

## Original Article

# Attitude of Cancer Patients toward Diagnosis Disclosure and their Preference for Clinical Decision-making: A National Survey

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## Abstract

**Objectives:** There is still contradictory evidence on disclosure preferences regarding cancer diagnosis. The aim of this study was to evaluate the preference of cancer patients for knowing the truth about their disease, as well as the factors that might have an impact on these preferences.

**Method:** This study was conducted in 11 cancer centers in Iran. A questionnaire was used to collect data, and all patients above 15 years of age who were willing to participate were included in the study. The patients were asked if they were aware of the malignant nature of their disease, and if they came to know about their disease at the time of initial diagnosis, or later. The patients were then asked about the way they looked upon their disease. In the final part of the questionnaire, the participants were asked the level of involvement they prefer to have in making treatment decisions.

**Results:** In total, 1226 patients were enrolled in this study, only 565 (46.7%) of whom were aware of their disease at the time of diagnosis, and 878 (72.7%) at the time of interview, while 980 (85.2%) were willing to receive information about their disease. Patients' awareness was significantly associated with age under 50 years, female gender, having breast, skin or head and neck cancer, and having medical care in Shiraz or Hamadan while it was not associated with the stage or accompanying illness.

**Conclusion:** While the majority of Iranian cancer patients prefer to be aware of the nature of their disease and have an active role in treatment decision making, they do not receive this information.

**Keywords:** Cancer, diagnosis disclosure, Iran

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## Introduction

Cancer is the third most common cause of death worldwide which affects more than 16 million people each year. In

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Iran, about 100,000 people are being diagnosed with this disease annually. In many countries and cultures including Iran, cancer is a taboo subject<sup>1</sup>; this is maintained and reinforced primarily because of the mutual concerns of patients and family members.<sup>2</sup> Being diagnosed with cancer has cultural, social and psychological consequences and many patients and their relatives experience physical, psychological, spiritual and family problems.

Cancer treatment is a complicated, expensive, and time-consuming process, which needs a full cooperation between patients and their relatives, physicians, nurses and many other healthcare professionals. Despite this, the practice of withholding the truth from cancer patients is still prevalent among physicians in many parts of the world. Many people and some physicians believe that telling the truth about the nature and prognosis of the cancer can result in anxiety and hopelessness in the patients and therefore, making the treatment process more complicated. However, this assumption has been challenged by international studies. There is evidence that lack of information can increase uncertainty, anxiety and dissatisfaction; and good communication has been reported to be associated with better emotional adjustment and higher levels of satisfaction with symptoms management.<sup>3,4</sup>

Despite cultural and geographical differences, there are many similarities in patients from different cultures in terms of their desire to be informed about the exact nature of their disease. In

different studies, 79% to 98% of patients desired to know their diagnosis.<sup>5-8</sup>

Despite the fact that the majority of patients prefer to be fully informed about their disease, there is still a variety of different views among specialists. In some parts of the world, particularly Asia and Latin America, communicating a disease with a poor prognosis is a challenge for doctors.<sup>9,10</sup> 5% to 66% of doctors in different studies believe that disclosure of diagnosis is required.<sup>8,11,12</sup> Supporters of withholding relevant information from the patients mainly assume that withholding the truth has a beneficial effect on the patients because it helps them live more hopefully with less anxiety.<sup>13-17</sup> However, there is evidence that lack of information can increase uncertainty, anxiety and dissatisfaction,<sup>18</sup> as well as having a negative effect on patient-doctor relationship.<sup>19,20</sup>

Sometimes professionals prefer to disclose the diagnosis indirectly by giving information to relatives rather than the patient himself.<sup>21-25,13</sup> Recent studies have shown that this can have a negative influence on patient and spouse relationship happiness and intimacy.<sup>26</sup> The main reason for non-disclosure in many studies was fear of developing psychological complications in patients that could interfere with the treatment process. On the other hand, family members who disclosed the disease to their patients mentioned the following reasons to do so: obtaining patient collaboration during treatment, impossibility to hide the diagnosis in the long run, and believing in the patient's psychological strength to handle the situation. Patients' education, and the age of family members were factors that affected diagnosis disclosure.<sup>27</sup> Despite the common practice of non-disclosure, there is evidence that the majority of patients (70.3%) want to be informed of their diagnosis.<sup>28,29</sup> Sometimes doctors communicate with the patients without using the word "cancer".<sup>10,30,31</sup> Level of education and location of the cancer in body are two factors that have an effect on patients' understanding about the disease<sup>31</sup> and it seems that many other factors including social, cultural, financial factors as well as age, family support, and marital status might have an effect on the desire of the patients to know about their diagnosis.

The aim of this study was to evaluate the preference of cancer patients for knowing the truth about their disease, as well as the factors that might have a correlation with these preferences. By learning these factors, it might be possible to categorize cancer patients based on the level of information that they should be given.

