



Breaking Cancer Bad News to Patients With Cancer: A Comprehensive Perspective of Patients, Their Relatives, and the Public—Example From a Middle Eastern Country

abstract

Purpose Empowering patients with cancer requires that they be continuously informed about their condition. In some Eastern cultures, this concept is often opposed by caregivers. We aim to compare the extent of disclosure desired by actual and presumed patients with cancer and their relatives in our practice.

Methods Nine questions reflecting possible bad news communication to patients from diagnosis to the end of life were designed to investigate the extent of desired disclosure and were answered by 100 patients (cohort I) and 103 accompanying relatives (cohort II) in an outpatient setting. In addition, 103 public participants attending a family medicine clinic (cohort III) each answered the questions from the perspective of a presumed patient (cohort IIIA) and the perspective of a relative (cohort IIIB). The primary end point was affirmative response to six or more questions ($AR \geq 6$), reflecting a preference to be informed of the majority ($\geq 67\%$) of possible bad news.

Results $AR \geq 6$ was reported in 85% of cohort I and 52% of cohort II ($\chi^2 P < .001$). On multivariable analysis, $AR \geq 6$ showed significant association with being a patient (in cohorts I and II) and having nonmetastatic disease (only in cohort I). In the public cohort, $AR \geq 6$ was reported in 91% in cohort IIIA and 63% in cohort IIIB ($\chi^2 P < .001$). On multivariable analysis, $AR \geq 6$ in cohort III was significantly associated with being a presumed patient and having at least a college education.

Conclusion Patients desire disclosure of the majority of cancer-related bad news. This is in contrast to the views and requests of relatives. The public participants would also desire similar disclosure if they were to be diagnosed with cancer.

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INTRODUCTION

Over the last few decades, traditional paternalistic models of patient care have given way to more emphasis on patient empowerment, autonomy, and shared decision making. This shift is well supported by currently available recommendations and guidelines.¹⁻³

The United Kingdom General Medical Council good medical practice guidance clearly stresses effective communication with patients. The guidance states that physicians must listen to patients, take account of their views, and respond honestly to their questions. They must also give patients the information they want or need to know in a way they can understand.⁴

Nevertheless, concealing diagnostic or prognostic information from patients with cancer is still common in clinical practice. Studies show that a significant proportion of patients with cancer are not provided with much of their health-related news.⁵ This is more prevalent in Eastern countries than in Western countries.⁶ In Eastern culture, family members often extend their support to the patient by stepping in and taking over some or all of the patient's responsibilities and rights. This supportive attitude may evolve into a dominating attitude that hijacks the patient's basic right to knowledge and a share in decision making.⁷ Conversely, evidence shows that a majority of patients with cancer in Western societies need to know the

nature of their diagnosis, and they want as much information as possible about their condition.⁸ There is no evidence to suggest that patients from Eastern cultures want less information.

Physicians, patients with cancer, and their relatives in Eastern cultures often find themselves in this dilemma, which continues to be an unresolved matter of public debate. Rational decisions can never be reached in the absence of data specific to this population. Motivated by these realities, we planned this study to shed light on the perspectives of patients with cancer, their relatives, and the general public in a Middle Eastern country on disclosing cancer bad news.

METHODS

After approval from our institutional review board, consecutive adult patients with cancer (cohort I) and their accompanying relatives (cohort II) were recruited from medical oncology clinics. Patients with cancer who were diagnosed at least 3 months before recruitment, were aware of their diagnosis, and had the ability to read and write or verbally communicate were included in the study.

The public participants (cohort III) were recruited from consecutive adult nonpatients with cancer presenting to one family clinic in the family medicine outpatient department. All individuals were recruited within 3 weeks.

Nine closed-ended questions were designed to test the individuals' (patients, their relatives, and the general public) perspectives regarding disclosure of bad news. The questions reflect possible bad news communication from diagnosis to the end of life (Tables 1 and 2). Questions presented to patients addressed their personal preference about having cancer bad news delivered to themselves. Questions presented to relatives of patients with cancer addressed their preference regarding delivering news to that patient (their relative).

Questions to members of the public were presented in two formats. Format A addressed their personal preference if they were diagnosed with cancer (self is a patient), and format B addressed their personal preference if a close relative were diagnosed with cancer (relative is a patient). The questions were designed so that an affirmative (yes) answer indicated willingness to be informed of the bad news. Patients who answered affirmatively to six or more of the first nine questions were identified as indicating a preference to be informed of a significant majority (six of nine or 67%) of the possible bad news. Another question was included to assess preference regarding who

should receive the bad news first (the patient, the family member, or to both at the same time).

