

Virtual Mentor

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From the Editor

Ethics and Multiculturalism in the Patient-Physician Encounter

The changing demographic landscape of the United States has received growing attention among physicians and has added new dimensions to the patient-physician encounter. According to a recent survey of the American College of Physicians (ACP), nearly two-thirds of internists report having active patients with limited English proficiency (LEP); and this group comprises 12 percent of active patients in the practices of ACP member internists [1]. The median age of immigrants in the U.S. is 39.3, [2], so we can expect even more such encounters as older immigrants—who are more likely to hold onto traditional cultural beliefs—enter the U.S. health care system in greater numbers. With the need for immigration reform looming, it is therefore a good time to explore the ways in which cross-cultural interaction can transform many core values of medicine and the medical encounter.

As this issue developed, a few central themes began to emerge. First, ethical principles or values which are well enshrined in Western medicine—patient autonomy or scientific empiricism, for example—are clearly not universal and may not be shared by patients of all cultural backgrounds. Second, language and culture are inexorably linked, so that, even if physicians are bilingual or use professional interpreters, they may still encounter cultural barriers by failing to ask the right questions or consider alternate explanations for a patient's illness. Finally, without prompting, several authors in this issue invoked the relatively recent concept of "cultural humility" as an approach that can help physicians identify and understand alternate belief systems, so it is worth exploring this new paradigm further in this introduction.

Conceived as a response to the discourse on cultural competency, the concept of cultural humility invites physicians to approach individuals and cultures as equals, rather than as groups that present challenges to be overcome in their practice [3]. Thus:

The starting point for such an approach would not be an examination of the patient's belief system, but careful consideration by healthcare providers of the assumptions and beliefs that are embedded in their own understandings and goals in the clinical encounter [4].

By this concept, an approach rooted in cultural humility would not require memorization of unique beliefs held by certain patients; rather, physicians should be encouraged to develop respectful partnerships through patient-focused interviewing

[4]. In this vein, readers of this issue are encouraged to explore their own values through the cases and discussions that we present.

The clinical cases invite us to examine issues which might emerge in the everyday context of a multicultural medical encounter. Perhaps no ethical principle is as legally enshrined in U.S. medical practice as “patient autonomy,” and yet, not all patients may be accustomed to a system where the emphasis is placed on their own individual decision making. A case commentary by Jennifer Blanchard presents a number of approaches to managing situations in which the locus of decision making is in question. The ramifications of relying on family members to interpret is also explored in this case, because some of the problems that give rise to the ethical dilemma might have been avoided if the patient’s true beliefs could have been ascertained earlier.

A second case examines what physicians might do when they encounter patients who do not share their beliefs. Of all the medical disciplines, psychiatry may be the one in which patient beliefs exert the greatest importance, and here commentator Andres Sciolla extends the ethical principle of benevolence—providing appropriate care to a patient—to include culturally appropriate care. In a third case, Lindia Willies-Jacobo explores how a physician can skillfully navigate a clinical encounter in which multiple beliefs are expressed, as happens when a physician cares for both a patient and his parents. The point of exploration is “susto,” a folkloric illness believed to result from psychological trauma to which the patient’s family attribute his illness. The patient’s medical illness—Guillain-Barre syndrome—is discussed separately in a clinical pearl segment by Adel Olshansky.

A similar scenario is described in an op-ed article by Matthew Wynia and Megan Johnson, who explore the tensions that can exist between differing belief systems, citing an example where a patient’s interpretation of his own illness is “scientifically incorrect.” Of course, the extent to which science is its own belief system—after all, we accept studies and evidence without attempting to reproduce the data ourselves—could be the subject of a separate *Virtual Mentor* issue.

For now, as Dr. Wynia argues, even if a physician believes a patient is wrong about the cause of his or her illness, the belief is important and should be acknowledged by the physician. To do so does not require a physician to accept the beliefs as his or her own but rather to understand and address them for the ultimate well-being of the patient.

Dr. Wynia’s view that culturally sensitive care and medical science can coexist in the same medical encounter answers the first part of the op-ed by Romana Hasnain-Wynia and Debra Pierce, which poses just that question. They explore whether it is possible to give culturally appropriate care within the confines of evidence-based medicine. The two approaches, they argue, may appear to be fundamentally opposed, but, much like the “art” and “science” of medicine, each approach offers insights, and physicians can and do utilize both approaches in providing effective care.

Yolanda Partida, director of *Hablamos Juntos*—a national project focused on language barriers in health care—invites us to think more broadly about the topic of multiculturalism, arguing that lessons learned from patients with limited English proficiency can translate into everyday practice for all patients. Viewed in this light, every patient-physician encounter is a multicultural encounter.

Education and research can further sensitize us to issues of cultural difference. Ruby Roy describes a course in which students learned innovative ways of accessing their own cultural assumptions through the use of narrative and includes several examples of student work in the article. Maria Luisa Zuniga explores several themes from a 2001 article by Marianne Sullivan et al.—“Researcher and Researched-Community Perspectives: Toward Bridging the Gap”—citing examples of cultural negotiation that have informed her own community-based research.

As with everything in medicine, there are important legal ramifications to the subject of language and cultural barriers. Mara Youdelman offers a thorough overview of both federal and state legislation which has affected the care of patients with limited English proficiency. Her article concludes with a consensus-driven statement of principles which rests on the premise that quality care can and must be provided to all individuals regardless of their language. Abigail Van Kempen alerts physicians to four areas that they must negotiate when confronted with language barriers if they are to avoid legal liability. She describes several cases where Youdelman’s principles might have helped. Unfortunately, as the cases illustrate, the presence of a language barrier can be an enabling condition for the delivery of substandard care—inadequate histories are taken, and assumptions are made that lead to poor outcomes and legal consequences. The physicians in these cases were not sued because they were not bilingual or did not have a professional interpreter on staff, but clearly they could have done a better job had they appreciated the extent to which a language barrier had compromised the care of their patients.

Finally, it is worth noting that culture is dynamic, shaped by a number of interactive forces and constantly changing. Allison Grady illustrates this notion by showing how American public health messages have evolved from images and cartoons which depicted immigrants as influences to be feared by the mainstream of society to today’s use of imagery as a means of communication for a wider audience, including individuals of diverse backgrounds.

As this imagery has changed, we also see that the daily practice and teaching of medicine—so rooted in tradition and itself a kind of culture—has evolved and will continue to adapt to the cultural values held by patients. The articles in this issue demonstrate the ramifications in the fields of medicine, law, education, and most importantly, in the interactions between patients and physicians. I would like to thank all the authors and fellow editors who have contributed to this issue.

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Robert Deiss, MD
San Diego, California

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Clinical Case

Western Medicine's Diagnostic Labels Are Not Universal

Commentary by Andres Sciolla, MD

Mr. Phal had a history of intermittent sharp neck pains and dizziness and was seeing his internist, Dr. Lang, for persistent abdominal pain. After a thorough work-up, including several visits, extensive laboratory analyses, and a negative abdominal CT, no explanation for the pain could be found. Dr. Lang therefore referred Mr. Phal to a psychiatrist in her group to screen him for somatization disorder, depression, or other psychiatric illness that might underlie his symptoms. Mr. Phal was Cambodian and 55 years old. He was resistant to seeing a psychiatrist because he believed that taking pills to feel better was an American practice. But because the work-up had revealed nothing so far, he decided he would try this too.

The psychiatrist, Dr. Hanson, greeted Mr. Phal and learned that he was employed as a store manager and that he enjoyed his work. Mr. Phal was widowed and had two grown children. He did not seem depressed to the psychiatrist. He stated that he did occasionally have bad dreams, but they were not frequent. When asked the question, "Have you ever had a panic attack, when you suddenly felt frightened or anxious or suddenly developed a lot of physical symptoms?" Mr. Phal replied, "No." Nonetheless, Dr. Hanson was worried because he was familiar with this patient population and realized that most adult Cambodians residing in the U.S. had suffered some form of trauma during the period of upheaval and genocide of the 1970s. He probed further and learned that the neck pains reminded Mr. Phal of pains he had had while he was in a labor camp. On the basis of this interview and other assessment tools, Dr. Hanson diagnosed Mr. Phal with post-traumatic stress disorder (PTSD) and explained to Dr. Lang in a letter that Mr. Phal's somatic complaints were most likely a manifestation of this diagnosis. Dr. Hanson recommended cognitive behavioral therapy in addition to treatment with an antidepressant (an SSRI, or selective serotonin reuptake inhibitor) for management of Mr. Phal's symptoms.

Dr. Lang was conflicted. She had thought the referral would result in a diagnosis of "somatization disorder," which she would use mainly for documentation purposes. She was not sure she agreed with Dr. Hanson's diagnosis, particularly given the lack of classic symptoms and therefore did not fully agree with the psychiatrist's management plan. At the same time, she had no alternatives and so she was willing to transfer management to the psychiatrist. Nevertheless she thought that Mr. Phal would probably resist medication for a psychiatric condition and did not think that

talking would do him much good. The internist wondered how she might best care for Mr. Phal.

Commentary

“I cannot see the true face of Mount Lu because I am standing on top of it”

Su Shi (1036-1101 CE) – Song Dynasty poet, painter, and calligrapher

Humans have surely striven to recognize, treat, and prevent health problems since before recorded history. Practitioners of the art and science of healing are known to exist in every culture. Psychiatry, however, is a conspicuously Western cultural artifact dating back barely 200 years. Deep in its ideological core lies the value placed by Westerners in the distinction between a “soma,” a physical body that is attached to but distinct from a “psyche,” or mind. Unsurprisingly, Western medicine has practitioners who treat *diseases* with physical causes and practitioners who treat *disorders* caused by mental mechanisms. Aside from the cultural ideologies of practitioners, patients themselves experience their problems and communicate them to others in culturally sanctioned ways. These “idioms of distress” reflect underlying values, such as the Western emphasis on individual agency and the *self* as the origin of problematic behavior.

Two clinical examples can illustrate this point. In Western countries, the paranoid subtype of schizophrenia is more common than the catatonic subtype, which is more frequent in nonindustrialized countries [1]. The private, subjective symptoms of delusions (outside forces controlling the self) and hallucinations (outside voices talking to the self) are prominent in paranoid schizophrenia. In catatonic schizophrenia, the most prominent symptoms are public and objective: patients fluctuate between mutism and immobility in awkward postures and seemingly random agitation.