## Material and methods

### Preparing the questionnaire and its instructions

A questionnaire was used to collect data. The first part, collecting data on age, gender, education, treatment options, city and province, relevant information about the diagnosis, sources of information, level of participation in decision making and the way patients looked upon their disease, was completed by residents, medical students, nurses, or other trained health-care professionals. The second part of the questionnaire collected data on the type, location, stage of cancer and accompanying illnesses and was completed by an oncologist.

An instruction section was also prepared to help the interviewers estimate the patients' awareness first and then proceed to other sections.

### Data collection

This study was performed in 11 cancer centers (2 in Tehran and

9 in other cities) over a wide geographical spectrum. For each center, a chief was selected to supervise data collection and entry. Each center was asked to collect data from all eligible patients in a one-month period. We included patients undergoing cancer treatment (chemotherapy, radiotherapy) for primary or recurrent disease at the time of completing the questionnaire as well as those whose treatment for primary or recurrent disease had ended more than three months prior to completing the questionnaire.

Written consent was taken from patients above 15 years of age who were willing to participate in the study. Strict procedures regarding patient anonymity were employed during data collection and entry.

The demographic and social data were collected from the patients and their relatives, and medical histories of the patients were obtained from hospital records.

The patients were then asked if they knew the malignant nature of their disease; if so, they would be asked about the time they came to know about their disease (at the time of initial diagnosis or later). The patients were then asked about the way they looked upon their disease—whether they called it a cancer, a malignancy, a tumor, a mass, an infection, etc. In addition, they were asked about their willingness to know their diagnosis and treatment process. In the final part of the questionnaire, the participants were asked about the level of involvement they prefer to have in making treatment decisions.

### Statistical analysis

Statistical analysis was performed with SPSS (version 21.0, IBM Co. Chicago IL). To compare the results between groups, we used logistic regression and its related odds ratio. To evaluate simultaneous effect of variables, we used multiple logistic regressions and its related adjusted ODDS Ratio. We used the GEE method in all the above regression analyses to consider the correlation of observations in the provinces. The 95% confidence interval was used to present the precision of the estimates.

## Results

In total, 1226 patients from 20 oncology centers in different parts of Iran (11 centers in Tehran and 9 centers in other cities) over a wide geographical spectrum were enrolled in this study. The mean age of participants was 49 years (95% CI = 48.11–49.89); 745 (61.1%) were female and 475 (38.9%) were male. At the time of completing the questionnaire, 737 patients (60.1%) were under treatment and 489 (39.9%) were under follow up. The most common cancers were breast (350 patients, 38%) and gastrointestinal (241 patients, 26.2%) cancers. Regarding the stage of the disease (based on TNM staging), 577 patients (57.4%) had localized disease, 271 (26.9%) had locally advanced and 158 (15.7%) had metastatic disease.

Table 1 shows the time when patients learned about their disease, and their willingness to receive more information about their prognosis based on various factors including age, gender, cancer type and stage, and the city where they were treated.

Among all participants in the study, 565 (46.7%) were aware of their disease since the initial diagnosis. However, at the time of completing the questionnaire, this figure increased to 878 patients (72.7%).

In addition, 980 patients (85.2%) were willing to receive more information about their disease. The main source of information

**Table 1.** Time the patients came to learn about their disease, and their willingness to receive more information about their prognosis.

