

Virtual Mentor

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CLINICAL CASE

Dilemmas in End-of-Life Decision Making for the Medical Tourist Patient

Commentary by Malika Haque, MD, and Hafzah Mueenuddin, JD

Mr. Abdullah had just been admitted to the ICU at a major academic medical center. He had traveled there to undergo surgery recommended by his doctor back home in Damascus, Syria. Shortly after his arrival, Mr. Abdullah suffered a heart attack and went into cardiac arrest. His son, who had accompanied him on the trip, called 911, and Mr. Abdullah received CPR for 18 minutes on the way to the hospital. Although his pulse returned, Mr. Abdullah was breathing on a ventilator and comatose on exam.

Neither Mr. Abdullah nor his son spoke English, so Dr. Kramer, the ICU physician, communicated through an interpreter. She explained what had occurred and ordered a neurology consult to evaluate the degree of hypoxic-ischemic injury to his brain and determine whether he was likely to regain consciousness. The consult concluded that Mr. Abdullah was unlikely to regain any significant neurological function.

During their conversation about Mr. Abdullah's prognosis, Dr. Kramer stated that there was a risk that he might code again and advised that a DNR order be written. Mr. Abdullah's son agreed that this was appropriate, and the order was written. The following day, however, the son asked that the DNR order be rescinded, saying that he had spoken with his older brother back in Syria and that his brother, who stood at the head of the family in their father's stead, thought the DNR was inappropriate. Confused by this sudden reversal, Dr. Kramer asked if any other family members had weighed in with their opinions. The son replied that they had not, nor had they been asked to; he and his elder brother were their father's only sons, and the feelings of their mother and sisters were irrelevant in this case.

"In fact," the son explained through the interpreter, "our mother has not been told about what has happened to our father since his arrival because my brother did not wish to upset her."

Dr. Kramer knew from previous experience that, by law, if a patient had not designated someone to exercise power of attorney for health care, the responsibility for decision making on the patient's behalf fell first to his wife. If he had no wife or if she declined to act as surrogate, then it fell to the majority decision of adult children. She explained this legal requirement to Mr. Abdullah's son and asked him to help her act accordingly. The son refused, upset by the doctor's apparent disrespect for his culture.

Commentary 1

by Malika Haque, MD

Proper case management of Mr. Abdullah, a Muslim patient from Damascus, Syria, who has suffered a severe hypoxic brain injury requires the services of several experts to ensure the best possible care for him and his family. Barriers to good care include language, culture, and religious differences and the physical distance that separates Mr. Abdullah from most of his family members. The services of a qualified interpreter are needed, as is the guidance of a physician who is knowledgeable in Islam and Islamic medical ethics. Finally, the assistance of an Islamic religious leader such as an Imam or an Islamic scholar will help achieve an outcome with which everyone involved can feel comfortable.

Since the patient is Muslim, Islamic law and Islamic medical ethics are important governing factors in decision making. Islamic law is derived from the Qur'an, the Muslim holy book, and from the Hadiths, the traditions of the Prophet Muhammad (peace be upon him). Islamic medical ethics is based on Islamic law as well as statements of Islamic scholars. The Ethics Committee of the Islamic Medical Association of North America (IMANA) offers clarification in the management of patients and has published a position paper that covers many medical and ethical dilemmas [1].

In this particular case, the prognosis for neurological recovery is poor. If Mr. Abdullah survives, he is unlikely to recover neurologically and will remain in a persistent vegetative state (PVS). IMANA does not endorse prolonging the misery of a patient who is dying of a terminal illness when death is inevitable or of a patient in a PVS. In such cases, IMANA's position is that the patient should be allowed to die without unnecessary procedures while at the same time receiving nutrition, hydration, antibiotic treatments, and palliative care [2, 3]. No additional attempts should be made to sustain life with artificial life support. If the patient is on mechanical support, this can be withdrawn with the consent of the patient's family members [1-4]. IMANA is, however, opposed to euthanasia and assisted suicide [2]. Initiating a DNR order is appropriate for Mr. Abdullah, according to IMANA's position [2-4]. IMANA also recommends that all Muslim patients have a living will and an advance directive to assist physicians in understanding the wishes of patients who are in situations akin to that of Mr. Abdullah [1].

