

Serious Illness Disclosure – Preference of Bahraini Patients

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Objectives: To describe the patterns of preference of Bahraini adults attending Shaikh Sabah Health Center regarding disclosure of information of cancer diagnosis.

Methods: A random sample survey of 200 persons attending Shaikh Sabah AL-Salem health center interviewed in August 2000.

Results: Eighty-four percent (84%) preferred the diagnosis of cancer to be disclosed to them. Eighty-eight percent (88%) preferred to share with their doctors the treatment decisions. Eighty percent (80%) preferred to discuss with their doctors issues other than their sickness, such as work, family or school.

Conclusion and Recommendations: The results of this study conclude that the majority of patients want to know the fact of the illness including any bad news. And the majority preferred to participate in the management plan of the disease.

Given the results of this study, it is reasonable to conclude that improvements can be made in the ways the diagnostic disclosure is handled.

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One of most difficult jobs of the doctor is disclosing bad news to a patient, or a truth that may negatively alters the person's view of her or his future. Bad news may be terminal disease or life-changing prognosis, eg. Metastatic cancer or multiple sclerosis. There are several reasons why breaking bad news is especially difficult task for doctors, irrespective of their age, speciality, or professional experience¹(Table 1).

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Table 1: Difficulties Involved in Breaking Bad News

Personal:
*Fear of own illness/death.
*Fear of expressing own emotions, eg. Crying.
*Recent bereavement.
*Identification with own experience.
*Embarrassment/distress/discomfort.
Social:
*Institutional death is unacceptable taboo
*Sickness stigmatized
Professional:
*Lack of experience or training.
*Fear of eliciting a difficult response, eg. anger.
*Fear of being blamed by person or superiors.
*Failure to provide cure.
*Fear of causing pain/emotional damage.
*Fear of destroying hope.
*Political: fear of litigation.

It may be made more difficult if family members want to protect the person from bad news and distress. Under these circumstances, the doctor may be asked to collude with the relatives in order to withhold the truth from the person. This situation often puts strain on a previously healthy relationship and can lead to feelings of mistrust and isolation on the part of the patient. Nowadays, most doctors believe that people should be made aware of their diagnosis and prognosis if they wish¹. In situations of collusion the doctor should find out the reasons for the relative's wish. If holding information is causing problems, the doctor should try to negotiate permission from the relative to inform the person.

The scientific principles used in diagnosis and treatment is accepted internationally, whereas the nature of the personal doctor/patient relationship reflects the values and norms of particular society². Bahraini population is characterized by certain values, social and cultural believes, it is of interest to study the peoples' attitudes regarding disclosure of serious illness.

Truth telling issue is an ethical dilemma, at which a doctor must consider both the Hippocratic obligation to do what is best for the patient and to respect patient's autonomy. The apparent discrepancy between these two rules has left most doctors uncertain as to the "right" approach to doctor/patient communication in cases of serious or terminal disease. Consequently, the majority usually opts for what is thought to be culturally acceptable norm: that is withholding disclosure from the patient and disclosing instead to close family members²⁻³.

Patients have reported that the lack of information presented to them served to increase, rather than decrease the suspicion of lethal outcome⁴. Additionally, a

recent survey of patient views on who should communicate and tell the diagnosis and where and when the disclosure should occur indicated that certain disclosure procedure (eg. receiving a diagnosis over the telephone) might adversely affect the physician/patient relationship⁵. A survey carried out in Lebanon 1995 where a sample of 212 physicians, showed that 53% would usually avoid disclosure of cancer diagnosis directly to patients. Fifty nine percent (59%) of those surveyed agreed that they would change their policy should the public's expectations change⁶.

Based on these results, a further survey was conducted to measure the preference regarding disclosure of a serious diagnosis, and its determinants of the Lebanese public. Non random sample survey of 400 persons interviewed in health care facilities in Beirut in 1995 showed that 42% of respondents generally preferred truth not to be disclosed directly to patients⁷.

In Bahrain there is a concept that physicians sometimes withhold information of the true nature of patient's diagnosis and prognosis, which might be related to personal discomfort within the physician or may be related to patients preferences.

The preference not to be told of a serious diagnosis in Bahraini has so far never been formally assessed.

