

Attitudes of the Lebanese public regarding disclosure of serious illness

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Abstract

Objectives—*To measure the preference regarding disclosure of a serious diagnosis, and its determinants, of the Lebanese public.*

Design and setting—*Non-random sample survey of 400 persons interviewed in health care facilities in Beirut in 1995.*

Results—*Forty-two per cent of respondents generally preferred truth not to be disclosed directly to patients. Preference for disclosure was associated with younger age, better education and tendency to rapport-building with physicians. There were no meaningful associations between place of residence (urban/rural), level of religious practice, or religious affiliation, and preference for disclosure.*

Conclusions—*Under one plausible interpretation, this survey suggests that the expectation for concealment will decrease as the advantage of knowledge in better coping with disease is understood by an increasingly better educated public, and that the Lebanese public will increasingly come to expect direct and full disclosure of serious diagnoses.*

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Keywords: Ethics; disclosure; survey; attitudes; Lebanon; Middle-East

Introduction

In Lebanon, physicians often withhold information on the true nature of a patient's diagnosis and prognosis, or give her false hopes about the illness when it is serious or terminal. A recent survey of a sample of 212 physicians in the capital, Beirut, showed that 53% would usually avoid disclosure of cancer diagnosis directly to patients. Remarkably, 59% of the entire group surveyed, including both those who usually do and do not disclose the diagnosis, agreed that they would change their policy should the public's expectations change.¹ This finding indicated that the common perception of what the Lebanese patient really expects from her physician, though vague, nevertheless profoundly determines the physician's choice to disclose or withhold the truth. The extent of the preference not to be told of a serious diagnosis in the Lebanese public has so far

never been formally assessed. This survey of preferences among outpatients and visitors at the American University of Beirut Medical Center (AUBMC) represents the first attempt to discover such attitudes.

Background

The Republic of Lebanon is a parliamentary pluralistic democracy located on the eastern shores of the Mediterranean. This small country (10,452 km² or 4,035 sq m) is bordered by Syria to the north and east and by Israel to the south. The Lebanese population is relatively young: 60.5% are under the age of 30.² Almost two-thirds of Lebanese are Muslims, and the rest mostly Christians. The majority (60%-70%) of the Lebanese population, estimated at 3.5 million, lives in the "Greater Beirut" area in and around Beirut, the centre of the economic and cultural life of the country. The official language in the country is Arabic. While the sociological structure is still largely traditional and patriarchal, there are marked differences between rural and urban areas, and between more or less educated Lebanese. All secondary-schooled Lebanese (60% of the population by some estimates) are fluent in either French and/or English, and are fairly exposed to non-traditional ideas and lifestyles. There are no restrictions on the amount of contacts that the Lebanese population can make (and the information they can obtain) either by travelling abroad or by interacting with foreign visitors at home. The Lebanese medical services are among the most sophisticated and up-to-date in the Arab-speaking countries of the eastern Mediterranean area. All major tertiary care centres in Lebanon are currently located within the Greater Beirut area. The American University of Beirut Medical Center, the health facility where this survey was conducted, was established in the early part of the 20th century. It is the largest tertiary health care centre in Lebanon, and it receives patients from all parts of the country.

The current Lebanese Code of Medical Ethics, enacted in 1995, does not mandate that physicians

should inform patients of their diagnosis if such a disclosure is deemed by the doctor to be "deleterious to the patient's recovery". On the other hand, the law clearly states that patients have the right to know all their options regarding treatment, and to refuse any or all of those options.³ The apparent discrepancy between these two statements has left most Lebanese doctors uncertain as to the "right" approach to doctor-patient communication in cases of serious or terminal disease. Consequently, a majority usually opts for what is thought to be the culturally acceptable norm: that is withholding disclosure from the patient and disclosing instead to close family members.¹ Problems arise, however, when mutilating therapies are proposed: how can a blinded patient exert her freedom of choice if she ignores the seriousness of her diagnosis? And how are the patient's prospects affected when a shattering reality is finally disclosed almost *in extremis*? These are some of the dilemmas which prompted the debate on disclosure, and finally won the day for it, in many "Western" societies.⁴ This paper aims to start the same kind of debate in Lebanon, and by extension in areas with similar cultural features and sociological structures. In this debate, the evolving opinions and expectations of the public must be taken into account. By revealing those expectations, we aim to help physicians adopt those practices most in tune with patients' freedom of choice as well as hope for recovery.

