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Information disclosure and decision-making: the Middle East versus the Far East and the West

A F Mobeireek,¹ F Al-Kassimi,² K Al-Zahrani,³ A Al-Shimemeri,⁴ S al-Damegh,⁵ O Al-Amoudi,⁶ S Al-Eithan,⁷ B Al-Ghamdi,⁸ M Gamal-Eldin⁹

¹ Department of Medicine, Consultant, King Faisal Specialist Hospital and Research Center, Professor, King Saud University, Riyadh, Saudi Arabia;

² Department of Medicine, College of Medicine, King Saud University, Riyadh, Saudi Arabia;

³ Taiba University, Al-Madinah, Saudi Arabia;

⁴ King Abdulaziz Medical City, Riyadh, Saudi Arabia;

⁵ King Saud University, Qaseem, Saudi Arabia;

⁶ King Abdulaziz University, Jeddah, Saudi Arabia;

⁷ Dammam Central Hospital, Dammam, Saudi Arabia;

⁸ King Khalid University, Abha, Saudi Arabia;

⁹ King Faisal Specialist Hospital and Research Center, Department of Biostatistics, King Saud University, Riyadh, Saudi Arabia

Correspondence to:
A Mobeireek, FRCP, PO Box 3354, MBC 46, Riyadh 11211, Saudi Arabia; mobeireek@yahoo.com

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ABSTRACT

Objectives: to assess physicians' and patients' views in Saudi Arabia (KSA) towards involving the patient versus the family in the process of diagnosis disclosure and decision-making, and to compare them with views from the USA and Japan.

Design: A self-completion questionnaire (used previously to study these issues in Japan and the USA) was translated to Arabic and validated.

Participants: Physicians (n = 321) from different specialties and ranks and patients (n = 264) in a hospital or attending outpatient clinics from 6 different regions in KSA.

Results: In the case of a patient with incurable cancer, 67% of doctors and 51% of patients indicated that they would inform the patient in preference to the family of the diagnosis (p = 0.001). Assuming the family already knew, 56% of doctors and 49% of patients would tell the patient even if family objected (p NS). However, in the case of HIV infection, 59% of physicians and 81% of patients would inform the family about HIV status without the patient's consent (p = 0.001). With regards to withholding ventilatory support, about 50% of doctors and over 60% of patients supported the use of mechanical ventilation in a patient with advanced cancer, regardless of the wishes of the patient or the family. Finally, the majority of doctors and patients (>85%) were against assisted suicide.

Conclusions: Although there was more recognition for a patient's autonomy amongst physicians, most patients preferred a family centred model of care. Views towards information disclosure were midway between those of the USA and Japan. Distinctively, however, decisions regarding life prolonging therapy and assisted suicide were not influenced to a great extent by wishes of the patient or family, but more likely by religious beliefs.

Full disclosure of diagnosis and respect for the patient's autonomy is considered to be the norm in Western countries.^{1,2} However, this "patient autonomy model" is not practiced by some ethnic groups in the USA or European countries where a "family oriented model" is still prevalent.^{3,4} Moreover, some Asian authors have advocated a "guided medical paternalism" approach as most suitable for the "Asian-ness" of the society; they also considered a liberal approach to patients to be harmful.^{5,6} Lastly, Western societies are largely secular, while many Asian countries still base values and regulation on religion. Religious belief was found to influence the doctors' attitudes in a manner that limits the patient's autonomy, especially in issues such as the right to practice doctor-assisted suicide or euthanasia.⁷⁻¹⁰

Saudi Arabia, being traditionalist, Asian, and religious, stands out as a country worthy of study. Oil wealth has transformed the society from a previously simple, nomadic life with little medical care to a modern lifestyle with state-of-the-art medical technology. There is also more awareness about health matters and higher public expectations from the health system and professionals, particularly physicians. Indeed, the country has witnessed rising medical litigation and complaints against physicians, in which poor communication was a major factor.¹¹ A previous survey limited to physicians had found defects with regards to disclosure of information to the patient in preference to relatives.¹² We therefore decided to conduct a large survey in several locations, which included both patients and physicians in academic and non-academic settings. Our aim was to study attitudes regarding information sharing and decision-making with patients, as well as use of life prolonging therapy and assisted suicide that are being actively debated amongst the public and in the medical community.¹³⁻¹⁷ To our knowledge, this is the first kind of survey addressing these issues in an Islamic country.