The other example is depression. In Western countries, subjective feelings of individual guilt and hopelessness are spontaneously endorsed, while elsewhere patients are more likely to volunteer physical symptoms (e.g., fatigue) and concerns over social role limitations (e.g., inability to work) [2].

In contrast to Western cultures, the East Asian cultures have regarded the mind-body as a whole and emphasized balance and complementarity between the individual and the collective, humans and the environment. More fundamentally, East Asian philosophers have ignored the typically Western distinction between the worlds of reality and appearance. Rather, they strive to grasp the order immanent in the one world of concrete reality, without recourse to a force or being that provides that order from outside. Asian medicine does not consider physical and mental disorders as qualitatively different, nor illnesses as stemming from a malfunction restricted to a single organ such as the brain. Where Western psychology emphasizes the *atomistic* tension between nature *or* nurture, agency *or* context, East Asian psychology sees a

holistic continuum of nature *and* nurture, agency *and* context to explain human behavior [3].

The case of Mr. Phal exhibits clinical and ethical dilemmas that presage poor outcomes. Dr. Lang, Mr. Phal's internist, suspects that he suffers from a somatization disorder. Dr. Hanson, the psychiatrist, disagrees and thinks that the patient has PTSD. Mr. Phal doesn't seem to agree with either of them, doesn't want to take pills, and is reluctant to engage in a treatment—psychotherapy—that relies on words to help patients. Incidentally, research has shown that Western types of psychotherapy need to be modified and delivered by culturally competent therapists in order to be acceptable and effective in ethnically diverse groups. Regrettably, Mr. Phal's doctors apparently have not asked what *he* thinks is the matter, nor what people in his culture would call his condition and how they would treat it.

Below is a problem list for this case.

Patient-physician communication problems. (Mr. Phal-Dr. Lang; Mr. Phal-Dr. Hanson). At this point, the physicians do not know what their patient thinks about their diagnoses and treatment plans.

Communication problems between clinicians. (Dr. Lang-Dr. Hanson). The internist disagrees with the psychiatrist's diagnosis and treatment recommendations.

Professional competence. This pertains to both medical knowledge and cultural competence (Dr. Lang's diagnosis of somatization when the more appropriate diagnosis is PTSD, and the failure of both physicians to establish a relationship with an ethnically discordant patient, a failure that can lead to poor treatment adherence).

I discuss below three interrelated principles together with examples of concrete approaches they could offer to address these problems.

Mindfulness Practice

Mindful practice was defined by Ron Epstein as attending in a nonjudgmental way to our own physical and mental processes during ordinary, everyday tasks [4]. This ongoing self-awareness enables physicians to listen attentively to patients' distress, recognize their own errors, refine their technical skills, make evidence-based decisions, and clarify their values. They can then act with compassion, technical competence, presence, and insight. Mindful practice would help Dr. Lang notice in herself the discomfort physicians often feel with patients who present with physical complaints without organic findings, or complaints of disability in excess of what would be expected. Could nonconscious frustration and helplessness drive a physician to diagnose a patient with a label—somatizing—that has negative connotations?

Patient-Centered Medicine

A well-known 2001 report by the Institute of Medicine defined patient-centered medicine as care that is respectful of and responsive to individual patient

preferences, needs, and values and ensures that patient values guide all clinical decisions [5]. Guided by patient-centeredness, a physician would elicit Mr. Phal's beliefs regarding his diagnosis and treatment preferences [6]. In the process of engaging the patient, this physician may find out that Mr. Phal values the opinion of his adult children. Later, by allowing Mr. Phal to elaborate, the physician may discover that his children are highly acculturated and have a favorable disposition toward psychotherapy, even if they are somewhat uneasy with psychotropic medication. Later still, the physician's interest may aid in setting up a family-centered intervention. In this intervention the patient's children may act as cultural brokers and help reach a compromise, whereby Mr. Phal agrees to see both a therapist and a traditional healer who uses herbs and massage.

Patient-centeredness amounts to little if it is a quality of individual clinicians. As the IOM report stressed, patient-centered medicine is a goal for health care teams and the health care system as a whole. This goal would suggest that Drs. Lang and Hanson (and eventually the therapist if Mr. Phal agrees to the referral) would agree that "documentation" and the correct diagnosis are important, but they are secondary to the chief issue at stake, namely, an assessment and plan built around Mr. Phal's preferences, needs, and values.

Cultural Humility

Melanie Tervalon and Jann Murray-Garcia defined cultural humility as a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations [7]. From this stance, the physician relinquishes the role of *expert about* the patient and becomes the *student of* the patient, confident in the patient's potential to become a capable and full partner in the therapeutic alliance. An awareness of the beliefs, values, and biases that she brings into an encounter with every patient would enable a physician like Dr. Lang to learn about Mr. Phal's own beliefs, values, and biases with interest and tact. Thus, the physician need not be knowledgeable about Cambodian culture, because she will become knowledgeable about this particular Cambodian patient. She would learn whatever is relevant of Cambodian culture and history to this patient, and avoid a cookie-cutter approach with a stereotypical Cambodian patient in mind.

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Andres Sciolla, MD, is assistant professor of psychiatry at University of California, San Diego, where he teaches patient-physician communication to medical students. He sees patients in UCSD's Outpatient Services Clinic and at the Maria Sardinias Center in San Ysidro, California. His research interests include medical and psychological outcomes of adult survivors of childhood trauma.

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Clinical Case

Susto: Acknowledging Patients' Beliefs about Illness

Commentary by Lindia Willies-Jacobo, MD

Junior Valez is admitted for treatment for presumed Guillain-Barre syndrome. On discussing the history of the 15-year-old boy's illness with the doctor, his mother volunteers her opinion that the illness resulted from a "susto"—a common folkloric concept among some Latino communities, where illness is thought to be provoked by psychological trauma. When asked what the inciting episode may have been, Junior's mother replies, "We don't want to talk about it."

"Is that right, Junior?" asks the physician.

"Yeah, it's fine."

The physician, Dr. Bernard, has to finish rounds but makes a note to herself to revisit the issue with Junior.

Dr. Bernard finds Junior alone the next day during her afternoon rounds and talks to him some more. They establish rapport, and he tells her that he is interested in science and wants to be a physician himself one day. Dr. Bernard decides now is a good time to ask the patient once more what might have caused the "susto."

"It was just something my father said."

"What did he say?"

"I don't want to talk about it."

Dr. Bernard, trained to search for underlying problems, is concerned that the boy may have been a victim of emotional abuse. At the same time, she has witnessed the interaction between the boy and his father, and also between both parents, and does not otherwise have any other reason to suspect abuse. Junior then asks, "Do you think he could have made me sick like my mom says?"

Commentary

As the racial, ethnic, and cultural portrait of the United States continues to change, it is increasingly important for health care professionals to become culturally competent. According to the 2000 U.S. Census Bureau Report, more than 47 million people speak a language other than English at home, and nearly 45 percent of these

have difficulty speaking English [1]. One in every 10 persons in the U.S. is foreign-born, and by the year 2020, an estimated 40 percent of school-age children will be members of minority groups. In California, Latinos are the fastest-growing minority group in that state, and one-third of these are children.

Cultural competence and sensitivity play an integral part in the effective delivery of patient care. Their importance has been acknowledged by several oversight bodies of medical education, including the Liaison Committee on Medical Education and the Residency Review Committee for Pediatrics. These groups have called for inclusion of the multicultural dimensions of health care in the curriculum and structured educational experiences that will prepare trainees for the role of health advocate within the community [2].

The American Academy of Pediatrics, in its December 2004 Policy Statement, recognized the need for culturally effective pediatric care. This policy states that

the needs of the pediatric population are influenced by factors relating to culture and ethnicity. Pediatricians must acquire the knowledge and practice skills that will allow them to recognize and address culture and ethnicity, make valid assessments of clinical findings, and provide effective patient management [3].

Awareness Assessment

This particular case presents several challenges. There are clearly cultural forces at play, with the added conflicts of adolescence and possible emotional abuse by the child's father. When interacting with patients and families from different cultural backgrounds, we must first understand and acknowledge that culture has a tremendous impact on a patient's health beliefs, practices, and behavior, regardless of the specific patient's cultural background. Then we should incorporate this knowledge into our treatment of the patient. Developing a systematic approach to interacting with patients and families from different backgrounds is essential.

Lee Pachter proposed a model for cultural competency known as "awareness-assessment-negotiation" [4] that can be applied to clinical encounters with patients from any background and is especially helpful when a family's beliefs about health and illness do not fit a standard Western biomedical model.

The first part of the model calls for awareness. The clinician must learn about the commonly held beliefs, practices, and values specific to the patient population that is being served. In this particular vignette, knowing about some of the normative cultural values of Latinos would have been helpful. Normative cultural values are beliefs, behaviors, and ideas shared by a group of people that are expected to be observed in interpersonal relations. Five normative cultural values of Latinos that can influence their expectations of the patient-physician encounter are *simpatia* (kindness), *personalismo* (formal friendliness), *respeto* (respect), *familismo* (collective loyalty to the extended family) and *fatalismo* (fatalism) [5].

Many Latino families prefer a warm, friendly style of communication and may value a more personal relationship with the physician. This can be in stark contrast to the manner in which many Western health professionals communicate. We often place significant value on “directness” and “getting to the point,” especially when there are distinct time constraints with each visit. The Latino culture may view this approach as offensive. In this particular vignette, depending on how the information about Guillain-Barre syndrome was discussed, the mother may have felt somewhat alienated from the beginning of the encounter. The danger here is that the person who feels alienated may withhold information.

Assessment of Family Beliefs

The second part of the model—assessment—asks whether the family with whom we are interacting embraces a particular belief system and, if so, under what circumstances. The risk of stereotyping is always present when we are dealing with people from other cultures, and this part of the model attempts to eliminate that element. Once you have become aware of some of the commonly held beliefs and practices of a particular culture, you should share that knowledge with the family and to find out whether the family subscribes to those beliefs and under what circumstances. Inquiring about the patient and family’s level of acculturation is important. There are many ways to do this, however. Using the Kleinman Cultural History [6], a physician asks open-ended questions to explore health-related belief systems.

