Care Across Cultures

Does Every Patient Need to Know?

By BARBARA A. SEGAL, M.A., and MARIAN HODGES, MD, M.P.H.

An 85-year-old Russian man is admitted to the hospital complaining of increasing back pain. In the ER, an abdominal CAT scan indicates evidence of new metastatic disease to his spine. The patient has limited English skills. When the admitting hospitalist and an interpreter enter the room, they see the patient surrounded by his daughter and other relatives talking in Russian, laughing and eating.

After greeting the patient and his daughter, the physician asks to speak to the patient in private about his condition. The daughter insists that she and her relatives stay in the room, as they have come "to help."

The doctor begins to talk about the patient's diagnosis, and the daughter interrupts, saying it is better if he does not say too much. The doctor then asks her if she and the patient understand how serious his condition is. She says she understands his condition and that her father "knows what he needs to know."

"It will hurt him," she says, "if he knows too much." The doctor begins to say that the patient likely has cancer, and the daughter frantically asks him not to say any more. She states emphatically, "Doctors in Russia would never do such an unkind thing!"

The doctor emphasizes that the patient must know about his condition and asks that everyone leave the room so he can talk to the patient privately. The daughter and patient worriedly confer in Russian, and the patient turns to the doctor and says, "Doctor, we want to do what is best."

This clinical encounter, adapted from an actual case at Providence St. Vincent Medical Center in Portland, Ore., raises several key questions: Why do the daughter and the physician have such different perspectives regarding the disclosure of the diagnosis to the patient? Why does the physician feel obligated to speak to the patient in private? Why does the family want to stay and be involved in the discussion? Are there ways in which the physician could provide good patient care other than directly informing the patient about the CAT scan findings? What does the patient, himself, want?

What each of these questions suggests is that the patient, family and the physician have different ideas about what it means to respect patient autonomy. In terms of making decisions regarding care, the physician thinks it means dealing directly with the patient, and that means fully disclosing his condition. The family thinks respecting the patient's autonomy means protecting him from certain information and holding information back. We do not yet know what the patient's understanding of autonomy is.

To better understand and respond to cases like the one recounted above, the Providence Center for Health Care Ethics in Portland developed a cul-

tural competency curriculum in 2007 for physicians. It is designed to help them develop communication skills in situations with patients of diverse backgrounds who have life-threatening illness. The focus of the curriculum was developed from a comprehensive survey and interviews of hospitalists in three Providence hospitals to identify the kinds of cultural challenges they commonly see, an extensive review of the literature and input from diverse communities in the Portland area.

The curriculum includes three educational modules and focuses on three key areas that the physicians identified as presenting communication challenges: disclosing a serious diagnosis and prognosis across cultures; discussing code status; introducing transition to hospice. Each module has its own video vignette that reflects one of these concerns, and each is based on an actual case. The video serves as the springboard for self-reflection, didactic presentation, interactive exercises such as role playing and large group discussions.

The curriculum focuses on four key objectives:

1. To recognize one's own cultural beliefs and biases
2. To understand diverse cultural beliefs related to key conflict issues
3. To ask questions and elicit preferences from each patient regardless of culture
4. To negotiate a solution in each dilemma that both meets patient and family concerns and does not violate the physician's integrity

These objectives can serve as a framework to better understand the autonomy conflicts related to disclosure, such as those highlighted in the case above, and provide some communication guidelines toward resolving them.

RECOGNIZING CULTURES

Culture can be defined as shared meanings, values, rituals and modes of interacting that influence how people understand and make sense of the world. Culture plays a key role in health care and particularly in palliative care because it influences how we understand autonomy, and it plays a significant role in defining how patients and families make meaning out of illness and suffering, expressions of pain, expectations about care, hopes for the future and views regarding death. Autonomy ultimately influences how and by whom decisions are made.

In addition to our different ethnic cultures, all of us in health care operate within another, often unacknowledged, culture: *the medical culture*. Medicine is a cultural system with its own specific values, language, and practices that inform the way clinicians practice, and it must be translated, interpreted and negotiated with patients and their families.

Our survey and interviews with physicians revealed how often we are unaware that we are part of this culture, and we take it for granted that the beliefs and practices of this culture are universally shared. It is important that we become aware of the influences of both our own ethnic culture and our medical culture because, as the anthropologist Arthur Kleinman states, "If you can't see that your own culture has its own set of beliefs and biases, how can you expect to deal successfully with someone else's?"[1]

SHIFTING STANDARDS

One of the basic tenets of the medical culture in the U.S., mirroring the larger culture, is the primacy of individual patient autonomy. Respecting autonomy in this setting essentially means allowing individual patients to make their own informed choices about their medical care. This had led to a standard of disclosure that includes telling patients everything about their life-threatening illness and obtaining their informed consent.