	Number	Percentage	Informed about the cancer diagnosis at the time of diagnosis				Informed about cancer diagnosis at the time of interview				Willingness to receive information			
			Yes Num(%)	No Num(%)	P-value Uni-Var.	P-value Multi-Var.	Yes Num(%)	No Num(%)	P-value Uni-Var.	P-value Multi-Var.	Yes Num(%)	No Num(%)	P-value Uni-Var.	P-value Multi-Var.
All patients	1226	100	565(46.7)	644(53.3)			878(72.7)	330(27.3)			970(85.2)	168(14.8)		
Age	1106	100	516(47.1)	580(52.90)			795(72.7)	298(27.3)			884(85.9)	145(14.1)		
<50	569	51.4	311 (55.1)	253(44.9)	<0.001	<0.001	454(80.5)	110(19.5)	<0.001	<0.001	487(90)	54(10)	<0.001	<0.001
≥50	537	48.6	205 (38.1)	327(61.5)			341(64.5)	188(35.5)			397(81.4)	91(18.6)		
Gender	1220	100	562(46.7)	641(53.3)			872(72.5)	330(27.5)			966(85.3)	166(14.7)		
Female	745	61.1	383(51.9)	355(48.1)	<0.001	<0.001	569(77.1)	169(22.9)	<0.001	<0.001	613(86.6)	95(13.4)	0.126	<0.001
Male	475	38.9	179(38.5)	286(61.5)			303(65.3)	161(34.7)			353(83.3)	71(16.7)		
Group of patients	1226	100	565(46.7)	644(53.3)			878(72.7)	330(27.3)			970(85.2)	168(14.8)		
Treatment group	737	60.1	315(43.3)	413(56.7)	0.003	—	511(70.1)	218(29.9)	0.013	—	565(83.1)	115(16.9)	0.013	—
Follow up group	489	39.9	250(52)	231(48)			367(76.6)	112(23.4)			405(88.4)	53(11.6)		
City of study	1226	100	565(46.7)	644(53.3)			878(72.7)	330(27.3)			970(85.2)	168(14.8)		
Ahvaz	199	16.2	147(74.2)	51(25.8)			157(79.3)	41(20.7)			185(93.4)	13(6.6)		
Arak	99	8.1	16(16.3)	82(83.7)			36(36.4)	63(63.6)			84(84.4)	15(15.2)		
Babolsar	79	6.4	37(46.8)	42(53.2)			66(84.6)	12(15.4)			68(87.2)	10(12.8)		
Esfahan	201	16.4	92(46.2)	107(53.8)			158(79.4)	41(20.6)			172(86.4)	27(13.6)		
Gorgan	91	7.4	33(37.1)	56(62.9)	<0.001	—	77(84.6)	14(15.4)	<0.001	—	73(82)	16(18)	<0.001	—
Hamadan	116	9.5	75(65.8)	39(34.2)			101(89.4)	12(10.6)			99(91.7)	9(8.3)		
Mashhad	100	8.2	51(52)	47(48)			82(82.8)	17(17.2)			85(88.5)	11(11.5)		
Shiraz	50	4.1	28(56)	22(44)			49(100)	0(0)			34(68)	16(32)		
Tabriz	95	7.7	9(9.6)	85(90.4)			35(37.2)	59(62.8)			48(69.6)	21(30.4)		
Tehran	196	16	77(40.5)	113(59.5)			117(62.2)	71(37.8)			122(80.3)	30(19.7)		
Cancer type	921	100	423(46.3)	490(53.7)			660(72.5)	250(27.5)			737(86.2)	118(13.8)		
Brain	44	4.8	18(40.9)	26(59.1)			27(61.4)	17(38.6)			37(90.2)	4(9.8)		
Breast	350	38	195(56)	153(44)			284(82.1)	62(17.9)			300(89.8)	34(10.2)		
GI	241	26.2	94(39.5)	144(60.5)			149(62.9)	88(37.1)			172(77.8)	49(22.2)		
GU	64	6.9	14(22.6)	48(77.4)			37(58.7)	26(41.3)			43(79.6)	11(20.4)		
Gyn	31	3.4	11(36.7)	19(63.3)			24(77.4)	7(22.6)			25(86.2)	4(13.8)		
H&N	38	4.1	16(42.1)	22(57.9)	<0.001	<0.001	32(84.2)	6(15.8)	<0.001	<0.001	32(97)	1(3)	0.002	<0.001
Hematologic	68	7.4	32(47.1)	36(52.9)			44(66.7)	22(33.3)			57(90.5)	6(9.5)		
Lung	30	3.3	15(50)	15(50)			23(76.7)	7(23.3)			25(86.2)	4(13.8)		
Sarcoma & Melanoma	26	2.8	9(34.6)	17(65.4)			16(61.5)	10(38.5)			19(82.6)	4(17.4)		
Skin	29	3.1	19(65.5)	10(34.5)			24(82.8)	5(17.2)			27(96.4)	1(3.6)		
Cancer stage	1006	100	493(49.4)	505(50.6)			742(74.4)	255(25.6)			829(87.4)	120(12.6)		
Localized	577	57.4	274(48)	297(52)			429(75)	143(25)			488(88.7)	62(11.3)		
Locally advanced	271	26.9	139(51.5)	131(48.5)	0.598	0.598	202(74.8)	68(25.2)	0.682	—	204(83.6)	40(16.4)	0.123	—
Metastatic	158	15.7	80(51)	77(49)			111(71.6)	44(28.4)			137(88.4)	18(11.6)		
Comorbidity	981	100	488(50.2)	484(49.8)			732(75.5)	238(24.5)			812(86.9)	122(13.1)		
Yes	216	22	114(52.8)	102(47.2)	0.391	0.141	158(73.1)	58(26.9)	0.370	0.543	185(86.9)	28(13.1)	0.967	0.801
No	765	78	374(49.5)	382(50.5)			574(76.1)	180(23.9)			627(87)	94(13)		

Num=number, GI=gastrointestinal, GU= genitourinary, Gyn=gynecology, H&N= head and neck