Knowing about some of the folk illnesses in the Latino community would be useful in approaching this particular family. The mother mentions *susto* as a concern. *Susto*, also known as “fright,” is one of the common folk illnesses seen in the Latino population. Illnesses from *susto* are believed to result from a shocking, unpleasant, or frightening experience that is believed to cause the soul to leave the body. Common symptoms of *susto* are restlessness during sleep and listlessness and weakness when awake. Traditionally, *susto* is cured by *curanderos* (folk healers) through the use of herbal teas and prayer ceremonies, during which the patient and family are present. Other Latino folk illnesses that we should be aware of are *mal de ojo* (evil eye), *empacho* (blocked intestine), and *mollera caida* (sunken fontanel) [7]. Knowing about folk illnesses and their treatments is critical because some of the therapies may not be benign. For example, giving lead oxide-containing substances is the treatment of choice for *empacho*, and there are many reports of lead toxicity in the literature as a result of this practice.

Negotiating Cultural Conflicts

The third part of the model calls for negotiation. While the physician is under no particular obligation to agree with a patient’s or family’s particular belief system, he or she should find ways of compromising with families if there is an area of cultural conflict that has significant consequences for the child. In this case, in addition to asking about the inciting event, it may be helpful to explore some of the treatments that the mother had in mind for the child. This may promote better dialogue and

improve the clinical encounter. Because Junior is an adolescent, it is imperative that the physician have the opportunity to talk to him alone to gain a better understanding of his relationship with his parents and, more specifically, with his father. It is only after this relationship is understood that issues of possible emotional abuse can be better explored. Based on his comments to Dr. Bernard, Junior may be significantly more acculturated than his parents, which may also be a source of conflict. The issue of possible abuse should be raised with the boy and his family, but only if there continues to be suspicion after all of the cultural issues are addressed.

Delivering effective care to our patients demands that we acknowledge the role that culture plays in people's lives. A person's culturally based health beliefs and practices determine what problems are recognized as needing traditional Western medical care and also whether the patient and his or her family will follow through with the prescribed treatment.

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Lindia Willies-Jacobo, MD, is associate professor of pediatrics at the University of California, San Diego School of Medicine and director of the Pediatrics Clerkship Program. She is especially interested in curriculum development and cultural competency in pediatrics.

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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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Jennifer Blanchard, MD, is an assistant clinical professor of medicine at the University of California, San Diego (UCSD). As a faculty member of the Owen Clinic, UCSD's HIV specialty clinic, she cares for patients and families with HIV, many of whom are of Mexican heritage, along with a cohort of patients from East Africa.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

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Medical Education

Teaching Cultural Sensitivity through Literature and Reflective Writing

Ruby Roy, MD

Teaching cultural competence to medical students in a meaningful way is challenging. Trying to teach cultural communication as a measurable skill oversimplifies both the complexities of culture, race, and ethnicity and their effect on the medical interaction. We want to embrace cultural understanding but avoid cultural stereotyping. To ask medical students to learn all the characteristics of a culture potentially categorizes future patients, thus denying them individual identity within the broader racial, ethnic, or cultural label we apply to them. For some, this approach has been denigrated as “political correctness,” while, from the standpoint of the patient who is pre-judged by his or her label, it can seem racist.

“Cultural humility,” a concept initially described by Drs. Tervalon and Murray-Garcia [1] is not only more respectful but also more pedagogically sound. Cultural humility asks physicians to understand their own culture(s) as well as that of the patient and view this understanding as a lifelong process of self-reflection and self-critique. If cultural humility is viewed thus, it may encourage the process of personal and professional growth.

Literature and reflective writing provide a natural tool to inspire questions and stimulate discussion on culture. Examining questions of culture, bias, and communication in a story or poem is emotionally safer than recounting personal experiences, but sharing of personal experiences and individual stories is also essential to apply the questions raised to one’s own life and one’s own medical practice.

We combined these techniques in teaching the Culture, Narrative, and Medicine elective at the Loyola University Chicago Stritch School of Medicine. We chose stories and poems by a variety of authors and two book-length narratives, *There Are No Children Here* by Alex Kotlowitz and *The Spirit Catches You and You Fall Down* by Anne Fadiman. This was not a literature class per se; the literary pieces were selected to inspire questions and discussion about cultural differences. We had four sessions: (1) the meaning of culture, (2) culture and discrimination: the nature of “otherness,” (3) cross-cultural communication: how to build bridges, and (4) culture and medicine.

Students were required to bring a short reflective piece to refer to during discussion. This writing could be a topic of their own choosing or a response to the reading—

and the students were given suggested questions in keeping with the theme of the day. The questions were selected to encourage personal reflection about the readings, for example: “How does your race, ethnicity, or cultural background affect the way you think about patients and their values?” or “Consider the nature of bias, differential care, and discrimination as depicted in this work. How have you experienced any of these?”

I asked the students to approach the reading as they would a patient who needed to be carefully evaluated: what can be learned from listening to the history, i.e., reading the story? We used literary analysis as an analogue to the physical exam: to evaluate the structure, language, diction, word choice, use of metaphor, and symbolism as we would evaluate physical signs.

The discussion followed a reflective listening technique taken from Rachel Naomi Remen’s Healer’s Art curriculum [2]. This format presumes confidentiality and an expectation that students will not be competitive with each other in discussion—no arguing, no advice-giving, acceptance of opposing viewpoints, and generous listening. The participation evaluation for these sessions looked at oral and written participation equally, so that students who expressed themselves better in writing did not feel obligated to speak.

We took the last hour of the session to do a reflective writing assignment. This writing technique was inspired by Rita Charon’s Narrative Medicine Workshop [3]. Both faculty and students participated in the assignment and reading. The prompts, unknown to the students in advance, included such questions as “Describe a time when you felt out of place or that you didn’t belong” and “Describe an interaction when you witnessed someone being affected by bias or prejudice.” Although this exercise was foreign to all of the students and not greeted initially with enthusiasm, it was the richest part of the course for all involved. It stimulated intense personal discussion and reflection on the difficult themes of personal identity and bias. All of the students shared an appreciation for the value of spontaneous reflective writing and I learned anew that personal experience could be a strong teaching tool. (Three examples are included at the end of this article.)

Both teaching and practicing cultural humility is counter to our medical culture. Medical culture prides itself on being scientific, objective, and evidence based, but is often rigidly hierarchical and still quite paternalistic. For medical students who have spent four years working hard to fit themselves into medical culture mores, it is difficult to then admit that medical culture can, itself, be a problem. It’s challenging to be humble in a culture that prizes expertise and knowledge. As one student wrote about one of the course readings, “Until I read this book, the ramifications of cultural humility had never really struck home. I had never considered myself to be culturally humble; as a matter of fact, I considered myself culturally proud.”

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Student Writing

1.
The man lit himself on fire
gasoline can on the driveway
Heat from an argument ignite a fuse
Horror. In a moment his wife fled
She was there at the bedside.

In the same time, I began
Second day on the smoking burn unit
Eager to please but without a clue
Given the task by my senior
Make sure she knows he's got a mountain

To climb without a harness
Every step a freefall
Te hablas ingles, I mustered
My broken Spanish could not reach
Her failed English no help either

Call the chaplain I was told
An older woman marched forward
In the room, by the bedside
Soft voice and gentle tones
Her broken Spanish barely exceeding mine

Compassion. Calm Clarity
Universal expression without accents
The wife sighed and walked back to her chair.

2.
Wearing a blue striped collared shirt and khaki pants in the back of a taxi I sat having had one too many drinks, a typical state of a young Caucasian male in Lincoln Park

on a Friday. Upon waking the next morning I found I had lost my cell phone, which became a mission to retrieve. I was directed to the office of Blue Cab, which is located on the south side of Chicago. I drove my car there the following day, entering a world I was unfamiliar with. I felt uneasy stepping out of my car and even more uncomfortable attempting to enter the unwelcoming facilities. I received many stares and not much help. I knew I did not belong. Although I had driven for only 30 minutes, I had entered a world very distant me. I was a foreigner, and not one that was welcome. My visit was brief and harmless. However, the mix of emotions I had that day, still occasionally crosses my mind. This experience was much more than a missing cell phone. To me, this was a realization of my life, where I have been and where I may be going.

3.

It used to be and sometimes still is that when I visit my family, I feel quite out of place. My family is my dad, brother & wife & 2 sisters & husbands & mom & half brother. Actually, I'm quite comfortable with my sisters and their kids. But my brother does some sort of stocking job—been to prison twice. My 1st brother-in-law drives a truck for the same company, grew up smoking weed and a high school dropout, like my brother. My 2nd brother-in-law is a janitor. These in-laws are wonderful men. I love my brother and Dad (also a dropout). But education has distanced us. I'm terrible at small talk & am frightened at times of the prospect of needing to be too long in conversation with any of them. My mom is a religious quack—and she happens to be quite bright. I think I can talk more with her than the others (except my sisters). Wish I could fit in, we all like each other, but topics that interest me don't usually interest them. When they do, the knowledge gap is so wide, I think it may be better to stare across the chasm than to build such a long bridge with such little time.

Ruby Roy, MD, is a general academic pediatrician who recently joined the Neiswanger Institute for Bioethics and Health Policy and began teaching medical humanities at Loyola University Chicago Stritch School of Medicine.

Related in VM

[How to Catch the Story but Not Fall Down: Reading Our Way to More Culturally Appropriate Care, May 2006](#)

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Journal Discussion

Tools for Culturally Effective Care Gleaned from Community-Based Research

Maria Luisa Zuniga, PhD

Sullivan M, Kone A, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW.
Researcher and researched-community perspectives: toward bridging the gap.
Health Educ Behav. 2001;28(2):130-149.