This paper aims to study the attitudes and preferences of Bahraini public towards disclosure of cancer diagnosis.

METHODS

(1) Study Population:

Sample size was 200 attendants from a total of 500,000 Bahraini adults.

Sampling Method:

The method employed for obtaining the sample is a **Multistage Sampling Technique**, which involves:

1- Selecting Health Centers:

One Health Center was selected - Shaikh Sabah Al-Salem health center because it is a homogenous center for many variables and it is placed in the capital of Bahrain.

2- Selecting Patients and Inclusion Criteria:

Bahraini Arabic speaking, above age of 20 years patients attending Sh. Sabah Al Salem HC during the period from 5th to 9th August 2000 were selected randomly by a doctor every day in a sequence of every 3rd attendance.

3-Total of 36 patients were selected every day and referred by the selecting doctor to be interviewed by three doctors. In a duration of 5 days the total number of selected patients was 180 patients in addition to 20 patients which were selected from the pilot study which was done on 2 August 2000 by the same method mentioned above in order to evaluate the time needed in selection and interviewing the participants.

(2) Method of Data Collection:

The main tool for conducting the survey is a questionnaire taken from Journal of Medical Ethics⁷. It consists of items covering the following main categories:

a- Demographic variables:

The variables addressed in the survey are age, sex, and education: low (primary and below), medium (intermediate and secondary) and high (above secondary), occupation, marital status, and presence of family history of cancer (Table 2).

Table 2. Description of Demographic Variable, Values and (%) Percentage

Age	Number (%)
20 –29	57(28.5%)
30-39	69(34.5%)
40 –49	30 (15 %)
50 – 59	27 (13.5 %)
60 +	17 (8.5%)
Sex	Number (%)
Male	112(56 %)
Female	88 (44 %)
Education	Number (%)
High	73 (36.5%)
Middle	85 (42.5 %)
Low	42 (21.0 %)
Occupation	Number (%)
1. Unemployed, retired and student.	36 (18 %)
2. Housewife	46 (23 %)
3. Manual Job	28 (14 %)
4. Business and Professional	90 (45 %)
Marital status	Number (%)
Single	41 (20.5 %)

Married	145 (72.5 %)
Divorced	8 (4 %)
Widow	6 (3 %)
Family History of disease	
	Number (%)
Yes	113 (56.5 %)
No	87 (43.5 %)

- b-** A series of statements with a dichotomy questions answered by either (Yes) or (No), eliciting participant’s attitudes, beliefs and expectations regarding disclosure of serious illness.

The questionnaire was conducted during a personal interview.

RESULTS:

Two hundred persons were interviewed. The mean age of participant was 38 (SD 13) yrs. Males were 56%. Participants with middle and high education accounted for 42.5% and 36.5% respectively.

Participants were mostly married 75.5%. The professionals were 42%. Fifty six percent had a positive family history of serious diseases.

Disclosure of cancer diagnosis

Eighty-four percent (84%) preferred a diagnosis of cancer to be disclosed to them and 160 (80%) preferred a diagnosis of cancer to be disclosed to them first rather than to another family member. One hundred thirty one (66%) preferred the disease to be called by its name “cancer”. Seventy-seven percent (77%) preferred to receive all the information regarding their disease good or bad and 79% wanted to know the truth about the disease even if it was incurable. Eighty percent (80) preferred to be told how far a malignancy had spread (Table3).

Table 3: Responses to questions – values & percentage (%)

Disclosure of Cancer diagnosis		Number (%)
Prefer to know a diagnosis of cancer		167 (83.5%)
Prefer to know first		160 (80 %)
Prefer to be called cancer		131 (65.5 %)
Prefer to know the whole truth		157 (78.5 %)
Prefer to receive all the information “good or bad”		154 (77 %)
Prefer to know about metastases		159 (79 %)
Sharing management		Number (%)
Prefer to know about all treatment options		193 (96.5 %)
Prefer to share the treatment decisions		176 (88 %)
Prefer to be told cure rate is high only if true		161 (80.5 %)
Prefer to be given a survival statistics		131 (65.5 %)
Prefer to know the truth even if cure not definite		173 (86.5 %)
Prefer to know about drugs side effect		187 (93.5%)
Rapport building with physician		Number (%)
with similar illness who were cured	Prefer to know about other patient,	195 (97.5%)
similar illness who have not been cured	Prefer to know about patients with	87(43.5 %)
Prefer my case to be studied by one doctor only		38 (19 %)
Prefer to seek a second opinion		192 (96 %)
Prefer to be reassured about receiving the best treatment		188 (94 %)
Prefer to share own feelings, fears, hopes with the doctor		163 (81.5 %)
or school issue	Prefer the doctor to discuss about work, family,	160 (80 %)

