Cross-Cultural Issues in the Disclosure of a Terminal Diagnosis

A Case Report

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As a result of the migration of Southeast Asians to the United States, increased attention has been focused on refugees' cultural beliefs and practices. Physicians have been encouraged to accommodate these cultural factors whenever possible, to minimize them as barriers to health care.[1–3] The need to do so is supported by evidence that refugees delay seeking medical treatment and underutilize existing health care systems.[4,5] The following report illustrates an unusual presentation of cultural factors having an interfering impact on health care. In this case, a Hmong family referred to cultural beliefs to which they did not subscribe so they could avoid disclosing to a family member the terminal nature of her illness.

Case Report

K.L., a 58-year-old non-English-speaking Hmong woman, was found to have a nonresectable pancreatic carcinoma unresponsive to radiation and chemotherapy. Her prognosis was considered poor. Nine months following the diagnosis, the patient's oldest son revealed that he and other family members, who had served as interpreters, purposefully withheld from the patient the terminal nature of her condition. He informed the physician that in the Hmong culture a terminally ill family member is never told of his or her prognosis; that to do so is the same as wishing death upon that person and may in fact bring about that person's death.

With time, because K.L. was unaware of her condition, management of symptoms became increasingly complicated. She complained of increasing pain as well as progressive adenopathy and wanted to know when she would be well. Unsure of how to proceed, the physician sought consultation with Southeast Asian and American health care providers familiar with the Hmong community. They verified that Hmong patients dying in their homeland are rarely, if ever, told their prognosis. All the consultants recognized that this practice conflicted with the value placed currently in Western medicine on open disclosure of a terminal diagnosis.

At this point the physician acknowledged his respect for the family's cultural beliefs but also emphasized his strong feeling that the patient should be told of her prognosis. This approach was initially met with resistance, but with further discussion, the family members admitted that they did not adhere to traditional Hmong beliefs. Rather, their overwhelming apprehension was that the patient, if told of her terminal condition, would be tearful, depressed, and reclusive, and they would be incapable of caring for her. For this reason, rather than cultural beliefs, the family chose to withhold the details of her prognosis for such an extended period.

With some prompting by the physician, the family did inform her of her prognosis. The patient was initially tearful but, to the family's relief, soon recovered and began to prepare for her death.

Discussion

Physicians who provide refugee health care have been described as practicing at an "invisible cultural border"[5] that can best be bridged by attempts to understand the refugees' cultural beliefs and by accommodating their health practices. This case report serves to emphasize the importance of also attending to basic, universal issues that enter into the relationship between the physician and

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the refugee patient. Specifically, the anticipated loss of a significant family member is a painful process that challenges the strengths and defenses of any family. It is well documented in Western society that disclosure of a life-threatening diagnosis can be extremely difficult for both the patient and the patient's family.[6–8] This process can be considerably more complicated when the patient is a member of a refugee family already undergoing the stress of adapting to a new culture.

In this case cultural beliefs were not the true barriers to effective health care. On the surface, the patient's care appeared to be compromised as a result of a conflict between Western and traditional Hmong beliefs; however, family members were using the pretext of cultural beliefs as a defense against an overwhelming threat to their stability as a family. The family's deception does not suggest that cultural beliefs are irrelevant in the care of the dying Hmong patient. Published information about this group's reaction to extended suffering and terminal illness is lacking, and there is a notable absence of published reports specifically describing how the dying person is treated by the Hmong social group.

In Western medicine, disclosure has become fundamental to patient care only within the past 20 years.[9] This practice is not accepted in all cultures, however. Being aware of these cultural differences, as well as basic human emotions that transcend cultural boundaries, can aid the physician in communicating effectively with refugee patients and their families.[10]

When family members are used as interpreters, as is often the case, knowing their personal and cultural beliefs about the topic being discussed can alert the caregiver to potential difficulties with the accurate exchange of information during patient encounters. Use of bilingual staff or professional interpreters familiar with Western as well as the Hmong culture can help assure adequate interpretation and patient understanding of the illness being discussed.[1,4,10]

No doubt the approach to the dying patient is heavily influenced by culture-specific factors. Obtaining outside opinions from health care providers familiar with refugee groups can be helpful in confirming a patient's cultural beliefs, but will not necessarily clarify the reason why family members are exhibiting avoidant behavior. Uncovering actual motivation can be accomplished only by being sensitive to the patient and his or her family's cultural beliefs while maintaining an adherence to the provision of informed high-quality health care.

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