Minorities and other underserved populations are frequently overrepresented in disease morbidity and adverse health outcomes when compared to mainstream, insured populations. To effectively address these disparities, the field of public health has sought to increase meaningful participation of diverse communities in research and health promotion activities. Engaging community members as mentors of physicians-in-training and as active participants in the physician training and feedback process also appears to have a positive impact on the ability of physicians-in-training to deliver culturally effective care, especially when they are provided with opportunities to be active learners within community settings [1, 2]. Involving communities in the physician training experience, therefore, may be one of many opportunities for drawing upon the field of community-based participatory research (CBPR) for guidance in improving delivery of culturally effective care.

In the report cited above, Sullivan and colleagues provide insight into differences between investigators and community member perceptions about research that are also relevant to understanding how physicians and patients perceive health and health care [1]. This qualitative study conducted in Seattle used semi-structured interviews to assess the experiences of persons involved at varying levels of CBPR that had taken place between 1992 and 1996. Study participants included community members who were familiar with community-based public health projects in their region, study investigators, and project staff.

Study results indicated problem areas that had also been found in prior community-based research, including researchers' misinterpretation of the cultural context of study participants, propagation of negative stereotypes in communities, and perceived power imbalances between community members and researchers. Although this was a small study that suffered from limitations common to other small studies (e.g., limited generalizability to other populations and cultural contexts), many of its findings suggest recommendations for improving opportunities to teach delivery of culturally effective care. Following are selected topics based on the work of Sullivan et al. that promote discussion about delivery of culturally

effective care and the potential for culturally *ineffective* care with examples relevant to the medical encounter that are drawn from this author's observations and specific examples derived from a community-based clinic.

Understanding the Patient's Cultural Context

Sullivan et al. report that study respondents voiced concern that researchers had misinterpreted the cultural context of some health-related behaviors. Drawing on the experiences of communities in studies, we find that clinician messages must be relevant to the realities of patients. For example, promoting use of condoms among patients living with HIV requires more than the patient's knowledge about how to use a condom properly. Clinicians must also consider the potential culture- and gender-specific implications of condom use in a given community. Teaching patients how to negotiate condom use in some cultures requires knowledge not only of the individual's perception of her or his power in the relationship, but also how she or he views use of condoms in the broader context of participation in risk behavior or acknowledgement of a partner's risk behavior.

In an ongoing study of barriers to participation of Latinos living with HIV along the U.S.-Mexico border in HIV/AIDS clinical trials, we heard from focus group members that access to research sites was difficult because of their reliance on public transportation. Public transportation, for example, involves considerable travel time [3]. Another group mentioned that, in an era of heightened sensitivity to immigration issues, persons of Mexican origin felt anxiety and fear over potential interactions with U.S. Border Patrol agents, who frequented public transportation stations in San Diego and requested identification of persons who fit certain profiles. These concerns were perceived as having a very real influence on patient participation in clinical trials.

Understanding the contextual reality of patients also forces us to figure out when we are doing the wrong thing for the right reason. Colleagues in a community-based HIV/AIDS clinic located in Southern California taught us an important lesson in caring for patients living with HIV. The red ribbon that has come to symbolize support for persons living with HIV/AIDS was worn by many staff and clinicians. When clinic leadership convened a community advisory board to get patient feedback about the clinic, they discovered that some patients felt uncomfortable because they were called from the waiting room by clinic staff members who were wearing the red ribbon. This reaction to social stigma was subtle yet poignant and real in the lives of persons living with HIV/AIDS. The lessons here are that care and clinician expectations must be firmly grounded in the patient's realities and that making opportunities to understand these realities can foster improved communication between clinicians and patients.

Reinforcement of Stigmatizing or Negative Stereotypes

Sullivan et al. found that some study participants felt as though negative assumptions about communities of color permeated the research project. This perception can indeed have an impact in the patient-clinician relationship. In our HIV clinical trials

participation study, for example, Latina focus group participants discussed how they had felt stereotyped by staff who made statements such as, “You Latinas tend to only eat *fritangas* (fried foods),” which some women found discounted their efforts to eat nutritiously and their earnest concerns about weight and body image [4].

Language Competence

Sullivan et al. do not mention overcoming language differences as a component of cultural research and clinical care arenas, perhaps because they take it for granted. Having health care workers who are able to speak with patients in their own language continues to be a priority among English-language learners. Among clinicians who are concerned about the limitations of using phone-based interpreter services, one realized that having an interpreter who is of a different gender than the patient can make the patient feel uncomfortable and can negatively impact the patient-clinician encounter.

Awareness of the possible influence of limited education on communication can help clinicians remember to use terminology that patients understand. In our research studies we have learned, for example, that terms including “stigma” (which is the same word in English and Spanish); “sexual orientation;” and “ethnic identity” may be foreign to patients or others who are unfamiliar with research terminology.

Different Perspectives on the Same Issue

In a recent study of barriers to HIV clinical trials participation, we observed a distinct difference in perception of barriers to participation between Latinas living with HIV and caregivers who serve them [4]. Latina participants’ primary concerns were about HIV-related stigma (e.g., concern that someone might find out they were HIV-positive if they participated in a study). HIV clinical staff and social services workers on the other hand, described the barriers to participation as more structural in nature, citing problems such as lack of child care and transportation. HIV stigma was not raised by any of the clinic staff interviewed. That perceptions of the same phenomenon—e.g., low participation in clinical trials—can differ drastically, has implications for a variety of clinical concerns, from medication adherence to patient willingness to discuss certain topics with their physicians and other caregivers.

Providing Clinicians-in-Training with Tools for Culturally Effective Care

Providers and physicians-in-training can create many opportunities to improve the delivery of culturally effective care through a variety of approaches. They can *promote patient-provider trust* through mitigating sometimes adverse circumstances faced by patients. We heard from recent focus groups that patients feel frustrated when they lose continuity with their clinicians or feel that clinicians are rushed. Often these structural and environmental forces are beyond the clinician’s control. Drawing from experiences in conducting CBPR, however, we can approach these situations by being honest and up-front with patients, letting them know that we are aware that a circumstance is not ideal, empathizing with them, and asking for an opportunity to work with them within the given circumstances. As Sullivan et al. put it, “To facilitate the development of trust, researchers were urged [by community

members] to be honest about their agendas, to follow through on promises, and to implement research findings” [5].

Physicians-in-training can *learn how to reflect on new experiences* and apply this reflective technique throughout their professional careers. To be effective, physicians must be comfortable with thoughtful reflection on why certain behaviors or poor adherence to clinical recommendations are occurring, even if they can’t do anything about it. In our study of before-and-after effects of a block rotation in community pediatrics [2], we found that prompting medical residents to reflect on their community experiences allowed them to express their understanding of culture and delivery of culturally effective care in community settings.

Drawing both from the fields of anthropology and CBPR, clinicians can also recognize how to approach patient encounters with cultural humility. In the context of CBPR, we approach our community experts as learners with sincere interest in working alongside the person or agency. The community is often a very willing teacher when asked for its expertise. Extending this to the patient-clinician relationship, expressing one’s sincere desire to learn from and about patients, may contribute to building trust.

In working with colleagues who are clinicians and researchers in CBPR projects, we know that physicians and other health professionals who are passionately devoted to improving opportunities for delivery of culturally effective care have raised some thoughtful questions that can indeed help us on our way to improve patient health: How do I help my patient feel comfortable if I do not speak her language and need to use a phone interpreter? How do I engage the community in a meaningful way? How do I provide feedback to the community? These are thought-provoking examples of the very nature of building relationships, reflective thought, and cultural humility, that can lead us to provide better care.

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Further Reading

Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health*. San Francisco, CA: John Wiley & Sons, Inc; 2005. This publication provides insights and practical guidance on approaches to improving community-level participation in research, from conceptualization of a study, to implementation to dissemination of findings.

Maria Luisa Zuniga, PhD, is an assistant professor and epidemiologist in the Division of International Health and Cross-Cultural Medicine at the University of California, San Diego (UCSD) School of Medicine and is also affiliated with the UCSD Division of Community Pediatrics and San Diego State University Graduate School of Public Health. She specializes in behavioral health and access to care in Latino populations living with HIV, particularly those living in the U.S.-Mexico border region.

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Clinical Pearl

Diagnosis and Treatment of Guillain-Barre Syndrome

Adel Olshansky, MD

Guillain-Barre syndrome (GBS) is a group of autoimmune conditions consisting of demyelinating and acute axonal degenerating forms of disease. GBS is sometimes known as Landry's ascending paralysis, French polio, acute idiopathic polyneuritis, or acute idiopathic polyradiculoneuritis. The disease is named for Georges Guillain and Jean Alexandre Barre, who discovered the characteristic feature of the disease—increased level of protein in cerebrospinal fluid with normal cell count—in 1916. Interestingly, however, the French physician Jean Landry had described the condition in 1859, a half-century earlier [1].

Diagnosis and Causes

The diagnosis of GBS is often made clinically. Complaints of symmetric weakness, increasing over the course of days, and absence of deep tendon reflexes on examination would make most diagnosticians think of GBS. Acute inflammatory demyelinating polyradiculoneuropathy (AIDP) is the most common subtype of GBS in the U.S. A typical patient reports rapidly progressing weakness, numbness, and tingling in the lower extremities. Sensory and motor abnormalities usually start distally and travel toward the trunk, arms, and face, but may have various patterns. On examination, patients have decreased or absent deep tendon reflexes [2-4].

In acute motor axonal neuropathy (AMAN), patients report progressive weakness but have no sensory complaints. Deep tendon reflexes may be normal. Patients with acute motor and sensory axonal neuropathy (AMSAN) have both motor and sensory deficits. A GBS variant, Miller-Fisher syndrome (MFS), is characterized by ophthalmoplegia, ataxia, and areflexia [2-4]. Motor and sensory deficits associated with the various forms of GBS progress over a two-week period in 50 percent of patients, and over four weeks in another 40 percent of patients [5]. One-third of patients require ventilator support due to paralysis of respiratory muscles [3]. Dysautonomia (hypotension, hypertension, arrhythmias, and urinary retention) occur in about 70 percent of patients.