**Table 2.** The way the patients looked upon their disease.

	Number	Percentage	How he/she named the disease						P-value Uni-Var.	P-value Multi-Var.
			Cancer Num(%)	Mass Num(%)	Injury Num(%)	Disease Num(%)	Other Num(%)	Multiple choice Num(%)		
All patients	1226	100	599(49.1)	343(28.1)	80(6.6)	121(9.9)	56(4.6)	20(1.6)		
Age	1106	100	536(48.8)	322(29.3)	74(6.7)	108(9.8)	44(4)	15(1.4)		
< 50	569	51.4	296(52.3)	178(31.4)	24(4.2)	41(7.2)	20(3.5)	7(1.2)	<0.001	0.287
≥50	537	48.6	240(45)	144(27)	50(9.4)	67(12.6)	24(4.5)	8(1.5)		
Gender	1220	100	596(49.1)	341(28.1)	79(6.5)	121(10)	56(4.6)	20(1.6)		
Female	745	61.1	400(53.9)	210(28.3)	35(4.7)	61(8.2)	28(3.8)	8(1.1)	<0.001	<0.001
Male	475	38.9	196(41.6)	131(27.8)	44(9.3)	60(12.7)	28(5.9)	12(2.5)		
Group of patients	1226	100	599(49.1)	343(28.1)	80(6.6)	121(9.9)	56(4.6)	20(1.6)		
Treatment group	737	60.1	321(43.9)	231(31.6)	56(7.7)	75(10.2)	37(5.1)	12(1.6)	<0.001	—
Follow up group	489	39.9	278(57.1)	112(23)	24(4.9)	46(9.4)	19(3.9)	8(1.6)		
City of study	1226	100	599(49.1)	343(28.1)	80(6.6)	121(9.9)	56(4.6)	20(1.6)		
Ahvaz	199	16.2	154(77.4)	19(9.5)	4(2)	9(4.5)	13(6.5)	0(0)	<0.001	—
Arak	99	8.1	41(41.4)	39(39.4)	4(4)	15(15.2)	0(0)	0(0)		
Babolsar	79	6.4	49(62.8)	20(25.6)	2(2.6)	7(9)	0(0)	0(0)		
Esfahan	201	16.4	82(41)	57(28.5)	20(10)	34(17)	6(3)	1(0.5)		
Gorgan	91	7.4	47(53.4)	24(27.3)	9(10.2)	5(5.7)	3(3.4)	0(0)		
Hamadan	116	9.5	69(60.5)	30(26.3)	2(1.8)	8(7)	4(3.5)	1(0.9)		
Mashhad	100	8.2	20(20)	56(56)	8(8)	11(11)	4(4)	1(1)		
Shiraz	50	4.1	35(70)	14(28)	0(0)	1(2)	0(0)	0(0)		
Tabriz	95	7.7	14(14.7)	32(33.7)	24(25.3)	14(14.7)	4(4.2)	7(7.4)		
Tehran	196	16	88(44.9)	52(26.5)	7(3.6)	17(8.7)	22(11.2)	10(5.1)		
Cancer type	921	100	448(49)	270(29.5)	62(6.8)	86(9.4)	36(3.9)	12(1.3)		
Brain	44	4.8	11(25)	25(56.8)	0(0)	2(4.5)	6(13.6)	0(0)	<0.001	<0.001
Breast	350	38	222(63.8)	91(21.1)	7(2)	20(5.7)	5(1.4)	3(0.9)		
GI	241	26.2	94(39.2)	72(30)	31(12.9)	27(11.3)	14(5.8)	2(0.8)		
GU	64	6.9	24(38.7)	17(27.4)	3(4.8)	11(17.7)	5(8.1)	2(3.2)		
Gyn	31	3.4	13(41.9)	12(38.7)	2(6.5)	1(3.2)	1(3.2)	2(6.5)		
H&N	38	4.1	19(51.4)	8(21.6)	3(8.1)	4(10.8)	1(2.7)	2(5.4)		
Hematologic	68	7.4	26(38.8)	23(34.3)	6(9)	10(14.9)	1(1.5)	1(1.5)		
Lung	30	3.3	16(53.3)	7(23.3)	1(3.3)	6(20)	0(0)	0(0)		
Sarcoma & Melanoma	26	2.8	9(34.6)	9(34.6)	2(7.7)	5(19.2)	1(3.8)	0(0)		
Skin	29	3.1	14(48.3)	6(20.7)	7(24.1)	0(0)	2(6.9)	0(0)		
Cancer stage	1006	100	503(50.4)	286(28.6)	62(6.2)	97(9.7)	41(4.1)	10(1)		
localized	577	57.4	282(49.2)	171(29.8)	38(6.6)	53(9.2)	22(3.8)	7(1.2)	0.495	—
Locally advanced	271	26.9	147(54.6)	71(26.4)	17(6.3)	21(7.8)	11(4.1)	2(0.7)		
Metastatic	158	15.7	74(47.1)	44(28)	7(4.5)	23(14.6)	8(5.1)	1(0.6)		
Comorbidity	981	100	498(51.1)	282(29)	51(5.2)	95(9.8)	40(4.1)	8(0.8)		
Yes	216	22	125(58.1)	48(22.3)	10(4.7)	26(12.1)	6(2.8)	0(0)	0.035	0.210
No	765	78	373(49.1)	234(30.8)	41(5.4)	69(9.1)	34(4.5)	8(1.1)		