METHODS

Six cities were selected for the survey (Riyadh, Jeddah, Khobar, Abha, Dammam and Buraidah), as they represented the main geographic regions in Saudi Arabia as well as academic teaching, in addition to Ministry of Health hospitals. This ensured representation for each of the two sectors. All doctors in the medical departments were included. Also, patients were randomly selected from the medical wards and clinics in these hospitals.

A questionnaire, previously developed collaboratively to compare the attitudes of US and Japanese physicians and patients, was used as the study instrument.¹⁸ It was specifically chosen to allow comparison with countries with different cultures. It contains four clinical situations covering the following areas: (1) a patient's right to be informed of incurable cancer, (2) permission to perform and disclose HIV tests, (3) the conflicting rights of patients, doctors, and the family in refusing ventilatory support, and (4) doctor-assisted suicide. The 4-point Likert Scale was used to mark the responses to the statements (strongly agree, agree, disagree, and strongly disagree). The order of the responses was changed randomly. The questionnaire was translated to Arabic, translated back to English, and validated on a group of doctors and patients before distribution.

Clinical ethics

Characteristics of the patients were summarised as mean and standard deviation for the age and as frequencies and percentages for all categorical variables. For individual items, chi square tests were used to compare physician and patient groups in Saudi Arabia with those obtained in the USA and Japan.¹⁸ For these comparisons, the 4-point Likert Scale was dichotomised into simply “agreed” or “disagreed”. A *p* value <0.05 was considered significant. Data were analysed using SPSS V.10.

RESULTS

A total of 321 doctors were included; the majority were Saudis (60.3%), males (87.5%) and Muslims (85%). Consultants and fellows accounted for 29.8%, specialists 24.1%, residents 30.7%, and 9.4% held other positions. The patients included numbered 264, of whom 85.7% were Saudis, 75% males and 97% Muslims. The level of education varied from a doctoral holder (2.6%) to illiterate (9%) (table 1).

The results are given as a comparison between our findings in Saudi Arabia and previous findings in the USA (Western

patient-oriented model) and Japan (Asian family-oriented model).¹⁸

Table 2 gives the findings regarding the patient's right to be informed of incurable cancer. While the majority of USA (80%) and Saudi Arabia (67%) doctors gave the patient the authority to decide whether the family should be informed, only 17% of Japanese doctors agreed. Similarly, only 8% of Japanese doctors thought that the family couldn't overrule the patient's right to be informed, versus 79% and 56% in the USA and Saudi Arabia, respectively. Patients in KSA were more supportive of informing the family than doctors (*p* = 0.001). When the family is already aware of the diagnosis and does not wish to inform the patient, 56% of doctors and 49% of patients would still inform the patient (*p* NS).

Table 3 gives attitudes towards HIV infection. When it came to informing the family of a positive test against the patient's advice, Saudi Arabia and Japan favoured telling the family. Compared with doctors, the patients in Saudi Arabia even more overwhelmingly gave the family the right to know about a positive test (*p* = 0.001).

Table 4 shows the results regarding ventilation support in the case of incurable illness with short life expectancy. Significantly more patients than doctors supported the use of supportive mechanical ventilation in all scenarios (*p* ≤ 0.002). Also, participants in KSA advocated its use more than in the USA and Japan, except if the family requested it in the latter. Whereas the Japanese doctors were significantly influenced by the family, the wishes of the patient, the family or the treating physician had minor effects on the responses of participants in KSA. Only when both the family and the treating doctor objected did fewer physicians recommend ventilation. When the patient was incompetent, the wishes of the doctors followed by those of the family were paramount.

Table 5 shows the results for doctor-assisted suicide. Only a minority of doctors or patients in Saudi Arabia accepted the practice even when the doctor knew the patient well for 20 years. There was no significant difference between doctors and patients (*p* > 0.05). This was unlike the USA and Japan, where more doctors and the majority of patients supported assisted suicide.

