

Virtual Mentor

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Clinical Case

Who Decides, Patient or Family?

Commentary by Jennifer Blanchard, MD

Mrs. Odundo was admitted to a Los Angeles medical center after several weeks of dysphagia. She was accompanied by her husband who provided the history of her illness. Originally from East Africa, Mrs. Odundo spoke no English, and no speakers of her particular dialect were available at the hospital.

“For the last few weeks, she hasn’t been able to swallow anything,” her husband said. “First, it was solid food, now liquids too.” The treating physician, Dr. Martinez, was concerned about esophageal cancer, and, indeed, an endoscopy performed the following day revealed a mass which was probably an advanced carcinoma. Treatment options were limited, and surgery was unlikely to be curative.

While awaiting further characterization of the mass, Mr. Odundo told Dr. Martinez, “We’ve talked about this, and she wants everything possible to be done. She’s 55; that’s too young to let her go.”

“You both understand that there’s only a small chance we can actually remove the entire mass and offer anything close to a cure.”

“We understand that.”

Mrs. Odundo’s husband repeated the statement—on many occasions, to many doctors—that his wife would want to exhaust all treatment options, including surgery, even if there were only a minimal chance for improvement or cure.

Several days after Mrs. Odundo’s hospitalization, her children spent some time alone with their mother, after which they spoke with Dr. Martinez. “Our mother is telling us that she doesn’t want any surgery.” They also stated their fear that she was acquiescing to her husband’s wishes. Dr. Martinez realized at this point that he had never heard directly from the patient what she would like to have done, nor was he certain about the extent of her understanding of her own disease, so he arranged to have an interpreter called in. Through the interpreter, Mrs. Odundo stated that she did not wish to have this discussion alone but wanted her husband and children to be present. During the discussion, she stated that she understood that surgery was unlikely to be curative but that she wished to proceed regardless. The children objected that these were her husband’s wishes and not her own—saying that this was

not what she had told them—but Mrs. Odundo insisted that she wished to have the surgery.

Commentary

American physicians are providing more and more care to patients from different ethnic and cultural backgrounds who frequently speak languages other than English. According to the 2000 U.S. Census [1], 65 percent of the population was white, and the remaining ethnic groups were black (13 percent), Hispanic (13 percent), Asian-Pacific Islander (4.5 percent; the great majority of whom speak Chinese), and American-Indian/Alaskan (1.5 percent). The number of people living in the U.S. who speak a language other than English at home was estimated to be 47 million in 2000, and the number of people with limited English proficiency (LEP) was estimated to be 21.4 million. In California, members of minority groups make up a greater percentage of the population than nonminority-group whites, and the percentage of those in minority groups is expected to rise [2]. It is projected that by 2010, 69 million Americans will speak a language other than English at home and approximately 28.4 million will have limited English proficiency.

Situations like the one described in this clinical case are increasingly common. It is critical that the physician and medical team be aware of and sensitive to numerous concerns when providing care to patients from another culture and those who speak another language.

Language Barriers

The first and most obvious problem is the language barrier. In this case, the patient speaks an East African dialect for which there are no translators available at the hospital. Her husband provided a history. This scenario is common even when the patient is Spanish-speaking and professional interpreter services are available. Very often, due to convenience and timeliness, family members are employed as interpreters. If family members are not available, other ad hoc interpreters (friends, untrained medical and nonmedical staff, or even strangers) are used. The real question, though, is whether this practice is truly in the patients' best interest. Everyone would agree that, in an emergency, getting any history is better than getting none. In nonemergent situations, however, the answer is not so clear.

Numerous studies [2] speak to the impact of interpreter services on patient care. Patients who need interpreting services but don't get them frequently don't understand their diagnoses and treatment. These patients report wishing their health care giver had explained things better. That said, having an interpreter does not guarantee understanding and clear communication—quite the contrary. Numerous studies have reported the high number of errors made in translation, including omissions, additions, editorializations, and false fluency [2]. More often than not, errors of this type have potential clinical consequences, e.g., changes in the history of the present illness or in diagnostic or therapeutic interventions. Ad hoc interpreters misinterpret or omit up to half of all physicians' questions [3]. Their errors are significantly more likely to lead to clinical consequences than those committed by

hospital interpreters [2], and ad hoc interpreters are more likely to omit mention of medication side effects.

When children are interpreting, they are more likely to ignore or leave out embarrassing remarks, such as those related to menstruation, bowel habits, or other bodily functions. Despite that, a study of Latino patients found that they were more comfortable discussing sensitive or embarrassing subjects when they had bilingual physicians, family members, or friends interpreting than when hospital or telephone interpreters were used [4].

It is impractical to expect to have a professional medical interpreter for every patient encounter. The service is time consuming—not only waiting for interpreters to arrive in person or be reached by phone—but the actual process of interpreting is laborious and lengthy. Using other hospital staff as ad hoc interpreters pulls them away from their regular duties. With the prevalence of cell phones and relatively easy access to phone interpreters (AT&T offers medical and legal translation services for 170 languages at an approximate rate of \$4.00 a minute), phone interpreters are almost universally available. In many parts of the world, though, costs of interpretative services are prohibitive, and the medical professional is much more dependent on ad hoc interpreters.

