between genders ($P = 0.232$, Table 3). Patients from the eastern region desired disclosure of the diagnosis significantly more frequently (99%) than those from other regions (74%, $P \leq 0.04$). However, there were no significant difference between genders (95% vs. 92%; $P = 0.649$) or patients with different education levels ($P = 0.496$), as shown in Table 4.

Discussion

Our survey showed unexpected findings; 98% of Saudi cancer patients wanted disclosure of the diagnosis and prognosis of their cancer, whereas

Table 2. Demographic characteristic of Saudi cancer patients.

Variable	No. (%)
Age range (18-95 years)	NA
Median age (50 years)	NA
Religion	
Muslim	332 (100%)
Non-Muslim	0 (0%)
Nationality	
Saudi	332 (100%)
Non-Saudi	0 (0%)
Sex	
Male	166 (50%)
Female	166 (50%)
Place of origin	
Eastern	199 (60%)
Central	17 (5%)
West	12 (3.6%)
South	85 (26%)
North	18 (5%)
Other	1 (0%)
Level of education	
Illiterate	145 (43%)
Cannot read & write	15 (4.5%)
Read and write	32 (9.6%)
Primary school	26 (7.8%)
Literate	54 (16.6%)
Intermediate school	60 (18%)
Secondary school	
University	
Type of neoplasm	
Breast	59 (17.8%)
Lung	19 (5.7%)
Other	254 (76.5%)

only 2% wanted partial information, the information to be hidden, or non-disclosure of the diagnosis. These figures are strikingly similar to studies reported in North America, Western Europe and recently in Japan, which indicate that the majority of patients would prefer to know their diagnosis, treatment options, the adverse effects of therapy and the prognosis of their malignant disease.^{4,9,22,24,29-31}

A survey of 1251 patients in the USA showed that 96% of them wished to be told if they were suffering from cancer and 85% wished to know how long they were going to survive.²⁸ European patients had similar attitudes. Meredith et al. studied 250 patients who attended an oncology

Table 3. Saudi cancer patients' responses on a 9-item questionnaire.

Questions asked to 332 Saudi cancer patients	Male		Female		P value (χ^2 -test)*
	Yes No. (%)	No No. (%)	Yes No. (%)	No No. (%)	
Want to know all information about cancer	163 (98)	3 (2)	163 (98)	3 (2)	0.649
Want to know only partial information	3 (2)	163 (98)	2 (1)	164 (99)	0.491
Want to withhold all information	1 (1)	165 (99)	2 (1)	163 (99)	0.507
Want the family to know	65 (39)	101 (61)	116 (70)	50 (30)	<0.001
Want friends to know	12 (7)	154 (93)	24 (14)	142 (86)	0.547
Want to be treated without knowing benefits of therapy	2 (1)	164 (99)	4 (2)	162 (98)	0.547
Want to be treated without knowing the diagnosis	1 (1)	165 (99)	3 (2)	163 (98)	
Want to know side effects of therapy	164 (99)	2 (1)	163 (98)	3 (2)	0.682
Want to know about the prognosis	159 (98)	3 (2)	162 (98)	4 (2)	0.232

* $P < 0.05$ = statistically significant

center in Scotland and found that 96% wanted to know if their illness was cancer.²⁴

In our sample, preferences for disclosure of a diagnosis of cancer, the prognosis, benefits and side effects of therapy were not associated with gender, age or level of education. Cultural and social factors in the Kingdom of Saudi Arabia play a major role towards giving bad news and truth-telling about the diagnosis, treatment and prognosis of cancer. Family members of Saudi cancer patients believe that telling the truth to patients could lead to harm and suffering. Some believe their patients are not educated; therefore, family members ask physicians to withhold or modify the information given to patients. Most of these caregivers request written medical reports. In this situation, family members ask the oncologist to breach confidentiality and tell the patient less than the truth. Furthermore, other members of the family complain about the contradiction in the medical report in comparison to information given to the patient. In addition, patients are curious to know the purpose of the drugs given or the diagnostic procedures done. These reasons may explain why doctors "collude" with Saudi cancer patients or their relatives.

A semistructured interview in 1996 regarding respecting the autonomy of cancer patients revealed that cancer patients were unanimous in their view that their own opinions about truth-telling and confidentiality should take precedence over those of their family, should they differ.³² In our study, we found that only 39% of the men and 70% of the women with cancer wanted to share

information with their family members. However, if patients were asked whether their family members should be informed even if the patients themselves were not informed, the outcome would be similar to the study mentioned above, in which all patients wished doctors to respect their views rather than those of their families.

Considering truth disclosure as the first step toward good doctor-patient communication and the first step of any decision-making in cancer patients, widespread acceptance of full disclosure is hardly achievable because of cultural reasons and social factors in Saudi Arabia. Nonetheless, this survey is an important step towards improving and changing the attitude and practice of Saudi patients and physicians regarding information and communication in the future.

This study was designed to explore the attitudes of cancer patients in the eastern region of Saudi Arabia. The findings might have disclosed different attitudes compared to the more individualistic philosophy of a developed society where the majority of cancer patients prefer disclosure of cancer information and want detailed information as part of their right to know.^{24,25,30,33-37} However, we found participants in this survey were not different from patients in more developed societies. Even though 60% of the cancer patients in this study were from the eastern region, there were participants from the other regions as well, and the findings of the present study show a consensus among our cancer patients regarding the need of information.

More local studies are needed with larger

Table 4. Characteristics of the sample by preference for disclosure or non-disclosure of cancer diagnosis.

Variables	Disclosure	Non-disclosure	P value (χ^2 -test)*
	No. %	No. %	
Region			0.04
Eastern (n=199)	197 (99)	2 (1)	
Other (n=133)	98 (74)	35 (26)	
Gender			0.649
Male (n=166)	163 (98)	3 (2)	
Female (n=166)	163 (98)	3 (2)	
Level of education			0.496
Illiterate (n=156)	153 (98)	3 (2)	
Literate (n=176)	173 (98)	3 (2)	

* $P < 0.05$ = statistically significant

numbers of patients from different regions to investigate patients' and physicians' attitudes. In addition, research is needed to explore the autonomy of cancer patients and confidentiality versus the right of the relatives to protect and support patients. More studies are necessary to confirm our findings and formulate national guidelines for the disclosure of cancer information, particularly in the absence of the principles of informed consent and patient autonomy as seen in North America.³⁸⁻⁴⁰

In summary, Saudi cancer patients wanted access to and disclosure of cancer information, and rejected the idea of therapy without disclosure of its benefits and adverse effects. In addition, our findings demonstrated that Saudi cancer patients want to know the truth about the diagnosis and prognosis of their malignant disease.

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