One strategy for overcoming these language, culture, religion, and physical distance barriers is to call on the services of an Imam or Islamic religious leader or scholar. Although Muslims are a diverse group of people with many different cultures and languages, they share universal respect for the knowledge and guidance of an Imam. The Imam's expertise along with the physician's medical explanations would be most effective in conveying the patient's status in Islamic terms to the family in the United States and the family overseas. In this case, for instance, an Imam could help the family understand that initiating a DNR order does not mean their decision resulted in Mr. Abdullah's death. The spiritual implications that accompany a

family's DNR decision for a loved one can be addressed by the Imam in religious terms. He can explain that accountability for the loved one's death does not rest on the shoulders of family members who do not request futile attempts at sustaining their loved one's life. The Imam can help family members understand that *letting go* does not equal responsibility for Mr. Abdullah's death.

Another matter of concern in managing this particular patient appears to be the role of gender in Islam. The Qur'an at 2:187 states that men and women are each others' garments or each others' protection [5]. Muslim women have the right to marry men of their choice, divorce, obtain education, spend their earnings as they wish, and raise their family with their husband's support. The equal status of the sexes is not only recognized, but insisted upon. The Qur'an at 3:195 cites that any good deed done by a male or female is never wasted, for one is the offspring of the other [6]. Independent and strong Muslim women are not foreign concepts in Islam. In fact, Khadija, the first wife of the Prophet Muhammad (peace be upon him), was a wealthy business woman who proposed to Muhammad (peace be upon him) and lived happily with him until her death at the age of 65. Khadija was the first person to accept Islam after it was revealed to her by Prophet Muhammad (peace be upon him) [7]. This example of an independent and strong woman in Islam is reflected doctrinally in the right of women to make decisions mentioned above.

Despite many examples of the equal status of women in Islam, various cultures label Muslim women as weak and lacking the strength to make important decisions—particularly decisions about life and death. Such notions are culturally based, arising from the beliefs that prevail in the woman's country of origin as well as the level of education the woman had obtained.

Pakistan, Indonesia, and Bangladesh all have had Muslim women as heads of state. Many Muslim women are also highly educated and succeed in the professional ranks while assuming the traditional roles of wife and mother. Prophet Muhammad (peace be upon him) has stated that paradise lies under the mother's feet—indicating the great respect due to mothers in Islam [8].

In this case, Mr. Abdullah's wife is the most appropriate figure to make a decision regarding her husband's life. Her sons seem to be protective of their mother and do not think it necessary to burden her with such a difficult decision. Perhaps they do not think she is strong enough to hear difficult news or decide upon the DNR order. Here, the Imam or an Islamic scholar can assist in conveying the difficult news to the patient's wife, but with or without an Imam's help, Mr. Abdullah's wife should have been informed and given the opportunity to decide upon the DNR order.

This particular case reflects several medical, cultural, and ethical issues that must be handled by a team of experts. The use of a physician knowledgeable in Islam and Islamic medical ethics is preferred, an interpreter should be employed, and an Imam or religious leader who can effectively communicate with the family will be most helpful.

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Malika Haque, MD, is a clinical professor of pediatrics in the College of Medicine at Ohio State University and a pediatrician at the Nationwide Children's Hospital, Section of Ambulatory and General Pediatrics in Columbus. Dr. Haque serves as the expert advisory panelist for the Joint Commission's expert advisory panel for culturally competent patient-centered care. She is a member of the ethics committee of the Islamic Medical Association of North America (IMANA) and of the IMANA Board of Regents.

Commentary 2

by Hafzah Mueenuddin, JD

As medical tourism becomes more common, whether due to complicated medical conditions or economic incentives, patients and physicians are quickly finding they are exchanging more than a fee for specialized medical services. Often, cultural constructs of autonomy and surrogate decision making are also being exchanged. Customs and laws that guide surrogate or proxy decision making have a significant impact on many traveling patients. In the following discussion, I explore how legal and cultural constructs of autonomy and surrogate decision making complicate Mr. Abdullah's care.

Addressing Legal Requirements with Family Members

Many approaches could have been taken when Mr. Abdullah's son refused to contact his mother, Mr. Abdullah's wife. Evidence requirements for establishing patients' wishes vary by state, as does the hierarchy of people who can make medical decisions for a patient who lacks capacity to decide. Most states place the patient's spouse at the top of the hierarchy for surrogate decision making, followed by the patient's children. In the present case, this means that the medical team would first refer its questions to Mr. Abdullah's wife (who is not present). The medical team is

legally obligated to make a good faith effort to contact the first person in the hierarchy of decision makers. If it is difficult to contact the patient's spouse, the team may discuss his medical condition with his children. But Mr. Abdullah's wife should be given the opportunity to accept responsibility for making these decisions or to pass it on to other family members.