Acute respiratory infection or gastroenteritis preceding the onset of weakness is frequently an important part of the medical history. Recent infection with *Campylobacter jejuni*, cytomegalovirus (CMV), Epstein-Barr virus and *Mycoplasma pneumoniae* have been serologically implicated in 32 percent, 13 percent, 10 percent, and 5 percent of patients with GBS, respectively [3]. *C. jejuni* infection is thought to induce an anti-ganglioside antibody. Molecular mimicry, involving similar

sequences of bacterial lipo-oligosaccharides and human gangliosides, are believed to underlie autoimmune attack on axonal membranes in AMAN [6]. Several gangliosides (GM1, GM1b, GD1a, and GalNAc-GD1a) on the motor axolemma were found to be likely epitopes for antibodies in AMAN [2]. Preceding *M. pneumoniae* infection was linked with high titers of anti-galactosyl-ceramide antibody (anti-GalCer), and elevated anti-CMV antibody correlated with high levels of anti-GM2 [6]. Antibodies against GQ1b are found in patients with MFS, and this test is 85-90 percent sensitive [6].

The clinical diagnosis of GBS needs to be confirmed by cerebrospinal fluid analysis and nerve conduction studies. Lumbar puncture is indicated in every case of suspected GBS. Albuminocytologic dissociation—an increase in protein with normal white blood cell count—is noted in nine out of 10 patients within one week of symptom onset. An increased lymphocyte would be inconsistent with GBS and may suggest sarcoidosis, Lyme disease neuropathy, or recent HIV infection [3]. Nerve conduction studies are useful to confirm the GBS diagnosis as well as to differentiate between the different subtypes, estimate the extent of injury, and formulate a prognosis [7].

All diseases that attack the spinal cord, peripheral nerves, muscles, neuromuscular junctions, and cerebral vessels may result in weakness, like GBS, and need to be considered in the differential diagnosis [8]. To make a formal diagnosis of GBS, two clinical criteria are required—progressive weakness in more than one limb and areflexia (or distal areflexia with proximal hyporeflexia). Albuminocytologic dissociation, nerve conduction findings, disease progression over days to four weeks, symmetry, mild sensory abnormalities, cranial nerve involvement, autonomic dysfunction, and recovery that starts in two to four weeks all support a diagnosis of GBS [2, 9]. Suspected GBS cases with progressive deficits over the course of eight weeks are considered chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) [2, 3].

Treatment

GBS requires hospitalization for supportive care and for close monitoring of respiratory function and signs of dysautonomy. Intravenous immunoglobulin G therapy and plasma exchange have been shown to be effective in AIDP. Use of steroids is not indicated [2]. Unfavorable prognosis correlates with older age, rapid onset of severe tetraparesis, early need for ventilator support, less than 20 percent compound muscle action potential, and AMSAN with preceding *C. jejuni* infection [10] or evidence of anti-GM1 antibodies. [3, 5].

The majority of patients begin to recover after two to four weeks from onset of symptoms. About 85 percent return to baseline within one year [9], and about 5-10 percent have remaining disabling motor and sensory deficits [3]. GBS mortality, estimated at about 5 percent, results from respiratory distress syndrome, aspiration pneumonia, sepsis, pulmonary embolism, and arrhythmias [9]. Relapse of disease may occur months to years from the first episode in 2-3 percent of patients [5].

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Adel Olshansky, MD, is in her first year of postgraduate medical training at St. Joseph's Hospital in Phoenix, and will begin a neurology residency at the University of Southern California in the summer of 2008. She graduated from UCLA with a BS in physiologic science and received her medical degree at University of California, San Diego School of Medicine.

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Health Law

Legal Risks of Ineffective Communication

Abigail Van Kempen

Two anxious parents rushed their 13-year-old daughter, Gricelda, to a Phoenix, Arizona, area emergency room [1] because she was suffering from severe stomach pains. They spoke only Spanish, the hospital staff spoke only English, and Gricelda, who often served as a translator for her parents, was too ill to explain her symptoms. She was given a pregnancy test, received a diagnosis of gastritis, and was sent home with instructions to schedule a doctor's appointment within three days. But Gricelda's symptoms worsened, so the next day her parents took her to a doctor recommended by the hospital. Although accompanied by a 14-year-old bilingual friend who served as translator, Gricelda still didn't receive treatment for her symptoms. The family returned to the hospital where Gricelda was finally diagnosed with a ruptured appendix. She died a few hours later.

Gricelda's death prompted outrage in Phoenix's large Spanish-speaking community, who saw this tragedy as clear evidence of the difficulties they faced in obtaining appropriate health care. The family ultimately filed a lawsuit against the hospitals and doctors who failed to treat Gricelda. That poor communication between a doctor and a patient could have such tragic results is both shocking and unusual, but the risks of ineffective communication between a doctor and a patient are not news to anyone working in the health care industry. Although secondary to patient injury, the legal consequences of ineffective communication between physicians and patients are real, important, and can have devastating results for all involved. There are four major areas of legal concern doctors should be aware of—medical malpractice suits due to improper medical care, legal vulnerability for a lack of informed consent, breach of the duty to warn of risks associated with treatment methods and medications, and breach of the patient's privacy rights.

Malpractice Suits

A physician who cannot communicate with a patient due to a language barrier may deliver delayed, incorrect, or improper medical care, potentially leading to a costly, time-consuming medical malpractice lawsuit. In one well-known case, an 18-year-old was rushed in to the emergency department, accompanied by his mother and girlfriend. The young man was unconscious, and the only clue to his condition was the use of the Spanish word "intoxicado" by his mother and girlfriend [2]. As no one in the ED spoke Spanish, hospital staff interpreted the word to mean that the boy was intoxicated or, more specifically, suffering from a drug overdose. What the women

had intended to convey, however, was that the boy was nauseated, not intoxicated. Nearly three days after his admission, all the while being treated for a drug overdose, the doctors ordered a routine neurological test. The test showed two blood clots in his brain, the result of a break in an artery that had been defective since birth. Finally receiving appropriate treatment for his condition, the boy regained consciousness, but was left with quadriplegia. He ultimately sued the hospital, the paramedics, the ED, and attending physicians for medical malpractice, and his settlement topped \$71 million.

The results in both cases are tragic, but the situations are not unusual. Without the help of an interpreter, doctors may fail to order necessary diagnostic tests or, as in the “intoxicado” case, may reach mistaken diagnoses based on what they believe their patients’ symptoms to be [3]. To avert serious or fatal consequences, some physicians rely on batteries of expensive, and often unnecessary, tests to fill in the gaps left by the language barrier, choosing to spend funds at the outset for the tests rather than for legal fees in the context of a malpractice defense. In reality, patients who have trouble navigating the health care system because of language barriers often have the same problems navigating the legal system, which makes suits of this type unlikely. But the very real risk of legal consequences due to improper medical care remains.

Lack of Informed Consent

In addition to lawsuits for improper care, physicians may be legally vulnerable if inability to communicate prevents them from obtaining adequate informed consent. *Quintero v. Encarnacion* is an illustration of this very problem [4]. Rita Quintero was found on the streets of a Kansas town. She was dressed oddly, hadn’t bathed recently, and was unable to communicate anything other than a few Spanish words. She was taken into protective custody, where doctors determined that she was mentally ill and in need of treatment. She was involuntarily committed, remained hospitalized for 12 years and was treated with psychotropic medications. Occasionally, Spanish interpreters were contacted to attempt to explain the treatment program to Quintero, but her grasp of the language was limited.

With the intervention of an advocacy group, the doctors and facility learned that Quintero was in fact a citizen of Mexico and a member of the Tarahumara Indian tribe and was not mentally ill. The behaviors that her first physicians had attributed to mental illness, including her dress and odd behavior, were actually either traditional aspects of her culture or side effects of the medications she had been on for years. Once an interpreter who spoke her language, Ramuri, was found, she was released from the facility and allowed to return home to Mexico, where she filed an action against the doctors and state.

The physicians argued that they had met the requirement of informed consent by offering all of the relevant information to Quintero, albeit in English or Spanish, languages she did not adequately understand. The court held that informed consent could not be obtained if the explanations were conducted in a language the patient

did not understand and allowed Quintero to proceed with her suit against the physicians. To prevail in a lack-of-informed-consent case, the plaintiff must prove both what a reasonable medical practitioner in the same or similar community would have disclosed to the patient and that the defendant (the physician) had departed from that norm [3]. If the patient's capacity to understand is limited by a language barrier, and the physician proceeds without addressing this barrier, though a reasonable practitioner in the community would, the physician may be liable for failing to obtain informed patient consent.

Breach of the Duty to Warn

Physicians also have a duty to warn their patients of the particular risks associated with individual prescription medications, courses of treatment, and no treatment. Under a number of legal doctrines, pharmaceutical companies fulfill their duty to warn customers by telling physicians of the known risks of prescription medications [5]. Physicians, in turn, must relate this information to patients, warn them of potential risks, and prescribe the appropriate type and dose of drug based on their medical expertise and their assessment of the patient. If a language barrier prevents doctors from ensuring that their patient understands the warnings or risks of a medication, those doctors may be liable in tort for breaching the duty to warn.

Breach of Patient's Privacy Rights

Courts have held that physician's ethical duty to protect their patients' privacy is a legal duty as well [6]. Thus, whenever an interpreter is used, the physician must ensure that the interpreter is trained and competent and that the patient's privacy rights will be protected. Generally, this isn't a problem when professionally trained interpreters are used, but it can be when informal interpreters, such as family members or other hospital staff, perform the service. Unauthorized disclosure of a patient's medical records, as can happen when informal interpreters are used, constitutes an invasion of privacy that may be the basis for a tort action for damages [3]. Many patients choose not to tell family members about the information they disclose to physicians when seeking treatment. Ultimately, although using family members or other informal interpreters may save interpretation costs, medical professionals should be aware that doing so they may make them liable for breach of the patient's privacy rights.

The legal risks of ineffective communication between doctor and patient may vary, but in most of these situations the physician could have avoided legal risk through the use of a trained, professional interpreter. While access to interpreters is sometimes limited or cost prohibitive, particularly in emergencies, telephone services or professional interpreters can usually be obtained within a short period of time, and their use can actually save costs and improve treatment outcomes. Physicians should be aware of the risks they face if they proceed with treatment without interpretation and should strive to find ways to communicate effectively. Doing so ultimately protects patients and physicians.