DISCUSSION

In this study, 67% of doctors and 51% of patients in KSA thought the patient should be told about a diagnosis of incurable illness in preference to telling the family. Also, about half of both groups thought it was inappropriate for the family to deny the patients full disclosure. These figures are generally midway between those expressed by the USA and Japanese groups.¹⁸ However, in the clinical setting of an HIV positive patient, the family's right to be informed against the patient's wishes is upheld by 59% and 81% of doctors and patients in KSA, respectively. AIDS generates fear worldwide, and in a religious and conservative society such as that in KSA, the condition is still viewed as a moral stigma and grave matter that warrant early family involvement. Participants in the study did not seem to be concerned that this may lead to ill treatment of the patient. Interestingly, our study showed that physicians were more in favour of patient autonomy, while patients leaned more towards family involvement. This disparity can be a source of conflict between physicians and patients or their families.

Most Western countries have moved towards a “patient autonomy model” in which full disclosure and respect for the patient's wishes and decisions is paramount.^{1 2 14} Such a liberal

Table 1 Characteristics of Physician and Patient survey respondents from Saudi Arabia

Characteristic	Physician	Patients
Age (years)	36.2+9.2 (20–65)	36.1+13.2 (13–71)
Gender		
Male	281 (87.5)	198 (75)
Female	40 (12.5)	66 (25)
Nationality		
Saudi	188 (60.3)	216 (85.7)
Non Saudi	124 (39.7)	36 (14.3)
Religion		
Muslim	273 (85)	256 (97)
Others	48 (15)	8 (3)
Specialty		
Internal medicine	130 (40.8)	
Surgery	69 (21.6)	
Pediatrics	22 (6.9)	
Obstetrics and gynecology	11 (3.4)	
Dermatology	9 (2.8)	
Psychiatry	12 (3.8)	
Others	66 (20.7)	
Level		
Cons/Fellow /PhD	95 (29.8)	
Specialist/Diploma	77 (24.1)	
Resident	117 (36.7)	
Others	30 (9.4)	
Occupation		
Employee		133 (49.6)
Student		54 (20.1)
Business		14 (5.6)
Housewife		35 (13.1)
Others		17 (6.3)
Education		
PhD		7 (2.6)
Degree holder		115 (43.4)
Secondary high school		68 (25.5)
Intermediate Education		29 (10.9)
Elementary Education		23 (8.6)
Illiterate		24 (9)
Area		
City		207 (77.2)
Town		61 (22.8)

Table 2 Clinical scenario 1: a patient has incurable advanced-stage cancer

Clinical situation	Agreement (%)			p Values (only given when significant)			
	USA	JAPAN	KSA	USA vs KSA doctors	USA vs KSA patients	Japan vs KSA doctors	Japan vs KSA patients
	Doctor/Patient	Doctor/Patient	Doctor/Patient				
a. The doctor should tell the patient, and also let the patient decide whether or not their family should be told.	80/81	17/42	67/51	0.018	0.001	<0.001	NS
b. The doctor should tell the patient's family, and also let them decide whether or not the patient should be told.	6/22	80/65	48/65	<0.001	<0.001	<0.001	NS
c. Assume the family has been told and they do not want the patient to be told; the doctor should tell the patient anyway.	79/72	8/24	56/49	0.001	0.001	<0.001	0.001

KSA, Saudi Arabia.

model, however, is not prevalent in certain ethnic groups like Koreans or Mexicans.^{3 4 19} Partial or non-disclosure of serious diagnoses is still present in Italy, a nation centred on family values.²⁰ A survey in Singapore found, that many doctors still believe that a number of their patients are incapable of rational thinking, which justifies not telling patients the whole truth.⁶ Such a paternalistic approach was attributed to the residual "Asian-ness" of doctors in Singapore. An academic review in Singapore in 2002 considered "guided medical paternalism" to be best, as it "promotes happiness".⁵ In Hong Kong, the liberal model of decision-making was criticised for exposing the patient to "abuse and neglect"; a family model was considered best in the context of terminal illness.²¹ Culture and not race may be the basis for the "Asian model"; another study in Singapore found that non-English speaking patients were more likely than English speakers to be denied autonomy and full disclosure of the diagnosis.²² "The Jewish view" in the USA is that full disclosure of a fatal illness is a negative approach, as it may make the patient give up hope, suffer mental anguish (*tiruf hadaat*), become despondent, and die sooner than otherwise.²³ Our findings suggest that, even in traditionalist Asian countries like KSA, many participants, particularly physicians, are advocating a Western model of disclosure and patient autonomy.