Contrary to the belief of some of the physicians we have taught, this standard of care is a relatively recent development in the U.S. The 1847 American Medical Association code of ethics called on physicians to withhold information from patients

— to protect them from bad news if it was viewed as harmful to their best interests. As late as 1961, a survey documented that 90 percent of the medical staff at a university hospital indicated a preference for not informing patients of a cancer diagnosis. However by 1997, when the survey was repeated, 97 percent of the physicians indicated a preference for informing cancer patients of their diagnosis.[2] Several other studies, while including slightly less dramatic statistics, also indicate that there was a major shift in attitude during this period.[3] This shift was influenced by a complex mixture of cultural and political factors including the consumer and patient rights movement, an emphasis on patient informed consent and developments in the legal arena.

Medical culture is not static, and it is often shaped by the prevailing culture in which medicine is practiced. How we respect autonomy within the medical culture can change in accord with the shifting cultures of patients.

DIVERSE PERSPECTIVES ON DISCLOSURE

While current U.S. medical culture places a high value on individual autonomy, this is not universal. A review of the literature on medical practices in other countries shows that the traditional practice in much of the world has been for physicians not to directly inform patients of a serious illness. Though only a small snapshot of this literature can be reviewed here, a survey of disclosure practices from around the world indicates that in many parts of Asia, Central and South America, the Middle East, Eastern Europe and parts of Western Europe, the most common practice has been for medical professionals to withhold from patients information regarding a serious illness.[4] Studies of patients in China,[5] Taiwan,[6] Japan and Italy,[7] Spain,[8] Lebanon[9] and Tanzania[10] all indicate that the majority saw a positive value inherent in the nondisclosure of a diagnosis and of a terminal prognosis.

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As culture and medical practice are not static, countries and subgroups within countries have shifted over time, and more open disclosure has become more common in some areas.[11] Nevertheless, direct disclosure has not been the usual standard of practice or culturally expected in much of the world and among diverse cultural groups in the U.S. Several studies comparing the cultural beliefs of Euro-Americans with those of Korean-Americans, Mexican-Americans and Chinese-Americans consistently indicate that the latter groups place a higher value on greater family involvement in decision-making and in protecting vulnerable family members from direct disclosure of bad news.[12]

Underlying these practices are differing, culturally shaped views of patient autonomy, the role of the family and the doctor-patient relationship. Respecting autonomy within other cultures can entail giving preference to other ethical values such as fidelity and connection to family and community over individual decision-making.

In many cultures, the family — not the individual — is traditionally the primary locus of decision-making. The family members' role is to protect and take care of each other, particularly of those seen as the most vulnerable. Thus the family expects to be involved in key decisions affecting the patient, often talking with the doctor to decide if, when and how to share information with the patient.

In these settings, respecting autonomy can mean that careful disclosure of medical information is key to patient care. The family perceives full or unfiltered disclosure as disrespectful, impolite or even cruel, and they may regard it as harmful to the patient. Their underlying concern is that information about serious illness can provoke depression, anxiety or even eliminate hope. They may believe bad news can even cause the feared outcome to happen. For example, among the Navajo it is traditionally believed that the spoken word can shape reality and to talk about death can actually cause it. The practice of some physicians in the Indian Health Services to inform patients about life-threatening illness was seen as potentially endangering.[13]

Although knowledge about diverse cultural beliefs and practices can be helpful, it is even more critical that clinicians do not make assumptions about individual patients and their health beliefs based on ethnicity, race or religion. Culture and religion are mediated by a variety of factors including level of acculturation, socio-economic status, gender and age. Individuals and their families can fall along a spectrum of beliefs and practices. Frequently the younger generation or the more acculturated members of a family will lean toward desiring more full disclosure of a serious illness. Regardless of culture, each individual has his or her own views regarding decision-making and disclosure and assigns his or her own meaning to illness. Clinicians must be careful not to prejudge.

BRIDGING CONFLICT

When there is a difference in beliefs and values between the clinician and the patient and his or her family, respect for autonomy means, first and foremost, building a relationship. A relationship starts with trust. Language barriers, age and gender can create differences in perspective, and the clinician must hear the patient's and the family's story before they can come to trust. The clinician can best elicit that story by asking open-ended questions and offering empathic listening. The clinician needs to show genuine interest in learning about the patient and family's understanding of the illness, what caused it, what can make it better, their hopes for what will happen and their fears for the future.

An interpreter will be necessary for any patient who speaks a language different from the clinician's. The patient and clinician may not agree about pathophysiology and they may not see beneficial therapies the same way. However, understanding the patient and family perspective is critical to showing respect for the autonomy of the patient. The value of respect is paramount in cross-cultural care, far more so than simply letting patients make their own decisions. No care plan is successful without it.