Participants were approached by the investigator (treating oncologist, family physician, or the research nurse) so the study could be explained verbally and to obtain verbal consent for participation. They were then given the questionnaire in their native Arabic language to self-complete within the clinic setting. For those unable to read, the investigator read the questions, documented the patient's exact response, and was available to explain any ambiguities.

We estimated that 70% of the participants preferred disclosure of bad news and thus would answer each question affirmatively. The total sample size required was calculated to be 267 if the estimate was within 6% of the true value (margin of error). The total sample was divided by using equal allocation; to increase the precision of the estimate, the sample size was increased to 100 participants in each cohort.

Collectively, 309 individuals were approached. Six individuals (three patients with cancer and three members of the public) did not participate in the study because of lack of interest. In all, 303 individuals (98%) completed the survey.

Results are presented as a percentage of affirmative responses (ARs) to each question. Responses to each question answered by cohorts I and II were compared by using the χ^2 test. Responses to each question in the two formats (to self and to relative) answered by cohort III were compared by using McNemar's test. Multivariable linear regression analysis was conducted to investigate the association between affirmative response to six or more questions ($AR \geq 6$) and possible relevant factors in cohorts I and II combined and in cohort III separately. SPSS version 12 (SPSS, Chicago, IL) was used for statistical analysis.

RESULTS

Patients and Their Relatives

Of the patients, 100 completed the questionnaire. Median age was 48 years (range, 18 to 80 years), 72% were females, and 28% were males. Eighty-seven percent of patients preferred to be informed of their cancer diagnosis, and 98% wanted to know the serious news about their health. Responses to other questions are presented in Table 1, and they show that the majority of patients preferred to be informed of other aspects of cancer treatment and possible unfavorable outcome. A relatively smaller majority (56%) preferred to be involved in end-of-life discussions. Eighty-three

Table 1 – Questionnaire and Frequency of Affirmative Response of Patients and Their Relatives

Question	Patients (%)	Relatives (%)	P
Should the patient be informed of:			
1. The diagnosis of cancer	87	68	.001
2. Any possible poor outcome	90	57	< .001
3. The term chemotherapy if it is part of treatment	71	67	.548
4. Failure of treatment	85	38	< .001
5. Every significant change about the condition and outcome	92	70	< .001
6. Serious health news	98	85	.002
7. The lack of specific anticancer treatment options	90	61	< .001
Do you:			
8. Agree that a physician should not withhold information about you at the request of a family member	80	56	.001
9. Agree that the patient should be involved in end-of-life discussions	56	30	< .001
Affirmative (yes) answers to six or more of nine questions	85	52	< .001
Should bad news be disclosed first to			< .001
The patient	43	9	
A family member	16	61	
Both at the same time	40	30	

percent of patients wanted to be the first to know of any bad news (either alone [43%] or accompanied by a family member [40%]). Eighty-five percent of patients answered six or more questions affirmatively. No patients (0%) answered yes to fewer than three questions.

Of the relatives, 103 completed the questionnaire. Median age was 39 years (range, 18 to 77 years), 44% were females, and 56% were males. Sixty-eight percent of relatives preferred that patients be informed of their cancer diagnosis in contrast to 87% of patients who preferred to be informed of their cancer diagnosis (68% v 87%; $P = .001$). Responses of relatives to other questions are provided in Table 1; data show that more patients than relatives were in favor of disclosure to the patient. For example, 85% of patients want to be informed of treatment failure compared with only 38% of relatives who agreed that the patient should be informed of this fact ($P < .001$). Comparison between patients' and relatives' responses is provided in Table 1. Only 39% of relatives wanted the patient to be the first to know of any bad news (either alone [9%] or accompanied by a family member [30%]).

The disclosure of the majority of bad news ($AR \geq 6$) to the patient was desired by 85% of patients but by only 52% of relatives ($\chi^2 P < .001$). On multivariable linear regression analysis, desire for major disclosure was significantly associated with being a patient in cohorts I or II and having nonmetastatic disease in cohort I (Table 3).

Public Participants

Of the public participants, 100 completed the questionnaire. Median age was 32 years (range, 18 to 75 years), 44% were females, and 56% were males. Ninety-eight percent preferred to be informed of the diagnosis if they were diagnosed with cancer (format A), whereas only 75% agreed that diagnosis should be disclosed to a relative if that relative were diagnosed with cancer (format B; 98% v 75%; $P = .001$). Twenty-four percent advocated disclosure of diagnosis to self but not to a relative.

Responses of the public to other questions are provided in Table 2, and all favored more disclosure to self than to a relative if both were patients with cancer. For example, 79% wanted to be informed of treatment failure (format A) compared with only 45% who agreed that the relative should be informed (format B; $P < .001$). Comparison of responses to both formats of the questionnaire is presented in Table 2.