Finally, there are legal constraints that must be adhered to. Use of a hospital interpreter must be documented in the patient's records. HIPAA further mandates that the patient's permission for an ad hoc interpreter must be documented in the record. University of California, San Diego's Medical Center policy is that only professional interpreters may participate in end-of-life-discussions. Some states prohibit children under the age of 15 from acting as interpreters.

What's a conscientious physician to do? Recognizing the limitations of ad hoc interpreters, it is a good idea to plan for a professional interpreter with the patient and family members, if appropriate, at significant times in a patient's care, specifically for reporting results of diagnostic tests and when discussing therapy and prognosis. In stable patients, it is also a good idea to schedule time with a professional interpreter periodically to maintain good communication. Studies have shown that misunderstandings in interpretation can be avoided if physicians develop a few good habits: Talk in simple sentences and stop frequently for the interpreter to speak; restate to the patient what he or she has said; clarify contradictory information; and pay careful attention to nonverbal cues [5]. Of course, it is desirable that the interpreter not edit what is being said and explain idioms for both the patient and the clinician.

Cultural Barriers and Differences

The next responsibility of the medical caregiver is to anticipate and negotiate cultural differences. In the United States, medical, legal, and ethical practices hold patient autonomy in the highest regard. The principle of patient autonomy asserts the rights of individuals to make informed decisions about their medical care. Thus, patients

should be told the truth regarding their diagnosis and prognosis, as well as the risks and benefits of proposed treatments, and should be allowed to make choices based on this information. The standard of care in this country is to tell patients the truth about even fatal illnesses and to obtain their informed consent for major procedures [3].

Not all cultures share these values. Asians and Hispanics classically value family-centered decision making over patient autonomy. In one study, Korean Americans were less likely than African Americans or European Americans to believe that a patient with metastatic cancer should be told the truth about his or her diagnosis [6]. They are also less likely to believe that a patient should be informed of a terminal prognosis and that the patient should make the decision about the use of life support. The majority of those surveyed believed that the family should make the decisions about the use of life support. In this same study, Mexican Americans fell between Korean Americans and European Americans in their beliefs about truth telling in diagnostics. Korean Americans and Mexican Americans are more likely to believe that only the family and not the patient should be told the truth, with no effect of gender of those surveyed. This study did find differences between older subjects and those with lower socioeconomic status and their younger, more highly educated counterparts. Likewise, those subjects who seemed to be acculturated to America had opinions closer to their European American counterparts. Another study [7] revealed that Korean Americans and Mexican Americans were more likely to see truth telling as cruel or even harmful to patients than European Americans.

Rather than envisioning the patient as an autonomous agent who needs information to make decisions and maintain control and dignity, the Mexican American and Korean American responders viewed the patient as sick, weak, and in need of protection by the doctor and the family. In these cultures, it is considered kinder to give hope. The ethical issue here is whether it is right to take hope away, since the truth about a terminal illness is thought to remove hope, causing depression and other pain and maybe even hastening death. The benefits of knowing the truth are “seen as insufficient to outweigh the pain caused by knowledge of the truth” [7].

Mexican American and Korean American responders did not want to suffer or see their loved ones suffer this pain of knowledge of a terminal illness. The ambiguity of not knowing for sure, even if one suspects it, is better than knowing, since it allows for the possibility of hope. The family may know the truth, but they protect the patient by preserving hope and keeping the truth from the patient; this protection is the family’s duty. In fact, subjects in this study thought physicians should check with the family prior to telling a patient the truth about a diagnosis or prognosis. Paradoxically, it’s possible that, in these cultures, patients maintain their autonomy by deferring to a family member. That said, it is acceptable to convey someone’s prognosis indirectly and nonverbally. For example, subjects in this study stated that it was appropriate to say the following to someone with terminal cancer: “You are very, very sick, but we are doing everything we can.” Or “If you would like to return to your home country before you die, you should go now.”

In preparing this commentary, I found very little data on the cultural beliefs or values of East Africans in Western medical literature. Due to their relatively small numbers here in the U.S. and with difficulties in translation, I don't expect there are any formal studies to guide physicians. It is incumbent on the physician to recognize that the American emphasis on patient autonomy and individual rights probably reflects a Western bias that may not be valued to the same degree in other cultures. We are still legally bound to provide enough information to the patients to obtain their adequately informed consent for medical care.

The Case at Hand

In the case above, Dr. Martinez did well to arrange for the interpreter to meet with the entire family. Given the contradictory reports from the patient's family about what Mrs. Odundo's wishes truly are, it is necessary to discuss the possible complications of the procedure since her husband or children may have omitted this. It would also be important to preserve hope (since this is a goal of medicine in any culture) and to emphasize that the medical team will continue to work in her behalf if she chooses not to have surgery.

We do not know what amount of deferral of autonomy is normal in East African cultures. Nor do we know whether this husband and wife have a healthy relationship, or whether his control of her care is part of an abusive relationship. I think it would be wise to ask the children privately about East African cultural norms as well as their parents' relationship. Obviously, if there are any red flags, surgery should be postponed until the patient's wishes are clear. If there are no concerns of abuse, and the deferral of autonomy is within the norm for this couple (whether in their culture or just in their relationship), then the surgery can proceed. In that case, the patient is maintaining her autonomy by choosing to defer to her husband.

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