Num = number, GI = gastrointestinal, GU = genitourinary, Gyn = gynecology, H&N = head and neck.

for 890 patients (72.6%) was their physician. Five hundred ninety nine (49.1%) patients called their disease "cancer", while 343 (28.1%) called it "mass", 80 (6.6%) called it "injury" and 121 (9.9%) called it "disease". Fifty-six patients (4.6%) used other (sometimes irrelevant) names for their disease and 20 (1.6%) used a couple of above-mentioned names. Regarding the level of desired involvement in treatment decision-making, 654 (56.9%) preferred to leave decisions up to their physician, 31 (2.7%) were willing to do it on their own, and 465 patients (40.4%) preferred shared decision-making with their physician.

Patients younger than 50 years of age, females, patients with skin or breast cancer, and patients from Ahvaz and Hamadan had significantly better awareness of the malignant nature of their disease since initial diagnosis ( $P < 0.001$  in all). Patients' awareness at the time of initial diagnosis was not associated with the stage of disease ( $P = 0.584$ ) or the presence or absence of an accompanying illness ( $P = 0.391$ ). In multivariate analysis, age (less than 50), gender (female) and cancer type (breast) were associated with better awareness of the malignant nature of their disease from the time of initial diagnosis ( $P < 0.001$  in all).

**Table 3.** Source of information about cancer diagnosis.

	Number Percentage		Source of information about cancer diagnosis					P-value Uni-Var.	P-value Multi-Var.
			Physician Num(%)	Professional caregiver Num(%)	Relatives Num(%)	Others (e.g. other patients) Num(%)	Unknown origin Num(%)		
All patients	1226	100	890(72.6)	25(2)	92(7.5)	75(6.1)	144(11.7)		
Age	1106	100	813(73.5)	20(1.8)	81(7.3)	63(5.7)	129(11.7)		
< 50	569	51.4	427(74.9)	10(1.8)	41(7.2)	40(7)	52(9.1)	0.034	<0.001
≥50	537	48.6	387(72.1)	10(1.9)	40(7.4)	23(4.3)	77(14.3)		
Gender	1220	100	884(72.5)	25(2)	92(7.5)	75(6.1)	144(11.8)		
female	745	61.1	560(75.2)	15(2)	56(7.5)	47(6.3)	67(9)	0.005	<0.001
male	475	38.9	324(68.2)	10(2.1)	36(7.6)	28(5.9)	77(16.2)		
Group of patients	1226	100	890(72.6)	25(2)	92(7.5)	75(6.1)	144(11.7)		
Treatment group	737	60.1	522(70.8)	12(1.6)	71(9.6)	37(5)	95(12.9)	<0.001	—
Follow up group	489	39.9	368(75.3)	13(2.7)	21(4.3)	38(7.8)	49(10)		
City of study	1226	100	890(72.6)	25(2)	92(7.5)	75(6.1)	144(11.7)		
Ahvaz	199	16.2	130(65.3)	2(1)	13(6.5)	31(15.6)	23(11.6)	<0.001	—
Arak	99	8.1	94(94.9)	0(0)	3(3)	1(1)	1(1)		
Babolsar	79	6.4	62(78.5)	4(5.1)	5(6.3)	7(8.9)	1(1.3)		
Esfahan	201	16.4	186(92.5)	1(0.5)	5(2.5)	4(2)	5(2.5)		
Gorgan	91	7.4	73(80.2)	2(2.2)	8(8.8)	2(2.2)	6(6.6)		
Hamadan	116	9.5	82(70.7)	9(7.8)	11(9.5)	3(2.6)	11(9.5)		
Mashhad	100	8.2	87(87)	1(1)	5(5)	1(1)	6(6)		
Shiraz	50	4.1	50(100)	0(0)	0(0)	0(0)	0(0)		
Tabriz	95	7.7	9(9.5)	0(0)	33(34.7)	8(8.4)	45(47.4)		
Tehran	196	16	117(59.7)	6(3.1)	9(4.6)	18(9.2)	46(11.7)		
Cancer type	921	100	682(74)	16(1.7)	67(7.3)	49(5.3)	107(11.6)		
Brain	44	4.8	30(68.2)	3(6.8)	5(11.4)	3(6.8)	3(6.8)	<0.001	<0.001
Breast	350	38	270(77.1)	4(1.1)	30(8.6)	22(6.3)	24(6.9)		
GI	241	26.2	171(71)	6(2.5)	13(5.4)	12(5)	39(16.2)		
GU	64	6.9	35(54.7)	3(4.7)	6(9.4)	1(1.6)	19(29.7)		
Gyn	31	3.4	26(83.9)	0(0)	2(6.5)	0(0)	3(9.7)		
H&N	38	4.1	32(84.2)	0(0)	0(0)	1(2.6)	5(13.2)		
Hematologic	68	7.4	51(75)	0(0)	4(5.9)	7(10.3)	6(8.8)		
Lung	30	3.3	26(86.7)	0(0)	2(6.7)	1(3.3)	1(3.3)		
Sarcoma & Melanoma	26	2.8	15(57.7)	0(0)	5(19.2)	1(3.8)	5(19.2)		
Skin	29	3.1	26(89.7)	0(0)	0(0)	1(3.4)	2(6.9)		
Cancer stage	1006	100	771(76.6)	17(1.7)	59(5.9)	58(5.8)	101(10)		
localized	577	57.4	443(76.8)	14(2.4)	35(6.1)	30(5.2)	55(9.5)	0.054	—
Locally advanced	271	26.9	195(72)	2(0.7)	17(6.3)	20(7.4)	37(13.7)		
Metastatic	158	15.7	133(84.2)	1(0.6)	7(4.4)	8(5.1)	9(5.7)		
Comorbidity	981	100	774(78.9)	20(2)	49(5)	54(5.5)	84(8.6)		
Yes	216	22	182(84.3)	3(1.4)	13(6)	12(5.6)	6(2.8)	0.011	<0.001
No	765	78	592(77.4)	17(2.2)	36(4.7)	42(5.5)	78(10.2)		