Methods

SELECTION OF PARTICIPANTS

Three groups of individuals were interviewed for the purposes of this survey on five consecutive weekdays in July 1995. These groups were:

- 1) The first 100 previously diagnosed cancer outpatients (COP) attending a specialised cancer clinic at AUBMC.
- 2) The first 100 outpatients (OP) attending all other clinics for any health-related problem during the same period.
- 3) The first 300 "healthy" visitors who could be located in waiting areas during the same period.

Some respondents who had mistakenly identified themselves as outpatients were subsequently re-classified as "healthy" visitors upon review of their responses. Two incomplete interviews were later discarded.

INFORMED CONSENT

The survey proposal was reviewed and approved by the Human Subject Board of the AUB Faculty

of Medicine prior to implementation. The aim of the interview was clearly stated to all potential participants who were totally free to opt out of the study at any moment. Only a handful of persons approached actually preferred not to participate.

INTERVIEW PROCEDURES AND TOOLS

Face-to-face interviews were conducted by medical interns and junior nurses. Special care was taken to avoid other people overhearing the interview. Whenever possible, the process was conducted in an empty room or cubicle. A slightly modified version of a questionnaire developed by Sardell and Trierweiler in 1993⁵ was used for this study. It consists of items covering the following large categories:

- 1) Socio-cultural and demographic variables, health status, and current health complaint.
- 2) A series of statements with a Likert visual scale, eliciting participants' attitudes, beliefs and expectations regarding disclosure of serious or terminal diagnosis.

STATISTICAL METHODS

Factor analysis was used to create two indices out of the list of attitude statements. The first index, "preference to sickness disclosure", was used as an outcome variable and included five questions. The second one, "tendency to building rapport with physician" (rapport-building), included two questions. To be included in an index, variables had to load in factor analysis with a principal component $\geq \pm 0.60$. Statements included in the indices are presented in the appendix. Some other statements failed to show any variability and were ultimately "pruned" to simplify the analysis. Frequencies of the outcome and various independent variables were computed. The association of seven independent variables with the outcome was assessed separately, controlling for sex and age. These variables were: health status (three categories), occupation (four categories), education (two levels), area of residence (Greater Beirut, urban province, rural province), religious denomination (Muslim or not), intensity of religious practice (three levels), and rapport-building (two levels). Associations were presented as odds-ratios (OR) with corresponding 95% confidence intervals (95% CI). The OR here represents the odds of higher preference for disclosure in a given category compared to the same in a reference category. Results are significant when the 95% CI does not include the unity. All data were entered and analyzed using the Statistical Package for Social Sciences (SPSS) on Windows.

Table 1 Preference for disclosure of serious sickness in the Lebanese public by demographic variables

	Lower	Higher	Total	p-value*
n (%)	207 (41.6)	291 (56.8)	498 (100)	
Sex (n, %)				
Males	73 (35.3)	138 (47.4)	211 (42.4)	<0.01
Females	134 (64.7)	153 (52.6)	287 (57.6)	
Age (mean years, SD)	41.2 (14.1)	33.5 (13.0)	36.7 (14.0)	<0.01

*Using the X-square test for "sex" and the Student t-test for "age"

Results

A total of 498 persons were interviewed: 88 cancer outpatients (17.7%), 99 non-cancer patients (19.9%) and 311 "healthy" persons visiting or accompanying patients (62.4%). The mean age of participants was 37 ± 14 years. Males were 42% of the group and females 58%. Participants were mostly Muslim (62%) residents of Greater Beirut (68%), and with a secondary education or more (60%). Most of them (63%) indicated strong levels of religious practice. Lower tendency to rapport-building with the physician was found in 59.2% of respondents, while lower preference for disclosure of cancer diagnosis was found in 41.6%. Overall about 42% of the total 498 respondents indicated a preference for non-disclosure of serious or terminal diagnosis.

As shown in table 1, male respondents were significantly more likely to have a higher preference for disclosure than females. There were also significant age differences between those with higher preference for disclosure (average age 33.5

years) and those with lower preference (average age 41.2 years). Further analysis, however, showed that the sex differential in disclosure preference was not significant in those aged 37 years (total average age for the group) or less. Age was significantly correlated with other dependent variables. Younger respondents were also better educated, less religious, and more likely to build a rapport with their physicians. In view of its significant effect on the outcome, age was used as a control variable in the subsequent analysis.