In the example above, the clinician was in too big a hurry. This is a common error. After entering the room and introducing himself, he needed to find out how this family "worked."

He could have asked with whom he should speak about the patient and whether he could question the patient directly. The daughter then might have volunteered a description of her father's pain and its progression, or she might have asked to speak to the physician privately — to which the clinician should initially agree. The clinician would then learn in private what the daughter's concerns were, and in this case how she did not want "bad news" revealed directly to her father. Thus, no information would have been voiced in front of the patient without it first being filtered by the patient's cultural context.

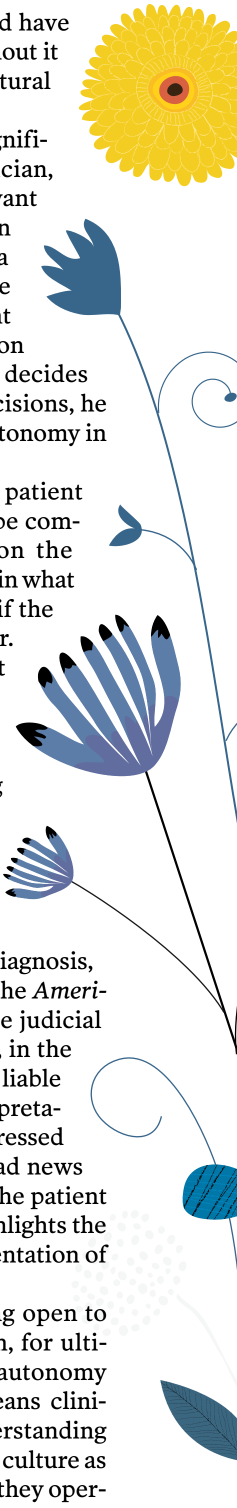
These delicate situations require significant negotiation. Frequently the clinician, coming out of her own culture, will want to ask the family member how they can approach the patient together to get a better sense of how much information he or she wants to know, and if the patient is comfortable with the way information and decisions are made. If the patient decides not to "take charge" of his medical decisions, he is exercising his culturally informed autonomy in the way decisions are made.

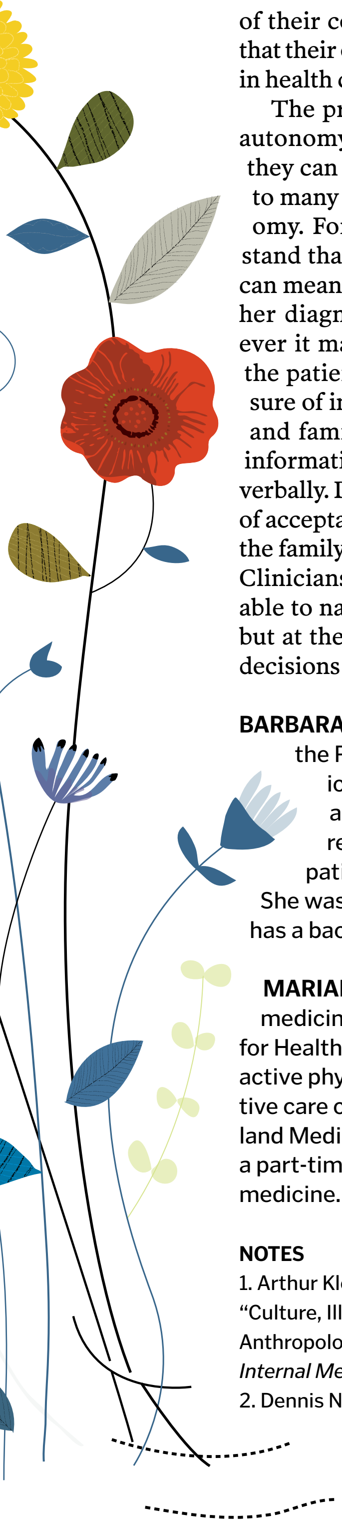
This careful consultation with the patient and his family allows the clinician to be comfortable with how much information the patient will be told about his condition, in what way he will be told, and it will reveal if the daughter is a reliable decision-maker. It is important to carefully document these discussions with the patient and family. New developments in the diagnosis will likely prompt the need to revisit any agreement regarding disclosure.