Only 54% advocated that the patient (relative) to be the first to know of any bad news (either alone [13%] or accompanied by a family member [41%]). In contrast, 90% advocated that the patient (self) to be the first to know of any bad news (either alone [66%] or accompanied by a family member [24%]). Ninety-one percent answered six or more questions in format A affirmatively compared with 63% in format B ($P < .001$).

The disclosure of the majority of bad news ($AR \geq 6$) to the patient was desired by 91% of the public participants if they were diagnosed with cancer but by only 63% of the public participants if their close relatives were diagnosed with cancer ($\chi^2 P < .001$). On multivariable linear regression analysis, desire for major disclosure was significantly associated with being a presumed patient and having a college or higher education (Table 3).

DISCUSSION

It is clear from daily practice in Middle Eastern countries that serious health-related information (including cancer bad news) is not disclosed to many patients. Aljubran⁷ described that in Saudi Arabia, family members' genuine cultural values

Table 2 – Questionnaire and Frequency of Affirmative Response of the Public

Question	To Self (format A)	To Relative (format B)	Yes to Self But No to Relative	No to Self But Yes to Relative	P
Should the patient be informed of:					
1. The diagnosis of cancer	98	75	24	1	< .001
2. Any possible poor outcome	85	60	28	3	< .001
3. The term chemotherapy if it is part of treatment	80	76	8	4	.388
4. Failure of treatment	79	45	36	2	< .001
5. Every significant change about the condition and outcome	93	84	12	3	.035
6. Serious health news	99	90	9	0	.004
7. The lack of specific anticancer treatment options	79	56	24	1	< .001
Do you:					
8. Agree that a physician should not withhold information from the patient at the request of family member	87	82	12	7	.359
9. Agree that the patient should be involved in end-of-life discussions	76	59	18	1	< .001
Affirmative (yes) answers to six or more of nine questions	91	63			< .001
Should bad news be disclosed first to					< .001
The patient	66	13			
A family member	10	46			
Both at the same time	24	41			

oblige them to support the patient. The boundaries of this support are unclear and often lead to taking over some or all of the patient's responsibilities. Eventually, that support may evolve into a dominating attitude that hijacks the patient's basic right to knowledge and a part in decision making. Bou Khalil⁹ reports similar situations across the Middle

East. This attitude is prevalent in many Eastern cultures. In Turkey, 66% of relatives of patients with cancer did not want the diagnosis to be disclosed to the patient.¹⁰ Communities in countries recognized as Western that have geographic proximity to Eastern countries show similar attitudes. In Italy, 84% of cancer physicians consider

Table 3 – Multivariable Linear Regression Analysis of Relation Between AR ≥ 6 and Possible Confounding Factors

Confounding Factor	HR (cohorts I and II)	95% CI	P	HR (cohort III)	95% CI	P
Age, years	0.53	0.26 to 1.08	.08	1.34	0.55 to 3.24	.52
< 50 (cohorts I and II)						
< 35 (cohort III)						
Male sex	0.98	0.44 to 2.22	.97	0.89	0.39 to 2.01	.78
Less than college education	0.95	0.48 to 1.90	.87	0.24	0.11 to 0.56	.001
Employment status	1.40	0.62 to 3.16	.42	0.83	0.35 to 1.99	.68
Being a patient v being a relative	4.35	2.15 to 8.79	< .001	7.11	3.05 to 16.59	< .001
Metastatic v nonmetastatic cancer*	0.18	0.04 to 0.70	.014			
Active v nonactive treatment*	2.66	0.69 to 10.25	.15			

Abbreviation: AR ≥ 6, affirmative answers to six or more of nine questions; HR, hazard ratio.

*Relevant to cohort I only.

the family to be an obstacle to direct communication with the elderly.¹¹ There is increasing evidence in Western countries that most patients want to know more about their health and their disease.^{8,12-14} Evidence, although limited, similarly supports that most patients from Eastern cultures want to be informed of their health-related issues.^{15,16}

Our results add to the literature from the Middle Eastern region and confirm that a majority of patients with cancer (71% to 98%) prefer to know most of the information about their diagnosis, outcome, treatment, treatment results, and progress (Table 1). In addition, 90% prefer to be informed about the more serious information if there are no specific anticancer treatment options available for their condition. End of life is an extremely challenging stage because it can be associated with uncomfortable physical symptoms, depression, dignity issues, and loss of hope.¹⁷ Even so, more than half of patients (56%) feel that they should be involved in the delicate and challenging discussions regarding the end of life.

We also attempted to investigate the amount of bad news patients want to know. We accomplished this by calculating the percentage of patients who answered different proportions of the first nine questions affirmatively. Answering yes to six or more questions ($AR \geq 6$) indicated a preference for wanting to know $\geq 67\%$ of the bad news. We found that 85% of patients prefer to know the majority of possible bad news. To the best of our knowledge, this is the only published report that addresses the amount of possible bad news patients with cancer want to know.