Num = number, GI = gastrointestinal, GU = genitourinary, Gyn = gynecology, H&N = head and neck.

Patients' awareness of the malignant nature of their disease at the time of completing the questionnaire was significantly associated with age under 50 years, being female, having breast, skin or head and neck cancer, and receiving medical care in Shiraz or Hamadan ( $P < 0.001$  in all). However, it was not associated with the stage of the disease (0.682) or the presence or absence of an accompanying illness (0.370). In multivariate analysis, age (less than 50), gender (female) and cancer type (breast) were associated

with better awareness of the malignant nature of their disease at the time of completing the questionnaire ( $P < 0.001$  in all).

Younger patients were more eager to be aware of their diagnosis ( $P < 0.001$ ), without any difference between the genders ( $P = 0.126$ ). Patients with cancers of the head and neck, skin, blood or brain were more likely to know more about their disease ( $P = 0.002$ ). Furthermore, patients from Hamadan or Ahvaz preferred to know more about their disease. The stage of cancer or having

**Table 4.** Patients' preference for decision-making about their disease.

	Number	Percentage	Patients' preference for decision-making about their disease				
			Physician Num(%)	Patient Num(%)	Shared Num(%)	P-value Uni-Var.	P-value Multi-Var.
All patients	1226	100	654(56.9)	31(2.7)	465(40.4)		
Age	1106	100	590(56.7)	29(2.8)	421(40.5)		
< 50	569	51.4	288(53.2)	13(2.4)	240(44.4)	0.027	0.006
≥50	537	48.6	302(60.5)	16(3.2)	181(36.3)		
Gender	1220	100	649(56.7)	31(2.7)	464(40.6)		
Female	745	61.1	407(57.7)	16(2.3)	282(40)	0.411	—
Male	475	38.9	242(55.1)	15(3.4)	182(41.5)		
Group of patients	1226	100	654(56.9)	31(2.7)	465(40.4)		
Treatment group	737	60.1	404(59.5)	16(2.4)	259(38.1)	0.087	—
Follow up group	489	39.9	250(53.1)	15(3.2)	206(43.7)		
City of study	1226	100	654(56.9)	31(2.7)	465(40.4)		
Ahvaz	199	16.2	89(44.7)	1(0.5)	109(54.8)	<0.001	—
Arak	99	8.1	11(11.1)	6(6.1)	82(82.8)		
Babolsar	79	6.4	39(52.7)	2(2.7)	33(44.6)		
Esfahan	201	16.4	151(76.3)	8(4)	39(19.7)		
Gorgan	91	7.4	41(47.7)	1(1.2)	44(51.2)		
Hamadan	116	9.5	75(68.8)	2(1.8)	32(29.4)		
Mashhad	100	8.2	91(92.9)	1(1)	6(6.1)		
Shiraz	50	4.1	42(93.3)	0(0)	3(6.7)		
Tabriz	95	7.7	7(11.9)	2(3.4)	50(84.7)		
Tehran	196	16	108(59)	8(4.4)	67(36.6)		
Cancer type	921	100	492(56.7)	25(2.9)	351(40.4)		
Brain	44	4.8	20(48.8)	0(0)	21(51.2)	0.007	<0.001
Breast	350	38	181(53.9)	5(1.5)	150(44.6)		
GI	241	26.2	137(60.4)	7(3.1)	83(36.6)		
GU	64	6.9	25(44.6)	3(5.4)	28(50)		
Gyn	31	3.4	16(53.3)	0(0)	14(46.7)		
H&N	38	4.1	25(73.5)	1(2.9)	8(23.5)		
Hematologic	68	7.4	40(61.5)	4(6.2)	21(32.3)		
Lung	30	3.3	17(58.6)	3(10.3)	9(31)		
Sarcoma & Melanoma	26	2.8	9(40.9)	1(4.5)	12(54.5)		
Skin	29	3.1	22(78.6)	1(3.6)	5(17.9)		
Cancer stage	1006	100	545(56.6)	27(2.8)	391(40.6)		
localized	577	57.4	301(54.4)	16(2.9)	236(42.7)	0.547	—
Locally advanced	271	26.9	151(58.8)	6(2.3)	100(38.9)		
Metastatic	158	15.7	93(60.8)	5(3.3)	55(35.9)		
Comorbidity	981	100	555(58.3)	26(2.7)	371(39)		
Yes	216	22	117(54.9)	10(4.7)	86(40.4)	0.103	0.284
No	765	78	438(59.3)	16(2.2)	285(38.6)		