As presented in table 2, higher preference for disclosure was significantly lower among those with only primary or with no education compared to those with secondary education and more (OR = 0.60). No significant differences in disclosure preference were found by occupation, except when comparing housewives to those in professional or managerial jobs. The latter were significantly more likely to prefer disclosure than the former (OR = 0.40). There were no significant differences in preference associated with either usual place of residence or level of religious practice. Non-Muslims, a heterogeneous group which included Christians (24% of all participants), Druze (2%) and those with unstated religious affiliation (11%), had significantly higher preference for disclosure than the 63% self-declared Muslims (OR = 1.52). However, that finding was heavily confounded by education. Almost half of the "Muslim" category (49.7%) in the sample

Table 2 Determinants of preference for disclosure of serious sickness in the Lebanese public

	Lower preference	Higher preference	Total	OR (95% CI)#
n (%)	207 (41.6)	291 (56.8)	498 (100)	—
Education				
None/Primary	121 (58.5)	76 (26.1)	197 (39.6)	0.60 (0.48; 0.74)
Secondary or more	86 (41.5)	215 (73.9)	301 (60.4)	reference
Occupation				
Unemployed/retired/student	26 (12.6)	73 (25.1)	99 (19.9)	1.26 (0.82; 1.92)
Housewife	112 (54.1)	73 (25.1)	185 (37.1)	0.40 (0.17; 0.94)
Manual jobs	30 (14.5)	34 (11.7)	64 (12.9)	0.95 (0.60; 1.50)
Professional/managerial jobs	39 (18.8)	111 (38.1)	150 (30.1)	reference
Residence				
Greater Beirut	128 (61.8)	209 (71.8)	337 (67.7)	reference
Urban province	32 (15.5)	37 (12.7)	69 (13.9)	0.84 (0.58; 1.22)
Rural province	47 (22.7)	45 (15.5)	92 (18.5)	0.86 (0.61; 1.21)
Religious affiliation				
Muslim	152 (73.4)	160 (55.0)	312 (62.7)	reference
Non-Muslim	55 (26.6)	131 (45.0)	186 (37.3)	1.52 (1.24; 1.86)
Religious practice				
Low	11 (5.3)	30 (10.3)	41 (8.2)	1.19 (0.72; 2.12)
Medium	40 (19.3)	105 (36.1)	145 (29.1)	1.31 (0.92; 1.86)
High	156 (75.4)	156 (53.6)	312 (62.7)	reference
Health status				
Cancer out-patients	27 (13.0)	61 (21.0)	88 (17.7)	1.51 (1.05; 2.16)
Non-cancer out-patients	50 (24.2)	49 (16.8)	99 (19.9)	0.98 (0.69; 1.40)
Healthy individuals	130 (62.8)	181 (62.2)	311 (62.4)	reference
Rapport-building				
Lower	153 (73.9)	142 (48.8)	295 (59.2)	0.63 (0.51; 0.77)
Higher	54 (26.1)	149 (51.2)	203 (40.8)	reference

#Age-adjusted.

described themselves as having had a primary education or less, while only 22.6% reported the same in the catchall "non-Muslim" category ($p < 0.01$). The same differential in education remained after a more conservative comparison was conducted using only self-described Muslims and Christians.

Cancer outpatients were significantly more likely to prefer disclosure compared to healthy participants (OR = 1.51). In contrast, non-cancer outpatients did not differ in preference from the healthy group. Those with a higher rapport-building tendency were also significantly more likely to have higher preference for disclosure than those with lower rapport-building tendency.

Discussion

Participants in this survey represent the Lebanese population in many aspects, such as the relatively young average age, the predominance of residence within Greater Beirut, and the Muslim affiliation of the majority. However, participants may be more heavily drawn from lower socio-economic groups, as more affluent or better educated patients may consult physicians outside the frame of the less expensive AUB outpatient clinics. This potential bias may have resulted in an underestimation of the higher preference for disclosure of serious or terminal diagnosis. Nevertheless, and despite this effect, it was still found that more than half those interviewed indicated a somewhat high preference to be told the truth about the diagnosis, extension and prognosis of serious or terminal disease.