Thus, different societies have developed different models for communication, reflecting the unique socio-cultural, legal, educational, and economical circumstances. In our view, this does not indicate that the basic ethical principles are not universal. In the Saudi culture, for example, these principles are not at odds with those of the West.¹² We believe that the difference lies in the priority and weight given to each of those principles, like patient rights, wishes of the family, and interests of the society as a whole. Even within the same culture, one

rigid model may not suit all patients and relatives, and a great degree of flexibility and skill need to be exercised by the practicing physician. Effective physician-patient communication is far more complex than simply giving information. Many authors in the field of Medical Ethics have formulated new concepts when it comes to dealing with those principles.²⁴ The "physician-centred" model is replaced with "patient-centred physician-patient relationship". The term "patient rights" would be replaced with a "mutual participation" type of relationship between the patient/physician/relatives.²⁵ Through listening and active participation, the patient and his relatives would be instructed in a manner to improve their level of responsibility towards their problems, and to help the patient perceive the concept of autonomy.

Withholding of life prolonging treatment and assisted suicide in the context of a terminal illness remain topics of considerable controversy, even within the same culture.¹³⁻¹⁷ Not surprisingly, remarkable differences were again observed between KSA and the American and Japanese groups. The great majority of Americans were against the use of such therapy, even with the family or treating physician's request, which was in contrast to the Japanese doctors, who would honour the family's wishes.¹⁸ In our study, many participants (particularly patients) supported use of mechanical ventilation against the wishes of the patient, family or treating doctor. Along the same line, only a minority of doctors or patients in KSA approved of doctor-assisted suicide, regardless of whether the family supported it or the doctor had known the patient well for years. We believe this represents the effect of the intense religious beliefs of the Saudi society, many valuing "sanctity of life".²⁶ It has to be pointed out, however, that although euthanasia and assisted suicide are prohibited in Islam, the use of life prolonging therapy in

Table 3 Clinical scenario of disclosure of diagnosis of HIV infection

Clinical situation	Agreement (%)			p Values (only given when significant)			
	USA	JAPAN	KSA	USA vs KSA doctors	USA vs KSA patients	Japan vs KSA doctors	Japan vs KSA patients
	Doctor/Patient	Doctor/Patient	Doctor/Patient				
The doctor has performed HIV test of a female patient and she was to be infected with the AIDS virus; assume the doctor has good reason to believe that the patient's family is interested in finding out about her infection and that they may be able to help her deal with the problem; the patient is not married. Assume the patient has been told she is infected with the AIDS virus. The doctor should also tell the family, even if the patient does not want them to be told.	14/37	55/73	59/81	<0.001	<0.001	NS	NS

KSA, Saudi Arabia.

Clinical ethics

Table 4 Clinical scenario 4: a patient has a severe, incurable disease and is expected to live no more than 6 weeks. His condition suddenly worsens, and he will die almost immediately if he is not connected to a breathing machine (ventilator). If he is placed on the breathing machine, he will live his last few weeks on the machine in an ICU. The patient is fully aware and is informed of his condition. The doctor has spoken with the patient about his recommendation regarding the breathing machine as well as the reasons for his recommendation.