The results also confirm the current perception that a significant proportion of relatives in the Middle Eastern region prefer not to keep patients informed (Table 1). Research from South Korea showed a similar pattern in which 96% of patients with cancer compared with 77% of family members believe that patients should be informed of a terminal illness diagnosis.¹⁸ In China, patients with cancer were more likely than families to believe that patients should be informed of the diagnosis (early stage, 90.8% v 69.9%; terminal stage, 60.5% v 34.4%).¹⁹

Personal experience and the literature show that relatives in Eastern cultures act as bearers to bad news and, in many cases, strongly demand a “do not tell” approach. Physicians in these cultures may be more likely to follow family wishes.^{6,7,9,10} To investigate this point, we asked patients and their relatives two direct questions: “Do you agree

that the doctor should not withhold information about you at the request of family member?” A majority of patients (80%) agreed compared with only 56% of the relatives. “To whom should bad news be disclosed first?” More patients (83%) than relatives (39%) wanted disclosure first to patients (either alone or with a family member).

Here we have some degree of conflict between the patient’s and the relative’s wishes. Physicians frequently face this dilemma during daily practice in the Middle East. From a practical point of view, direct communication is about more than providing information. It establishes good therapeutic relationships and acknowledges the humanity of patients. The information provided by the physician will help the patient understand and consent to the management plan. Without adequate information, a patient cannot make autonomous decisions. All these factors impose a duty on the physician to provide information to patients in an appropriate way.

Worldwide, few research groups attempted to study the attitude and opinion of the public and healthy individuals toward disclosing bad news. Horn and Waingrow²⁰ reported the American public’s views and beliefs about many issues related to cancer, including disclosure of diagnosis at three time points: in 1948, 1955, and 1962. Their results showed that at least 63% (1948), 64% (1955), and 60% (1962) of participants indicate that the patient should be informed of the diagnosis. A survey of 200 individuals age 65 years or older from 31 senior citizen centers in Los Angeles, CA, found that ethnicity was the primary factor that influenced attitudes toward truth-telling.²¹ In Japan, 85.4% of the responding public wanted full disclosure, and 11.3% wanted partial disclosure.²² A survey of the general population in Nepal showed that more than 80% wanted to be informed if they were diagnosed with cancer.²³

Views in Eastern cultures about disclosing serious health-related information to patients are divided and continue to be a matter of unresolved public debate. In addition, there is a scarcity of data regarding the preferences and attitudes of the public in Middle Eastern countries. The current perception is that the public’s attitude is conservative and favors limited or no disclosure to patients.

To better understand the public’s attitude, members of the public sample were presented with two questionnaire formats: format A addressed their personal preference if they were diagnosed with cancer (self is a patient); format B addressed their

personal preference if their close relative were diagnosed with cancer (relative is a patient).

In the public cohort, 79% to 98% answered the first eight questions affirmatively, indicating that the majority would prefer to know most of the information about their diagnosis, outcome, treatment, treatment results, and progress if they were diagnosed with cancer (Table 1). For example, 98% preferred disclosure of a cancer diagnosis. A smaller study from the Middle Eastern region published in 1998 reported a similar outcome (93%) in 40 members of the public.¹⁵ Among 2,422 individuals from the general population in Japan, 73% answered that they would want to know about their disease and prognosis if an incurable disease were diagnosed; 90% desired direct disclosure to themselves.²⁴

Interestingly, there was a significant difference in the public's response to both formats of the questionnaire, indicating preferential desire for more disclosure to self (91%) if the responder were diagnosed with cancer and less desire for disclosure to the relative (63%) if the relative were diagnosed with cancer (Table 2). The response to the question "To whom should bad news be disclosed first" shows that a majority of individuals wanted to retain their right to be informed about

their own condition. Conversely, many individuals would deny their relatives this right. One can only assume that applying different principles to similar situations in this context arises mostly from a sincere and genuine protective motive, although intermediate-term and long-term implications were not considered. An uninformed patient will not be able to make a rational decision and cannot be expected to make a valid consent to treatments. Unaware of the prognosis, this patient may miss the opportunity to plan social, professional, and financial matters appropriately.

We recruited patients from one hospital, which may be considered a limitation. However, our hospital is a tertiary referral center serving all regions of the country. Therefore, we believe our results can be generalized to the whole Saudi population.

Interventions and reforms are urgently needed to guarantee that appropriate attention is paid to patients' wishes and rights to be kept informed of their health-related issues. Physicians have a duty to explain to relatives the importance and positive consequences of informing the patient. In addition, significant action should involve educating the public on a wider scale.

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Final approval of manuscript: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or jgo.ascopubs.org/site/ifc.

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