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## **Informing Terminally ill Patients in Yemen** Kangas, B.

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Middle East

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**Biomedicine's ability to postpone death and prolong life generates ethical dilemmas that are best answered in their cultural context. Medical anthropological fieldwork conducted in Yemen<sup>1</sup> has allowed for an exploration of doctors' and religious scholars' responses to the interesting cross-cultural issue of whether to inform patients of their terminal conditions. This research is part of a larger study on Yemeni patients and family members who leave their country for reliable, high-tech medical care only available abroad.**

For Yemen, international medical travel is not limited to the wealthy and well connected. Nonetheless, economic disparity does exist in terms of the ease with which certain patients and companions can travel, the medical conditions for which they seek treatment, and their therapeutic destinations. While families with abundant resources are said to bypass local facilities for even basic check-ups and minor complaints, those with few resources often make large sacrifices to provide a lifesaving cure for a seriously ailing loved one. Bombay and sanctioned Iraq offer the least expensive care. Jordan and Egypt are more expensive but also more popular. Germany provides excellent care but at a high price. Britain and particularly the United States are desired destinations, but are accessible only to high-level government officials or wealthy businessmen.

#### Disclosure

Doctors in four governmental hospitals in Yemen's capital said they generally do not inform their patients directly about their condition, imparting the information to family members instead. More specifically, 165 out of the 205 doctors (or 80%) said they would not tell a patient if he/she were almost certain to die within a short time. Eighty-four per cent said in that in the same situation they would indeed inform the family. If the patient has a 50% chance of dying shortly, almost 90% of the doctors said they would not inform him/her, while 77% said they would inform the family. The approximately 10% greater unlikelihood of informing either the patient or the family in the case of a 50% chance of dying is probably due to the possibility of a wrong prognosis, which would unnecessarily upset the family and hurt the doctor's reputation.

In a follow-up question concerning what occurs if the patient specifically asks about his/her condition, the number of 'yes' and 'it depends' responses increased in both the 'almost certain' and '50% chance of dying' cases. Doctors said they would be more likely to tell an inquiring patient if he/she demonstrated the ability to understand the disease and prognosis, or had complete faith in fate and destiny. One doctor, however, said that in Yemen patients do not usually ask, making the added survey questions somewhat hypothetical.

Doctors listed several common reasons for not informing patients of their condition. First, learning about their fatal condition would harm patients psychologically, which would contribute to their further physical demise. Second, doctors explained, life and death are in God's hands and much depends on *al-qada' wa al-qadr* – fate and destiny – so there is always room for miracles. Indeed, when reviewing an initial draft of the survey, one doctor recommended to change the original 'a patient is almost certain to die within six months' to 'a patient is almost certain to die within a short time' since only God can specify a time. Moreover, most patients come to the hospital at the final stage of their illnesses, generally imply-

# Informing Terminally ill Patients in Yemen

ing a prognosis for life expectancy much shorter than six months. And finally, doctors said that if terminally ill patients learned of their condition, they would discontinue treatment, leaving the doctors even more ineffective than they would be otherwise.

Readers familiar with Middle Eastern societies will recognize a general preference for not telling someone bad news outright, especially when the recipient lacks the necessary social support to help him/her cope with the distressing information. For example, a Yemeni, Iraqi or Afghan living in the United States whose father has just died back in their home country might be first told he is sick, then worsening, then close to death, and then recently deceased. Informing the person is a gradual process, whereas the death may actually have occurred well over a year prior. In this way, the person far from home is protected from shock, or *fija'*, believed to lead to ill health<sup>2</sup> and from the desire to join the grieving family when circumstances are not conducive to this. If people are reluctant to tell even healthy individuals disturbing news for fear of its deleterious effect on their psychological and physical well being, why would they tell the patient, who is just barely holding on to life as it is?

Doctors said that they generally tell the patient: 'Everything is fine. You are getting better. *Inshallah*, you will recover soon.' They then tell the family: 'The patient's condition is very bad. You had better prepare yourself for the worst.' The family needs to know, doctors said, so that the death does not surprise them and so that they do not blame the doctor instead of the disease. Most family members, doctors said, are also inclined not to inform the patient, although they thought that a very few might prefer to offer the patient a chance to repent for his sins, return any entrusted items, and write a will. Along with physicians, the family tries to raise the patient's morale by hiding the truth and speaking only words of encouragement. Doctors' opinions differed widely on whether patients suspect the true nature of their disease. Some said patients sense the proximity of their death, particularly from overheard conversations, looks of worry and grief on their family members' faces, and a lack of physical improvement. Other doctors believed that patients never know when they are about to die.