Sharing management

Ninety percent preferred to be told about all of the options for treatment and 88% preferred to share with their doctors the treatment decisions . Eighty one percent preferred to be told that the cure rate is high only if it was true and 87% preferred to know the truth about their illness even if their cure is possible, but not definite. Only 66% preferred that doctor must give a survival statistics. Ninety four percent of participants preferred to be told about the side effects of drugs used in cancer treatment.

Ninety eight percent of participants preferred to be told by their doctors about patients with similar illness who have been cured. However, 44% of participants preferred to be told by their doctor about patients with similar illness who have not been cured. Only 19% like their cases to be studied by one doctor only, and (96%) preferred a second opinion. Ninety-four percent preferred to be reassured by their doctors that they would be offered the best treatment . Eighty one percent preferred to share their feelings, fears and hopes with their doctors and 80%

preferred their doctors to discuss with them issues not related to their sickness, such as work, family or school.

DISCUSSION

Participants in this survey were selected from one health center in Bahrain, so results cannot be generalized to the whole Bahraini population. A dichotomy response with yes or no to each question were entered and analyzed

The majority of participants in the current study preferred disclosing the diagnosis of a serious illness and indicated that a cancer diagnosis should be disclosed to them first. The findings of this study conform with other studies, which showed that over 80% would like to be told the truth about their illness⁹. Preference for disclosure was also assessed in other Arab countries. A survey conducted in 1995 in a non-random sample in Lebanon indicated that 42% of respondents preferred truth not to be disclosed directly to patients⁶. In 1995 non-random survey in United Arab Emirates revealed that 40% did not favour disclosure of terminal diagnosis under any circumstances¹⁰. In both previous studies the preference for disclosure was associated with younger age, and better education, which could be the case in our study since the sample of the participants is mainly of young age with a mean age of 38 (SD13) years, and two-thirds of them possessed either high or middle education.

The preference to be informed declined as participants were faced with questions that suggest a negative prognosis. It may seem contradictory for patients to demand all medical information, while at the same time, to reject information suggesting a negative prognosis. This was not the case in all other studies. A survey conducted in 1982 indicated that 85% wanted to be given a realistic estimate of their time to live, even if this were less than 1 year¹¹. Attitudes toward disclosure can vary from one culture to another. In one study a greater percentage of Korean-born patients preferred to be given less information than did US-born patients¹². In our Islamic culture, people believe in optimism¹³.

In general, patients want physicians to adopt an attitude of openness and to act as supportive rather than acting as detached and independent clinicians. Although, the unfortunate reality is that many patients will not achieve complete recovery, physicians and patients might benefit from considering other aspects of hope, and this was the case in our observation to the questions related to sharing feelings, fears and hopes with their physician. Moreover, it could be noticed that participants preferred to be involved in treatment decisions and informed about side effects of cancer drugs. On the other hand, the majority preferred more than one doctor to study their case and thought that the physician should help them get a second opinion. This could be due to the serious nature of cancer and fear from it. Eighty-one point five percent of patients preferred to share feelings, fears, and hopes with the doctor. Finally as mentioned earlier because of the limitations in this study, it is difficult to say whether the results can be generalized. Therefore,

future studies directed toward identifying factors associated with public preference regarding disclosure of serious illness would be useful.

CONCLUSION AND RECOMMENDATIONS:

The major findings of this study are:

1. There is a high preference to disclose serious and terminal illness
2. There is a high tendency to rapport building with physician
3. Participants have high tendency to be shared in management plan.

Given the results of this study, it is reasonable to conclude that improvements can be made in the ways diagnostic disclosure is handled. It is apparent from our data that physician's attention to patients' psychological needs (including discussing fears, feelings, and impact on family and function) is greatly valued by participants, and should be highly considered by the physician in handling patient with serious illness.

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