Abigail Van Kempen is the fifth DePaul-American Medical Association Law and Medical Ethics Scholar. She recently completed her first year at DePaul University College of Law, where she is a health law fellow and member of the Health Law Institute student board of directors. She is interested in the legal and ethical aspects of end-of-life care.

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Policy Forum

Can the Care Be High Quality if the Communication Is Not?

Mara Youdelman, JD, LLM

What do the following things have in common: a 40-year-old law, the recent focus on quality health care, and 23 million people? Each offers a compelling reason for health care professionals to focus on accurate patient-centered communication with their patients who are of limited English proficiency (LEP).

In 1964, more than 40 years ago now, Title VI of the Civil Rights Act was enacted [1]. One of its goals was to prevent discrimination from being funded with federal money:

No person in the United States shall, on ground of race, color, or *national origin*, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance (emphasis added) [2].

The federal Department of Health and Human Services (HHS) and the U.S. Supreme Court have construed “national origin” to include language, and thus recipients of federal funds can not discriminate against those who do not speak English [3]. Since virtually all health care organizations receive some federal funding [4], they must make certain that language barriers do not impact the quality of care provided to their LEP patients. Accurate communication is essential to a physician’s ability to obtain a patient’s history, make a correct diagnosis, and reduce medical errors; it is also critical to a patient’s understanding, so she can give informed consent and comply with treatment regimens.

According to the U.S. Census Bureau, more than 12 million individuals speak English “not well” or “not at all” and more than 23 million (8.6 percent of the population) speak English at a level lower than “very well” [5]. The number and diversity of languages is growing rapidly in rural states and counties as well as in urban environments [6]. Between 1990 and 2000, 15 states experienced more than 100 percent growth in their LEP populations [7]. Moreover, 80 percent of hospitals and 81 percent of internists encounter patients with limited English proficiency at least monthly [8].

Recognizing the changing demographics and the need to reinvigorate Title VI, President Clinton issued Executive Order 13166 (EO), entitled Improving Access to Services for Persons with Limited English Proficiency, [9] The EO—affirmed by

President George W. Bush—required each federal agency to issue a guidance statement to its federal funds recipients on making government-funded programs more accessible to these individuals. The HHS Office for Civil Rights’ “LEP Guidance” outlines four factors for evaluating whether a health care organization is doing enough to comply with Title VI: the number or proportion of LEP individuals eligible to be served or likely to be encountered by the program or grantee; the frequency with which LEP individuals come in contact with the program; the nature and importance of the program, activity, or service provided by the program to people’s lives; and the resources available to the grantee or recipient and costs.

Because there is no one-size-fits-all solution, the Office for Civil Rights evaluates compliance on a case-by-case basis, examining the totality of the circumstances. But the LEP Guidance does include a model plan [10], and the Office of Minority Health has released the “CLAS Standards” (Standards for Culturally and Linguistically Appropriate Services in health care) that, while reiterating the requirements of Title VI, also provide additional information on ensuring language access [11].

Beyond legal requirements, there are other equally vital reasons to support language access for patients with limited English proficiency. Health care providers from across the country have reported that language difficulties and inadequate funding of language services are major barriers to access to health care and a serious threat to the quality of the care patients with limited English proficiency receive [12].

In one study, more than a quarter of the patients who needed—but did not get—an interpreter reported they did not understand their medication instructions. This compared with only 2 percent of those who either did not need an interpreter or needed and received one [13]. Language barriers also impact source of care—non-English-speaking patients are less likely to use primary and preventive care and public health services and are more likely to use emergency rooms. Once at the emergency room, they receive far fewer services than do English-speaking patients [14].

Recognizing that quality of care should not be affected by the language one speaks, a national coalition of stakeholders formed in 2003 to develop a consensus-driven agenda to improve policies and funding for access to quality health care for individuals with limited English proficiency. This coalition, coordinated by the National Health Law Program and supported by The California Endowment, represents an ongoing, constructive approach for achieving consensus on addressing language access issues. The coalition includes numerous health care organizations, advocates, interpreter organizations, and accrediting organizations. It reflects the diversity of health care disciplines and perspectives found in the public, not-for-profit, and for-profit sectors of the U.S. health care system.

Statement of Principles

The national coalition’s Statement of Principles offers a conceptual guide for achieving quality care for patients with limited English proficiency by addressing

language access at the national, state, and local levels. The principles seek to ensure that language barriers do not affect health outcomes. Reaching consensus on these principles required a frank and thoughtful exchange about the health system's response to the needs of LEP populations. Coalition members sought to answer a fundamental question: Is it necessary that health care professionals offer linguistically competent care, and if so, why? The groups decided that such care is indeed necessary because providing quality and safe health care in our pluralistic society cannot be done without erasing language barriers. Thus the Statement of Principles guides the work of the coalition as it seeks to achieve practical solutions to the difficulties of providing care in an increasingly multilingual society [15]. The coalition's principles are:

Effective communication between health care providers and patients is essential to facilitating access to care, reducing health disparities and medical errors, and assuring a patient's ability to adhere to treatment plans.

Competent health care language services are essential elements of an effective public health and health care delivery system in a pluralistic society.

The responsibility to fund language services for LEP individuals in health care settings is a societal one that in all fairness cannot be visited upon any one segment of the public health or health care community.

Federal, state and local governments and health care insurers should establish and fund mechanisms through which appropriate language services are available where and when they are needed.

Because it is important for providing all patients the environment most conducive to positive health outcomes, linguistic diversity in the health care workforce should be encouraged, especially for individuals in direct patient contact positions.

All members of the health care community should continue to educate their staff and constituents about LEP issues and help them identify resources to improve access to quality care for LEP patients.

Access to English as a Second Language instruction is an additional mechanism for eliminating the language barriers that impede access to health care and should be made available on a timely basis to meet the needs of LEP individuals, including LEP health care workers.

Quality improvement processes should assess the adequacy of language services provided when evaluating the care of LEP patients, particularly with respect to outcome disparities and medical errors.

Mechanisms should be developed to establish the competency of those who provide language services, including interpreters, translators and bilingual staff/clinicians.

Continued efforts to improve primary language data collection are essential to enhance both services for, and research identifying the needs of, the LEP population.

Language services in health care settings must be available as a matter of course, and all stakeholders—including government agencies that fund, administer or oversee health care programs—must be accountable for providing or facilitating the provision of those services [16].

Among the health care provider associations endorsing the principles are: American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, American Hospital Association, and American Medical Association, to name a few. Both The Joint Commission and National Committee on Quality Assurance have endorsed them, along with over 50 other organizations [16].

Forty-three states have passed laws addressing language access, including a few that require cultural competency education in schools that train health professionals or for ongoing licensure [17]. While the federal requirements have existed for over 40 years, renewed focus on quality of care has reinforced the need for patient-centered communication that overcomes language barriers. The national coalition's principles recognize that effective communication is crucial to providing quality health care services and public health programs to patients with LEP. Thus, ensuring that language barriers do not impede health care access and quality is not merely an issue of law but also an issue of quality care.

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to support policies consonant with these principles. It is important to note that endorsement of these principles by an organization should not be interpreted as indicating its support for, or opposition to, any particular legislation or administrative proposal that may emerge.

16. Other endorsing organizations include American Medical Students Association, American Nurses Association, American Psychiatric Association, American Psychological Association, American Public Health Association, Association of Clinicians for the Underserved, Catholic Health Association, National Association of Community Health Centers, National Association of Public Hospitals and Health Systems, National Association of Social Workers, National Hispanic Medical Association, National Medical Association, Physicians for Human Rights, and Society of General Internal Medicine. For a list of current endorsing organizations see <http://www.healthlaw.org/library.cfm?fa=detail&id=56882&appView=folder> . Accessed June 20, 2007.
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Mara Youdelman, JD, LLM, is director of the National Language Access Advocacy Project, funded by The California Endowment, to increase awareness of language access issues at the federal level. She coordinates a national coalition to develop a consensus-driven agenda to improve policies and funding for individuals with limited English proficiency. She has worked at the National Health Law Program (NHeLP) since 2000 on issues including Medicaid, language access, racial and ethnic disparities, data collection, and immigrants' issues.

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Medicine and Society

Language Barriers and the Patient Encounter

Yolanda Partida

If they haven't already, many young physicians are likely to confront a reality that their mentors and teachers have not prepared them for: patients who cannot understand them. Research tells us that communication failures between patients and their caregivers contribute to adverse events and medical errors. Linguistic diversity within the United States today is far greater than in the whole of Europe [1]. Rapid growth of the population with limited English proficiency (LEP) is emerging as a new risk that few doctors are prepared to handle.

Communication challenges when patients and doctors do not speak the same language is not surprising, but, according to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the skills required to comprehend typical health information exceed the abilities of the average American [2]. Like the canary in the coal shaft warning miners of impending danger, patients with limited English proficiency may be the harbinger of challenges that go beyond language differences. This article takes the perspective that learning how to effectively communicate with patients when there are language differences may offer insights and skills transferable to communicating with English-speaking patients.

Speaking to patients through interpreters while actively considering inherent cultural factors offers a model to increase awareness of potential communication breakdowns with all patients. This is one of the essential lessons we've learned at *Hablamos Juntos* (Spanish for "We Speak Together"), the Robert Wood Johnson Foundation (RWJF)-funded initiative to develop affordable solutions for eliminating language barriers in health care. Since 2001 the national program office of *Hablamos Juntos* has tracked the literature on interpretation and translation and created an open dialogue with national experts, practicing interpreters, and translators with a shared interest in developing best practices.

Ten demonstration projects funded under *Hablamos Juntos* gave us an opportunity to explore solutions and gain an understanding of the challenges health care professionals face in providing high-quality, safe care to patients with limited English proficiency [3]. While focused on Spanish speakers with limited English, we came to the same conclusion as the JCAHO report—communication breakdowns occur even when patients and doctors speak the same language. The RWJF project has come to view every health care encounter as a cross-cultural encounter; the

culture and language gap between patients and their doctors is growing wider with every innovation in medical care and health reimbursement policy.