#### Treatment abroad

One clear indication that a patient's condition is serious is the need to go abroad. Anyone with a progressive life-threatening illness, such as cancer, heart conditions, or kidney failure, cannot be treated in the country and must pursue advanced medical care elsewhere. Hearing they must go abroad alerts patients to their condition. Doctors were divided on the consequences of patients learning their diagnosis and prognosis in a foreign country where disclosure practices might be different. Some maintained

that the news would be as devastating as in Yemen. Others said patients would accept reality when hearing it from a foreign doctor whom they may tend to trust more than a Yemeni one. Still others said patients could cope with the news in an environment with suitable medical capabilities, especially when seeing their family's efforts to care for them by taking them abroad.

Two patients of the 71 Yemeni medical travellers interviewed in Jordan and Bombay stand out as not knowing the full extent of their medical conditions. One whose cancer had spread throughout his body, producing further complications as well, praised the Jordanian doctor for all he had done for him and for his vast improvement. His young son inquired later, outside of his father's hearing range, if there were perhaps other countries where a cure could be found for his father, in Germany or anywhere else. The other patient was a woman in Bombay who cried about having to sell their house to seek treatment. This interview was abbreviated as her son had previously requested that no questions be asked about the particularities of her condition. That is the difficulty inherent in research on patients' perspectives on disclosure of terminal illnesses. One cannot very well ask: 'So, what is it like to have cancer and not know about it?'

Other Yemeni patients, particularly those in one governmental hospital's radiation department in Jordan, said unhesitatingly that they had cancer. Progressing through a course of radiotherapy surrounded by their compatriots also undergoing such treatment no doubt sustained their hopes of recovery.

The most detailed religious opinion collected on informing terminal patients, particularly in light of treatment abroad, came from the deputy mufti, or *na'ib al-mufti*. In his written answers, *al-'allama* Hamud 'Abbas al-Mu'aid responded: 'The doctor should not frighten the patient. It is better to tell him "*Inshallah* we hope for your recovery and health", so he comforts him and does not frighten him.' Shaikh al-Mu'aid then elaborated, drawing on religious texts and practical experience:

'It is from *al-sunna* [the ways of the Prophet] that a person gives the patient good news so as not to frighten him. How many very sick patients have received their cure from Allah, and how many healthy people has death taken suddenly? And how many dead persons have come back to us from London, or Germany, or India, or Amman, where the patient had travelled for a cure but only his corpse returned. This [...] matter is mentioned by our Almighty God: "If Allah touch thee with affliction, none can remove it but He" [*wa an yamsuska allahu bi durin fa la kashifa la hu illa huwwa*]. Also, "And when I am ill, it is He who cures me" [*wa idha muradtu fa huwwa shafini*].'

As the doctors also indicated, it is God who ultimately decides who lives and dies. Informing patients of a terminal illness

could cause a shock that proves more detrimental than the disease itself. Doctors and family members should reaffirm the possibility of a cure rather than speak perhaps unnecessary words of doom.

Answers to bio-ethical questions will seldom be universal, given varying cultural ideas of what constitutes a good life and death. Approaches contradictory to one's own can appear inhumane, often rendering cross-cultural debates unyielding. Most Yemeni doctors spoken to were appalled to hear that in the United States, doctors almost always tell patients their diagnosis and prognosis. Also unsettling to them was the fact that patients, usually visiting doctors on their own, are then the ones to tell their family about their grave illnesses. For someone already struggling with a serious disease, they said, this is unnecessary and cruel. Examining practices in their sociocultural context can help us in understanding the 'humaneness' in others' actions.

#### Notes

1. In 1998, the author surveyed 205 doctors in four governmental hospitals in San'a, the capital of Yemen, on whether they inform terminally ill patients of their condition. All but 19 doctors were from Yemen. Ten were from Iraq, five from Cuba, and four from Egypt. Additionally, opinions were solicited from nine religious scholars concerning treatment abroad and advanced medical care in general. These scholars ranged from the mufti to heads of *shari'a* courts to *shari'a* law college professors. In addition to fieldwork in Yemen, Yemeni medical travellers in Bombay and Jordan were interviewed.
2. Cf. Swagman, Charles F. (1989), 'Fija': Fright and Illness in Highland Yemen', in *Social Science and Medicine* 28 (4), pp. 381-388. See also Good, Byron J. and Delvecchio Good, Mary-Jo (1982), 'Toward a Meaning Centred Analysis of Popular Illness Categories: Fright Illness and Heart Distress in Iran', in *Cultural Conceptions of Mental Health and Therapy*, Marsella, Anthony J. and White, Geoffrey M. (eds.), Dordrecht: Reidel, pp. 141-166.

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