Because Mr. Abdullah's son is worried about how his mother may take the news, Dr. Kramer will need to adjust her approach to discussing Mr. Abdullah's condition with her. Dr. Kramer may simply state that she is calling to determine whether Mrs. Abdullah would like to make decisions regarding her husband's medical care if he becomes unable to do so. Should Mrs. Abdullah agree to make medical decisions for her husband, the team will have to include her in all decisions requiring consent. Dr. Kramer should further state that Mrs. Abdullah is not required by law to accept the responsibility; she can choose to forgo being her husband's surrogate decision maker, in which case the responsibility will shift to her children. Alternatively, Mrs. Abdullah may appoint a person she feels is trustworthy and more knowledgeable about what her husband would want and someone who is in a better position to make medical decisions for him. This would allow the medical team to fulfill its legal responsibility of affording Mrs. Abdullah an opportunity to accept or refuse decision-making responsibility and may allow family members to continue to provide for Mrs. Abdullah's comfort in the best way they know.

Another option is to present the situation to a multidisciplinary group, which may support Mr. Abdullah's son and open novel ways of discussing options and decisions for his care. In this case, it would be helpful to ask an Imam to discuss how Islamic law and culture interpret the patient's medical condition. The Imam would be able to explain that U.S. law offers an opportunity for Mr. Abdullah's wishes to be heard from those who know him best. Involving the patient's spouse in medical treatment decisions by no means shows disrespect, but rather enables the patient's autonomous wishes to be heard from a trustworthy source (here, his wife). One 2002 study showed that medical teams in the ICU found involvement of religious scholars and extended family extremely important in helping Muslim decision makers cope with their responsibilities [1]. In this case, Dr. Kramer should stress that she hopes to gather more information about Mr. Abdullah and create family support for his son in the United States.

Addressing DNR Status in the Islamic Context

Another important concern for the physician and patient is Mr. Abdullah's DNR status. Before a decision about resuscitation can be made, medical benefit must be clearly defined and agreed upon by Dr. Kramer and Mr. Abdullah's family. In this instance, it may be that Mr. Abdullah's condition could become more painful and difficult if he were resuscitated, and, in Dr. Kramer's view, resuscitation may offer Mr. Abdullah no benefit while prolonging his life in a state of greater suffering. By contrast, Mr. Abdullah's family might view resuscitation as a chance at "life." Because physicians, patients, and families may interpret the "benefit" of treatment in vastly different ways, discussing these views and the reasons behind them with

patients (when possible) and families is extremely important. In general, Islam views withholding treatment as morally permissible where physicians determine that continued aggressive treatment is not providing any medical benefit [2]. This is because delaying the patient's death with continued life-sustaining treatment is not in the patient's or the community's best interest [2]. The prolonging of life, in Islam, is not as important as the quality (moral and otherwise) of the life lived [3].

Another option Dr. Kramer has if she feels very strongly that a DNR order is best for Mr. Abdullah is stating that she will institute the DNR order after enough time has passed to allow (1) an independent physician in the hospital to evaluate Mr. Abdullah's condition to determine if DNR status is necessary, or (2) the family to make arrangements to move Mr. Abdullah to another hospital or let him return home. In most states, physicians may institute a DNR order after informing the family of these options. Nonetheless, to continue strengthening the relationship with the family, decision makers, and the medical team, it is important to inform all parties involved in the patient's medical care of changes in treatment plans or goals and provide them an opportunity to voice their opinions.

Autonomy and the Muslim Patient

Islam values autonomy and free will as unique characteristics of humankind, but respect for autonomy is often eclipsed by the greater importance of family and community, inasmuch as an individual's welfare is intimately linked with that of his or her family's [2]. This differs significantly from the Western or American concept of autonomy and individual liberties. Hence, while American patients or families may feel they have a right to demand treatment options as an exercise of their autonomy, Muslim patients are likely to take a broader view shaped by input from external sources such as family and community. Muslim patients and families are more likely to understand that limiting use of resources on one individual may contribute to the greater good. This is not simply a recognition of the medical constraints of one's community, it also recognizes an overarching responsibility toward preserving the welfare of one's community resources. In Mr. Abdullah's case, appealing to this sense of familial and communal good both in reaching out to his wife and in discussing his DNR status will help his son and family understand the centrality of these points of view and help them place decision making in a context they understand.

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Hafzah Mueenuddin, JD, is a fellow in the Cleveland Fellowship for Advanced Bioethics at the Cleveland Clinic. She graduated from Cleveland-Marshall College

of Law in 2007, and is particularly interested in end-of-life decision making and reproductive ethics.

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