Language Barriers Influence Every Patient-Physician Encounter

As we listened to how the role of the interpreter was conceptualized, observed interpreter-mediated speech, and, in particular, studied translated text from English into Spanish we identified three factors inherent in language-discordant communication: (1) language and culture are inextricably linked; (2) relationship building is hindered with interpreter-mediated communication; and (3) cultural competency and effective communication are interdependent. Understanding how these factors affect communication with patients whose proficiency in English is limited can raise awareness of potential failures in communication with all patients.

Ninety million English-speaking Americans have trouble understanding complex texts common in health care [3]. Among those unable to comprehend typical health information were college graduates and professionals such as teachers and engineers. Beyond reading and writing skills, health literacy includes listening, speaking, and conceptual knowledge that make it possible to understand health interactions, forms, and instructions. In essence, health care environments have cultures of their own, ways of doing things, and uses of language that are different than what average persons experience in their day to day lives.

Rarely are physicians asked to think about how patients discern meaning from the information they receive during a visit. Language professionals tell us that words have no meaning until meaning is assigned; that is, as we learn new words we associate them with concepts that give them meaning. Comprehension, then, is based on our ability to link experience and knowledge of the world to the words we hear.

Scenes-and-Frames Semantics

Scenes-and-frames semantics is a theoretical model for understanding how we comprehend written words. In this model, words are “frames” that activate mental pictures or “scenes” related to past experiences and knowledge of the world. In order for comprehension to take place “frames” must activate proper “scenes.” In essence, words acquire meaning through context activation associated with particular “scenes.”

Generally, the mental maps we form of frames and scenes (words and associated concepts and meaning) are culturally determined—acquired formally through education, dictionaries, and thesauruses and informally through our lived experiences with family, friends and coworkers, and other socializing events such as movies, news reports, etc. Common experiences lead to common “frames of reference.” Speaking a language other than English in the U.S. obviously means that one’s lived experiences are likely to be quite different than those of English speakers. The greater the difference between our lived experiences and those of others, the more likely our frames of reference will be different. Therein lies the potential for misunderstanding.

In daily communication, minor misunderstandings are common. A simple command “Put it down” can be laced with ambiguity. Place it down on the table or drop it on the floor? Next to the phone or near the window? Our mental maps of word-concept associations help us draw conclusions about what is meant. The context in which the command is heard, the speaker, and our previous experience all help inform what is meant in a specific time and place. What is the likelihood that the scenes and frames used by American doctors are the same as the average English-speaking person’s? For example, the newly diagnosed diabetes patient may encounter familiar words such as blood, sugar, diet, and exercise but in a context that may be unfamiliar and possibly confusing. Not surprisingly, the idea that one can catch diabetes from someone else or that people with diabetes can’t eat sweets or chocolate are common myths.

If simple explanations can cause doubt, imagine what can happen when we consider that a typical health dictionary contains about 40,000-45,000 entries. Moreover, completely unrelated confounders such as reimbursement practices, local and national policies, economic trends, and technology—all of which influence how health care is organized and how medical care is delivered from city to city and state to state—can infuse unintended meaning. The nature of local institutions and relationships plays a pivotal role in determining the character of each community’s health care system. Without intending to do so, the cultures or referral patterns concerning who can be seen by which doctors also create a web of context that patients experience and must navigate. We have found that patients who have limited English proficiency are often victims of confusion introduced by local referral patterns. Being told they cannot be seen can lead to poor compliance or a belief that nothing can be done. In the end, language discordance is but one of many obstacles to good communication with patients.

Relationship-Building via Interpreters

Clear communication between caregivers and patients is essential to safe, high quality health care services. Developing rapport and gaining patient trust relies on understanding. When patient and doctor do not speak the same language, there is less opportunity to develop rapport or use “small talk” to obtain a comprehensive patient history, learn relevant clinical information, or increase emotional engagement in treatment. Rather than solving these problems the introduction of an interpreter may raise another set of questions.

Unfortunately, most interpreters learn their trade through on-the-job training. Their language proficiency and how accurately intended meaning is conveyed from one party to the other is often not known. Using untrained interpreters or family members who are less skilled in being transparent and impartial can result in incomplete patient assessments. How are subtle nonverbal communication cues (e.g., emphasis, alarm, urgency, or emotions such as empathy or concern) conveyed from one speaker to the other? The skills of an interpreter are critical—they are the sender and receiver of our message and the patient’s. Interpreter-mediated communication

brings attention to how normal communication is altered and how the connection and trust important to an effective patient-physician relationship may be more difficult to develop.

How then can we know when an interpreter-mediated communication has been effective? Training in working with interpreters and experience using interpreters can help. Speaking indirectly to patients requires active listening and engagement. Intermittent pauses, necessary to allow the interpreter to convey our message, can be opportunities to pay attention to facial expressions, gestures, or body language of the patient and to create new ways to maintain a connection and cultivate a relationship with the patient.

Uncertainty about what is being said or whether two-way understanding is taking place provide opportunities to explore doubts. Considering these obstacles can increase awareness of how we are connecting or not connecting with a patient, whether we are developing trust or not. Active engagement can make interpreter-mediated encounters more productive, while humanizing our ability to communicate with all patients, irrespective of language.

Cultural Competency and Communication Go Hand-in-Hand

Graduate medical education now includes content on culturally determined aspects of patient care—different disease explanatory models, ways of interacting with health care professionals, communication style, whether patients make eye contact or not, and differences in decision-making styles and in understanding of disease and health. Moreover, beliefs, attitudes, intentions, and behaviors toward health care—all derived from a patient's culture—factor into the patient-physician relationship. Modesty, refusal to eat certain foods, and observance of religious rituals are examples of cultural factors that must be negotiated in clinical encounters. At the same time, variability from one group to another and within groups can be stunning, particularly as we consider acculturation, education, and other factors that serve to broaden a person's world view.

Less attention has been paid to how the clinician's background influences the way he or she diagnoses disease and treats the patient [4]. And even less recognition has been given to how the culture of medicine determines interactions or how the culture of health care organizations influences what patients understand and how they experience care.

Too often we learn of life-and-death dramas in local newspapers—reminders of the potential affects of communication failure on patients with limited English proficiency: the young Savannah mother of two, unable to speak English, who died after being treated for a possible stomach infection in the emergency department and told to leave [5]; or the 41-year-old native of Haiti who died of tuberculosis after giving birth to a son, [6] never mentioning her coughing fits during regular visits to her obstetrician during pregnancy. These cases bring attention to the extreme outcomes, but, while language and cultural differences are markers for variability

that require attention, they can serve as reminders of the importance of effective communication in all clinical encounters. And the lessons should not stop there.

When 90 million American have trouble understanding and acting on health information, effective communication between patients and their doctors is a problem even when language is not a barrier [7]. Physicians need to understand that the health world is a foreign country to many Americans and pay closer attention to understanding the language patients use and how they draw meaning from what they hear. Interpreter-mediated encounters, as difficult as these may be, offer lessons for active listening and culturally aware communication—not just listening to what patients are saying but looking for what they may mean. In cross-cultural communication words alone are often insufficient. Looking and listening, making a human connection, even when the languages we speak are different, will go along way to understanding what patients need to comprehend the important advice physicians have to offer.

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Yolanda Partida is director of the national program of Hablamos Juntos, dedicated to eliminating language barriers in health care. The program's national office is at the Center for Medical & Education Research, at University of California, San Francisco's branch campus in Fresno.

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Op-Ed

Practicing Evidence-Based *and* Culturally Competent Medicine: Is it Possible?

Responses by Romana Hasnain-Wynia, PhD, and Debra Pierce and by
Matthew Wynia, MD, MPH, and Megan Johnson

Response 1

Romana Hasnain-Wynia, PhD, and Debra Pierce

Can evidence-based medicine (EBM) and cultural competence in medicine (CCM) be practiced simultaneously? To answer this question we must understand what each is. Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence, primarily from clinical trials, in making decisions about the care of individual patients. In general the goal of EBM has been to improve quality through the standardization of medical care. Cultural competency in medicine, by contrast, is the delivery of health services by workers who understand cultural diversity and factor it into the clinical setting and who respect individuals' health beliefs, values, and behaviors. Given these definitions, it would appear that the two practices conflict [1].

EBM and CCM share a common goal; both fundamentally work to improve the quality of health care, but they work at different levels—EBM focusing primarily on the standardization of care for all populations; CCM focusing on the individuals who make up those populations. Recently, however, EBM has begun to integrate aspects of CCM by incorporating individual circumstances and preferences into decision protocols. CCM has likewise developed methods to elicit patients' explanatory models—how they understand their illness—to avoid stereotyping and oversimplification of culture [2]. And there is increasing recognition that CCM could use a dose of EBM.

The two approaches share another trait—both are experiencing some backlash. Like many new ideas, EBM and CCM were initially applied in overly simplistic ways. This problem was exacerbated by the fact that both base their recommendations on modal information derived from populations and subgroups. EBM guidelines derive from population-based studies, while early teaching modules on CCM were based on general, or average, health beliefs among subpopulations—learning about Asian health care meant listening to a lecture about alternative treatments such as coining. EBM experienced a backlash over fears of “cookbook medicine” or clinical stereotyping, while CCM experienced a backlash over fears of cultural stereotyping.

As a result, as EBM and CCM evolve, they seem, in fact, to be merging. Today, both fields often claim to offer evidence-based and culturally competent care that is also patient centered [3-4]. But on face value, EBM's emphasis on standardization and CCM's emphasis on uniqueness remain at odds. Ultimately, for the two approaches to work together, we will need to see that EBM can be patient-centered and culturally competent and that CCM can demonstrably improve health outcomes. Can implementation of EBM guidelines make patients feel more listened to, empowered, and respected? Can CCM lead to fewer medical errors and better health outcomes? These important questions remain to be answered.

More to the point, physicians may ask whether it is possible to practice culturally competent and evidence based medicine. Patient preferences may be considered where multiple legitimate options for care exist, but this might not always be the case. Are there always multiple acceptable options from which to choose, and who gets to decide what is "acceptable?" And given today's more complex understanding of CCM, before clinicians can apply principles of cultural competence, they need to know how to identify patient preferences and values effectively. This raises another question: Is there evidence that such a nuanced understanding can even be measured, let alone affect health outcomes? Skeptics of cultural competence note the relative lack of empirical evidence linking training in CCM with improvements in health outcomes [5].