WHAT AUTONOMY MEANS

Some physicians have raised concerns about legal liability for not directly informing the patient about a diagnosis, but as Cochella and Pedersen state in the *American Family Physician*, "U.S. law and the judicial system's application of it suggest that, in the appropriate context, physicians are not liable for choosing non-disclosure. This interpretation would apply when a patient has expressed a clear desire not to be informed of bad news or when the truth telling could cause the patient significant harm ... This possibility highlights the need for thorough and prompt documentation of the discussion in the medical chart."[14]

Respecting autonomy requires being open to another's culture as well as one's own, for ultimately it is culture that shapes what autonomy means. In health care, this openness means clinicians must be aware of how their understanding of autonomy is influenced by their own culture as well as by the medical culture in which they operate — and they need to recognize that the patient or family may not share this same understanding.





Sometimes physicians or nurses will be pulled out of their comfort zone, especially when they see that their own cultural beliefs about what is "best" in health care are not shared by a family.

The prevailing Western idea that respecting autonomy means full disclosure to patients so they can make their own decisions runs counter to many other culturally shaped ideas of autonomy. For clinicians, it is important to understand that respect for patient values and beliefs can mean that a patient is not directly told his or her diagnosis and prognosis. Sometimes however it may mean that the clinician works with the patient and family toward a gradual disclosure of information to the patient, the physician and family inform the patient together or the information is communicated indirectly or nonverbally. Depending on the case, there are a range of acceptable solutions that respect the culture of the family and the ethical values of the physician. Clinicians need to be clinically competent to be able to navigate how to practice good medicine, but at the same time they must respect the way decisions are made in different cultural settings.

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NOTES

1. Arthur Kleinman, Leon Eisenberg and Byron Good, "Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research," *Annals of Internal Medicine* 88, no. 2 (Feb. 1, 1978): 251-58.

2. Dennis Novack et al., "Changes in Physicians' Attitudes Toward Telling the Cancer Patient," *JAMA* 241, no. 9 (1979): 897-900.

3. George E. Dickinson, Robert E. Tournier and Brenda J. Still, "Twenty Years Beyond Medical School: Physician Attitudes toward Death and Terminally Ill Patients," *Archives of Internal Medicine* 159 (1999): 1741-44.

Also, see Angel Lee and H.Y. Wu, "Diagnosis Disclosure in Cancer Patients — When the Family Says 'No!'" *Singapore Medical Journal* 43, no. 10 (2002): 533-38.

4. Marjorie Kagawa-Singer and Leslie Blackhall," Negotiating Cross-Cultural Issues at the End of Life: 'You Got to Go Where He Lives,'" *JAMA* 286, no. 23 (2001): 2993-3001.

5. Yali Cong, "Doctor-Family-Patient Relationship: The Chinese Paradigm of Informed Consent," *The Journal of Medicine and Philosophy* 29 (2004): 149-78.

6. We-Yu Hu et al.: "Solving Family-Related Barriers to Truthfulness in Cases of Terminal Cancer in Taiwan: A Professional Perspective," *Cancer Nursing* 25, no. 6 (2002): 486-92.

7. Elisa J. Gordon and Christopher K. Daugherty, "'Hitting You over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients," *Bioethics* 17, no. 2 (2003): 142-68.

8. Jill L. Mitchell, "Cross-cultural Issues in the Disclosure of Cancer," *Cancer Practice* 6, no. 3 (May-June 1998): 153-60.

9. G. N. Hamadeh and S. M. Adib, "Attitudes of the Lebanese Public Regarding Disclosure of Serious Illness," *Journal of Medical Ethics* 25 (1999): 399-403.

10. Susan R. Harris and Edith Templeton, "Who's Listening? Experiences of Women with Breast Cancer in Communicating with Physicians," *Breast Journal* 7 no. 6 (Nov.-Dec. 2001): 444-9.

11. Ho Yung Yun et al., "The Attitudes of Cancer Patients and Their Families Toward the Disclosure of Terminal Illness," *Journal of Clinical Oncology* 22 no. 2 (Jan. 15, 2004): 307-14.

12. Leslie Blackhall et al., "Ethnicity and Attitudes toward Patient Autonomy," *JAMA* 274, no. 10 (1995): 820-25.

Also, see Walter F. Baile et al.: "Oncologists' Attitudes toward and Practices in Giving Bad News: an Exploratory Study," *Journal of Clinical Oncology* 20, no. 8 (2002): 2189-96.

Also, see Jill L. Mitchell, "Cross-Cultural Issues in the Disclosure of Cancer," *Cancer Practice* 6, no. 3 (May-June 1998): 153-60.

13. Joseph A. Carrese, Lorna A. Rhodes, "Western Bioethics on the Navajo Reservation: Benefit or Harm?" *JAMA* 274 (1995): 826-9.

14. Susan Cochella, Donald Pedersen, "Curbside Consultation: Negotiating a Request for Nondisclosure," *American Family Physician* 67, no. 1 (Jan. 1, 2003): 209-21.

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