Num = number, GI = gastrointestinal, GU = genitourinary, Gyn = gynecology, H&N = head and neck.

an accompanying illness did not have any significant effect on the patients' desire to know about their disease. In multivariate analysis, age (less than 50), gender (female) and cancer type (brain and breast) were associated with the patients' desire to know about their disease ( $P < 0.001$  in all).

Table 2 shows the way the patients looked upon their disease based on factors similar to Table 1.

Patients under 50 years of age, females, patients with breast cancer and those with an accompanying disease called their disease "cancer" more than the others ( $P < 0.001$  for all). While "cancer" was the most common name used by patients in all centers, patients from Tabriz and Mashhad more often called their disease "ulcer" or "mass". In multivariate analysis, gender (female) and cancer type (breast) were associated with applying the word "cancer" to the disease ( $P < 0.001$  in all).

Table 3 shows the source of information about cancer diagnosis based on factors similar to Table 1.

In patients under 50 years of age ( $P = 0.034$ ), females ( $P = 0.005$ ), patients with lung, head and neck, gynecological or breast cancer ( $P < 0.001$ ), patients with metastasis ( $P = 0.05$ ) or with an accompanying disease ( $P = 0.011$ ), the treating physician was the main source of information about the diagnosis, while in Tabriz, patients usually became aware of their disease from other sources ( $P \leq 0.001$ ). In multivariate analysis, age (under 50), gender (female), cancer type (skin) and having co-morbidity were associated with taking information from physician as main source ( $P < 0.001$  in all).

Table 4 shows the patients' preference for decision making about their disease based on factors similar to Table 1.

Most of the patients preferred to leave management decisions to their physician; however, patients under 50 years ( $P = 0.027$ ), patients with sarcoma, melanoma, genitourinary or brain tumors ( $P = 0.007$ ) and patients in Tabriz or Arak ( $P < 0.001$ ) more often preferred shared decision-making with their physician. The patients' gender ( $P = 0.411$ ), tumor stage ( $P = 0.547$ ) and having an accompanying disease had no significant effect on patient's decision regarding the level of involvement in treatment decision-making.

## Discussion

Our study showed that the majority of patients (72.7%) were aware of their disease at the time of completing the questionnaire but only "five hundred ninety nine (49.1%) patients called their disease 'cancer'". It means that many patients, who already knew the "bad" or "malignant" nature of the disease, did not use the word "cancer" for their disease.

This study showed that the probability of being informed about the disease at the time of initial diagnosis or during the treatment, and the willingness of the patients to know about their disease significantly decreased with increasing age. There is contradictory evidence in the literature regarding the effect of age on patients' preferences to know the truth. While results of some studies show that younger patients want to know more about their disease,<sup>32</sup> in some other studies, older patients were more willing to know further.<sup>33,34</sup> Age was a key factor in determining the source of information. While the majority of younger patients (younger than the mean age of participants in our study) obtained their information about diagnosis and prognosis from the treating physician, most older patients obtained information indirectly from other healthcare professionals, relatives, friends, other patients and even from non-medical hospital staff, or unknown sources. Also, younger patients in our study more often used the term "cancer" for their disease, while older patients most often used the terms "illness", "tumor" or "mass". Furthermore, for younger patients, autonomy was more important compared to older patients, and young patients were more willing to be involved in treatment decision-making.