Preference for disclosure was associated with health status: cancer patients were more likely to prefer disclosure compared to all others. However, this finding may be biased by those patients' previous knowledge of their diagnosis, which may have already helped them perform the mental adjustment needed to cope with further adverse events. The preference for disclosure was significantly associated with younger age regardless of sex. Older women, especially self-described housewives, were less likely to prefer disclosure than older men. Better educated and rapport-building participants were generally more likely to prefer disclosure than otherwise. These characteristics were associated with the outcome even after controlling for age. There were no associations between place of residence, level of religious practice, or religious affiliation and preferences for disclosure, once education was taken into account.

Overall, this analysis showed that 42% of Lebanese respondents generally preferred truth about serious and terminal illness not to be disclosed to

patients. Preference for disclosure was also assessed in recent years in other Arab countries. A survey conducted in 1995 in a non-random sample in the United Arab Emirates (UAE) indicated that about 40% did not favour disclosure of terminal diagnosis under any circumstances. That proportion decreased only slightly when the respondent was the patient in question. Younger, better educated respondents were significantly more inclined to prefer disclosure than older ones.⁶ A 1985 non-random survey of healthy Saudis revealed that 31% preferred a cancer diagnosis not to be disclosed directly to the patient. There too, the preference for disclosure was associated with younger age, and with family history of cancer.⁷ In Greece, a country sharing eastern Mediterranean heritage with Lebanon, a 1992 survey of healthy subjects revealed that about 35% of respondents thought that patients with terminal illness should not be told the truth. As in Lebanon, UAE and Saudi Arabia, this preference was associated with older age. Also, as with Lebanon, higher preference for truth was associated with professional status but not with religious practice.⁸ In none of the studies reviewed did gender emerge as a factor significantly associated with disclosure preference.

Preference for concealment is thought to be the prevalent attitude in traditional cultures where "paternalistic/beneficent" attitudes of physicians predominate over the respect for the "autonomy" rights of patients.⁸⁻¹⁰ However, surveys from Lebanon and other countries with overlapping cultural characters indicate that opinions on the issue are actually very widely distributed. Moreover, higher preference for truth is consistently associated with younger age, better education and better professional achievement. Under one plausible interpretation, these findings indicate that denying information "is more a historical than a cultural phenomenon".¹⁰ With such an interpretation, the expectation for concealment can be expected to decrease as the effectiveness of medicine is demonstrated, and the advantage of knowledge in better coping with and resisting disease is understood, by an increasingly better educated public. Physicians who are currently faced with the dilemma of disclosing a serious diagnosis to patients in Lebanon and countries with similar cultures might still feel the need to tailor their decision according to the socio-demographic profiles of patients. Great care should still be taken to respect the openly declared or implicit preference of patients who do not want to be told the truth. This used to be the case in "Western" cultures about 20 years ago.¹¹ But the dynamics which eventually rendered truth-telling a moral absolute

in those cultures are also active in Lebanon. Given the above interpretation, it is very likely that the expectation of full disclosure in the Lebanese public, and its full implementation by Lebanese physicians, will soon reach "Western" levels. Monitoring of changes must be conducted within the coming few years to ascertain the accuracy of these predictions.

Appendix

QUESTIONS INCLUDED IN PREFERENCE INDICES

PREFERENCE TO KNOW THE TRUTH INDEX (OUTCOME INDEX)

- 1) I want to know the truth about my disease even if it is incurable. ($\alpha = 0.61$)
- 2) I prefer a diagnosis of cancer to be disclosed to me first. ($\alpha = 0.67$)
- 3) I prefer to be told how far a malignancy has spread in my body. ($\alpha = 0.60$)
- 4) I prefer to receive all information regarding my disease, good or bad. ($\alpha = 0.77$)
- 5) The doctor must call a disease by its name, even if it is cancer. ($\alpha = 0.77$)

RAPPORT-BUILDING WITH THE PHYSICIAN

- 1) I prefer to share my feelings, fears and hopes with my doctor. ($\alpha = 0.70$)
- 2) I like it when my doctor discusses with me issues not related to my sickness, such as work, family or school issues. ($\alpha = 0.71$)

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