Clinical situation	Agreement (%)			p Values (only given when significant)			
	USA	JAPAN	KSA	USA vs KSA doctors	USA vs KSA patients	Japan vs KSA doctors	Japan vs KSA patients
	Doctor/Patient	Doctor/Patient	Doctor/Patient				
Patient is fully competent and is aware of his condition							
a. The patient and his doctor both agree that he should be allowed to die immediately, but his family wants him placed on the breathing machine. He should therefore be placed on the breathing machine	1/15	50/63	43/58	<0.001	<0.001	NS	NS
b. The patient wants to be allowed to die immediately, but his doctor and family both want him placed on the machine. He should not be placed on the breathing machine even though he will die sooner.	86/81	44/45	56/34	<0.001	0.004	NS	NS
c. The patient, his family, and his doctor all want him to be allowed to die immediately. However, he should be placed on the breathing machine anyway.	1/2	22/34	35/59	<0.001	0.001	0.001	0.001
d. The doctor wants him placed on the breathing machine, but the patient and his family both want him to be allowed to die immediately. Therefore, he should not be placed on the breathing machine, even though he will die sooner.	95/85	69/62	48/30	<0.001	<0.001	<0.001	<0.001
Patient is mentally incapacitated							
a. The doctor wants the patient placed on the breathing machine, but the patient's family wants him to be allowed to die immediately. He should be placed on the breathing machine.	18/39	35/54	53/80	<0.001	<0.001	<0.001	0.001
b. The patient has an advance directive stating his desire to be allowed to die in such a situation. The doctor and the patient's family both want him placed on the breathing machine. However, he should not be placed on the breathing machine, even though he will die sooner.	92/83	55/57	57/37	<0.001	<0.001	NS	0.006
c. The patient's family wants him placed on the machine, but the doctor wants him to be allowed to die immediately. He should not be placed on the breathing machine even though he will die sooner.	87/73	35/62	66/53	<0.001	<0.003	<0.001	NS
KSA, Saudi Arabia.							

Table 5 Clinical scenario of assisted suicide

Clinical situation	Agreement (%)			p Values (only given when significant)			
	USA	JAPAN	KSA	USA vs KSA doctors	USA vs KSA patients	Japan vs KSA doctors	Japan vs KSA patients
	Doctor/Patient	Doctor/Patient	Doctor/Patient				
A patient is terminally ill with irreversible stomach cancer and will die within 6 weeks; she is in severe pain, which is not expected to go away; the patient tells the doctor that she wants a large number of pain-relief pills to end her suffering sooner by overdosing and killing herself. The doctor has seen the patient once.							
a. He should provide this large number of pills	5/23	8/49	7/11	NS	0.046	NS	<0.001
b. Assume the doctor has talked to the patient's family; if the family agrees that the patient should have the large number of pills she wants, the doctor should provide them.	27/45	22/72	4/8	<0.001	<0.001	<0.001	<0.001
c. Assume the doctor has talked to the patient's family; if the family does not want the patient to have the large number of pills she wants, the doctor should still provide them.	13/33	8/40	7/12	NS	0.002	NS	<0.001
The doctor has known the patient very well for 20 years							
a. He should provide this large number of pills.	39/57	25/68	10/17	<0.001	<0.001	<0.001	<0.001
b. Assume the doctor has talked to the patient's family; if the family agrees that patient should have the large number of pills she wants, the doctor should provide them'	48/71	35/83	5/8	<0.001	<0.001	<0.001	<0.001
c. Assume the doctor has talked to the patient's family; if the family does not want the patient to have the large number of pills she wants, the doctor should still provide them.	30/56	14/50	8/17	<0.001	<0.001	NS	<0.001
KSA, Saudi Arabia.							

incurable conditions is left to the discretion of physicians.^{27 28} The reasons why the participants in our survey did not appear to appreciate the distinction between these two scenarios are not clear and warrant further study. Religion was found to be the most consistent factor in shaping the doctors' attitudes towards doctor-assisted suicide.⁷⁻⁹ Sanctity of life and the belief that no one has the right to take one's own life are common to all religions, Islam included. In Europe and the USA, religiousness was more important than a doctor's age, gender, specialty, and type of practice.^{7-9 29 30} In Israel, physicians who described themselves as very religious were much less likely to approve of withdrawing life-sustaining treatment (11% vs 51%) or agree with euthanasia (5% vs 70%) when compared with secular doctors.¹⁰ The ethical debate regarding these issues internationally is ongoing, with no consensus yet on legal resolutions.¹⁵⁻¹⁷ It is quite unlikely, however, that assisted suicide will be implemented in KSA in the foreseeable future, where many are still advocating life prolonging therapy even in futile situations.

In conclusion, while there is more recognition for a patient's autonomy amongst physicians in Saudi Arabia, most patients still favour a family centred model of care. Responses were midway between those from the USA, where participants strongly favoured a patient centred model, and Japan, where a family centred model was preferred. Decisions regarding life prolonging therapy and assisted suicide were not influenced to a great extent by the wishes of the patient or family, but more likely by religious beliefs. Further studies are needed to examine the clinical practice to verify the findings of this study.

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