Gender was also an important factor in our study. We found that female patients were more aware of their diagnosis and prognosis at the time of completing the questionnaire, and they were also more willing to know more about their disease. This is in contrast with the results of many other studies, including one conducted in Singapore, which showed no difference between the genders.<sup>32</sup> The reasons for this difference might be due to the younger age of the women in our study compared to men (47 vs. 52), and cultural differences. In addition, female patients more often used the word "cancer", while the majority of male patients used other words, such as "illness" or "mass". The important point to consider is that female patients in our study were younger than male patients. Therefore, it is not clear which factor (female gender or younger age) had a more prominent effect on the above mentioned results. Regarding source of information, female patients more often obtained their information from their treating physician, while male patients more often received their information from a person other than their treating physician.

Another important factor in our study was "time". At the time of diagnosis or during active cancer treatment, patients were more willing to leave decisions to their treating physician, and more often called their disease "mass" or "illness". However, after finish-

ing the treatment and during follow up visits, more patients were willing to have an active role in decision-making and they called their disease "cancer" more often. It seems that the majority of patients prefer to leave more difficult and complicated decisions to their treating physician and get involved in making less critical decisions.

We found a significant difference among different cities regarding knowing the diagnosis, as well as the desire to know more. While more than half of the patients in all cities were willing to receive information about their disease, this figure was highest in Ahvaz and lowest in Shiraz. Besides, among all cities studied, patients in Ahvaz were more aware of the nature of their disease at the time of diagnosis; while this figure was lowest in Tabriz. At the time of completing the questionnaire, patients from Shiraz had the highest level of knowledge about their cancer, while this figure was lowest in Arak. It seems that cultural issues play an important role in patients' level of awareness and the way they receive information.<sup>35</sup> In different countries, the percentage of patients who are aware of their cancer varies from 38% to 98%.<sup>36</sup> A Malaysian research reported that patients from China, India and Malaysia were different in ways of obtaining information about their disease.<sup>37</sup> A study from Nepal showed that only 20% of patients were aware of their diagnosis and prognosis,<sup>7</sup> and this figure in a similar study from Taiwan was 37.2%.<sup>38</sup> One Iranian study showed that 52% of patients were aware of their disease<sup>39</sup>; while a study from Portugal showed that 68.9% of patients had proper information about their situation.<sup>40</sup>

The names that the patients used to refer to their disease were also different in different cities. Patients from Ahvaz used the word "cancer" more than other cities, while in Tabriz and Mashhad the majority of patients used the word "mass". In Tehran, many different words were used for this purpose, which can be due to the fact that Tehran is a metropolitan, and besides, patients from different parts of the country are referred to Tehran for treatment. A study from Saudi Arabia also showed that only 16% of patients used the word "cancer" and 34% called their disease "tumor".<sup>41</sup>

We found that people in different cities used different sources of information. While most of the patients received their information from their treating physician, this figure was highest in Shiraz and lowest in Tabriz. Furthermore, medical staff in Hamadan, relatives and unknown sources in Tabriz, and other people (e.g. other patients) were important sources of obtaining information about the disease. Regarding involvement in decision-making, except for Ahvaz, Arak, Tabriz, and Gorgan, in other cities the majority of patients preferred to leave decision-making to their doctor and this figure was highest in Shiraz. In Tabriz, while patients had the lowest level of awareness about their disease compared to other studied cities, they were more willing than other patients to be involved in treatment decision-making.

The site of cancer in body was also an important factor in our study. Patients with brain tumors called their disease "tumor", which is probably because most physicians also call it "tumor". In other malignancies, the word "cancer" is more often used, especially for breast cancer, which is called so by the majority of patients.

The present study showed that the stage of cancer has no effect in the factors discussed above, including awareness of diagnosis, prognosis and the way the patients looked upon their disease.

Patients with moderate to severe comorbidities used the word "cancer" more than healthier patients; in addition, the former were

more likely to receive information from their treating physician. This might be due to the fact that patients with rather severe comorbidities have been involved with medical care for years and as a result, they do not consider diseases as “taboos”.

In all subgroups, physicians were the main source of information. In a study from Turkey, 62.5% of professionals believed that patients should know the diagnosis, but only 29.5% disclosed the diagnosis.<sup>42</sup> Also in Greece, only 39% of physician told about the diagnosis.<sup>43</sup>

The present study is one of largest studies of its kind, covering the majority of large cancer centers in Iran. Our results showed that while the majority of patients prefer to know the whole truth (about the nature, treatment methods, prognosis and side effects) about their disease, they are usually not provided with such information and in some cases, they are the last person to be informed of the diagnosis, following relatives and friends. The best approach is probably increasing social awareness about cancer and its treatment options, and then providing the patients with as much information as they ask for about their disease.

## Conclusion

The majority of Iranian cancer patients prefer to be aware of the nature and prognosis of their cancer, and many of them are willing to have an active role in treatment decision-making regardless of gender, stage of cancer and co-morbidity. By learning the factors that have an effect on this preference, it might be possible to categorize cancer patients based on the level of information that they should be given.

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