To evolve in complementary ways, EBM and CCM need to move toward clearer definitions of what they are and how they can be measured. Even more fundamentally, both need more clarity on the core ways in which they aim to improve health care quality. Our health care system and the individuals who provide care struggle to treat patients from a multitude of backgrounds with respect and dignity, while at the same time providing the best evidence-based medicine possible. For a truly open dialogue to exist, EBM should admit that it tends toward standardized clinical decisions, which can reduce individual discretion for both clinicians and patients. On the other hand, the CCM movement should admit that it promotes individual discretion, and therefore might lead to greater variability in clinical decision making. All of which is to say that we need a comprehensive research agenda to examine the intersection between EBM and CCM and to show that respect for cultural preferences is worthwhile and that the tools of EBM may be adapted to foster patient participation in their own health care decisions.

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Romana Hasnain-Wynia, PhD, is vice president of research at the Health Research and Educational Trust, the research and educational affiliate of the American Hospital Association, and adjunct associate professor at Northwestern University's Feinberg School of Medicine, both in Chicago. She is the principal investigator on a number of studies that examine quality of care for diverse populations.

Debra Pierce is project manager for Knowledge Networks at the Health Research and Educational Trust, the research and educational affiliate of the American Hospital Association in Chicago. The Knowledge Networks include the Center for Health Management Research and an Agency for Healthcare Research and Quality (AHRQ) ACTION Network.

Response 2

Matthew Wynia, MD, MPH, and Megan Johnson

What should a doctor do if a patient refuses useful or even lifesaving care because of cultural or religious beliefs? Does respect for other cultures mean the doctor should acquiesce without a challenge?

In our increasingly multicultural society, physicians are certain to encounter patients whose culture is different from their own. Some of these patients will have beliefs, practices, or health care values that are at odds with scientific medical practice. If a patient wants to pursue treatment that is alternative to and unproven in scientific medicine, should a doctor push the patient to use the treatment that he or she believes will give the best medical outcome? What if the reason for declining care is that the patient is afraid? In some cultures, hospitals are avoided; they are viewed as places where people go only to die. If patients are refusing not just helpful but lifesaving care, is it disrespectful to push back against cultural or religious beliefs that might seriously compromise their medical well-being?

In a recent series of visits to hospitals around the country, researchers from the American Medical Association's Institute for Ethics spoke to doctors and other staff members about their experiences in caring for patients from diverse cultural backgrounds [1]. Though we were not conducting a formal research study on cultural relativism in health care, what we learned can shed light on these challenging ethical dilemmas.

Lesson 1: Cultural Beliefs Deserve Respect, and They Are Not beyond Criticism

We heard about situations where, for cultural reasons, patients or their families initially asked for care that was not appropriate according to Western medicine and perhaps even harmful. The most extreme example of this was female genital mutilation, which no doctor was willing to condone even though it stems from a religious and cultural belief system. This extreme case shows that most doctors are not complete “cultural relativists,” who believe that one can never judge another’s cultural or religious belief systems. Doctors understand that cultures are malleable, intertwined and, though they are to be respected, they are not beyond criticism.

Philosopher Mary Midgley’s well-known essay from 1984, “Trying Out One’s New Sword,” soundly debunked the notion of extreme cultural relativism by telling the story of an ancient society in which warriors appear to have been allowed to test out their new swords by slicing a few unfortunate wayfarers “from shoulder to the opposite flank” [2]. These acts might have been considered morally acceptable in this ancient society but, Midgley says, we would be wrong to believe we cannot critically appraise them just because we aren’t living in that culture.

Midgley argues, in part, that if we couldn’t criticize other cultures then, by the same reasoning, we could never praise them either, nor could they ever have standing to praise or criticize us. More importantly, she notes that extreme cultural relativism is internally inconsistent—it claims that we cannot fully understand other cultures, yet we must respect them. But to truly respect something, one must understand it. So-called “respect” without understanding and the capacity to criticize would be a shallow form of respect indeed.

Lesson 2: Cultural Beliefs Affect Medical Care

Among philosophers, Midgley’s essay nailed tight the coffin lid on extreme cultural relativism. But among doctors, we could add yet another criticism; when it comes to some medical outcomes, results of decisions can be worse or better in an objective sense, not merely a subjective one. To give a medical example, imagine that members of a certain cultural group believe that most peptic ulcer disease (PUD) results from mental stress rather than infection. Such a belief might be strongly held; it might even have general intuitive appeal—but it would still be scientifically incorrect.

In this way, the mere fact that a belief is rooted in “culture” or even “religion” does not give it privileged status in the realm of medicine—privileged status in medicine comes from studies proving that one’s belief reflects what actually happens in most cases. For this reason, unlike many unconventional medical belief systems, science-based medical beliefs actually change frequently, as new data accrue. So while homeopathy still follows the same fundamental understanding of treatment that Samuel Hahneman proposed almost 200 years ago, so-called “conventional” medical treatments have changed dramatically even in the last 20 years [3].

But we chose PUD as an example for a reason: it is a nice illustration of how beliefs and other psychosocial factors can play a substantial role in disease causation,

symptoms, and outcomes. A solid body of research demonstrates that social class, stress, and associated risks like smoking, sleeplessness, irregular meals, heavy drinking, and use of nonsteroidal anti-inflammatory drugs, all play important roles in PUD pathogenesis [4]. So even though the cultural belief that stress causes ulcers would be scientifically incorrect, paying attention to culture is critical to a full understanding of this disease and to effective treatment for individual patients.

In other words, though some cultural beliefs might be legitimately criticized on medical grounds, culture must always be taken into account in the care of patients. And it must be taken into account in sensitive and respectful ways to get optimal health outcomes.

Lesson 3: Medical “Culture Clashes” often Reflect Misunderstandings

We learned in our visits that, in the vast majority of cases where patients or families at first seemed to be asking for something inappropriate because of a cultural belief, they were amenable to conventional care once better lines of communication and trust were established. In other cases, caregivers hadn’t really understood what the patients and families were asking to do. Once communication improved, good outcomes were common; and what seemed like a cultural barrier turned into a learning experience for both sides.

Many cultural misunderstandings turn out to be easy to fix. In one example, an interpreter explained why Somali women were moving chairs around in the waiting room. It was not culturally appropriate for them to sit back to back with men. In another case, a Seventh Day Adventist kept missing dialysis sessions. The staff were silently frustrated, until it was pointed out that the patient’s religion precluded his coming in for routine dialysis on Saturday mornings.

Some encounters turn into broader learning experiences. At one hospital, a Spanish-speaking patient, newly quadriplegic, seemed to be refusing to eat. The staff worried that his refusal was a symptom of depression. When an interpreter became involved, it was discovered that the patient just didn’t like the food being offered. He was happy to eat plain eggs and tortillas. Diabetes educators there now ask patients what they usually eat before telling them what foods they should eat. This allows the educators to tailor their recommendations, thereby enhancing compliance.

In other cases, being attuned to the patient’s culture was the cornerstone of effective care. At one hospital we visited, a Haitian patient reported abdominal pain. The hospital brought in a voodoo priestess to help with the workup; she determined that the patient was suffering from guilt after having an affair. At that same hospital, a pediatrician reported working with an interpreter to discover that an infant with an electrolyte imbalance was being given a traditional cough remedy containing fish oil and herbs. Once the family understood the risks of giving this mixture to their baby, they stopped.

Lesson 4: Be Cautious about Cultural Stereotyping

Finally, we heard stories of cultural stereotypes leading to misunderstandings. In one instance, an Hispanic patient was dying, and the staff wanted to call a Catholic priest. When one of them pointed out that they should ask about the patient's religion, they discovered that the family was Protestant.

In other cases, patients have come from traditionally family-oriented cultures, and staff sometimes assumed the patient would want the whole family to be involved in decision making. But each patient is different, and each should be asked how he or she wants to handle discussions and decisions about medical care.

Conclusion

Every individual comes from a unique background of health-related values and experiences. In this respect, doctors should consider every single patient encounter to be a "cross-cultural" encounter. Sometimes, patients really would rather risk an unproven treatment than go against their religious or cultural values, and a doctor needs to respect such decisions. Respect, however, does not mean instant acquiescence; respect actually demands forthright, honest, and clear communication to safeguard against misunderstandings or stereotyping. Patients deserve to make their own decisions about their care, and they also deserve to make those decisions with the best information available.

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Suggested Reading

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Matthew Wynia, MD, MPH, is the director of the Institute for Ethics at the American Medical Association, Chicago. Dr. Wynia practices infectious disease medicine at the University of Chicago Hospitals, where he is a clinical assistant professor of medicine.

Megan Johnson is a research assistant at the Institute for Ethics, where she assists with the Ethical Force program, an initiative to develop performance measures for ethical behavior across the health care system.

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Medical Humanities

Use of Images in Public Health Campaigns

Allison Grady

Illustrations have long been used to make statements about the current culture—pop, political, or otherwise. In the past, these images, which included cartoons, commented about culture and society’s often-negative perception of the “other,” but today they are more culturally diverse and place higher value on ethnic and racial variety. Rather than advancing cultural stereotypes, physicians and government health officials now use cartoons and other visual media to encourage greater health awareness among the entire population. The evolution of cartoons and animated images effectively demonstrates shifting attitudes about the intersection of culture, society, and medicine.

Cartoons as a Social Barometer in 19th Century America

Cartoons have been used by newspapers since the 1800s to offer stinging assessments of public officials and affairs.

...an essential characteristic of the cartoons is their agitational characters. They strove for change...often strident in their attack on political figures, their sole purpose was advocacy...the bold poster designs that have now become the sine qua non of every public health and safety campaign [1].

The best known cartoons during this era began appearing in newspapers in the 1870s and usually presented strong views about “hypocrites, industrialists, the professions, the rich, the idle, immigrant groups, workers, and participants in the latest fads and fashions” [2].

The venom of the cartoonist’s pen extended to medicine, physicians, and racial minorities and still managed to include some political editorializing. The general framework for these political-medical cartoons was “observation of a problem, fear of the spread of disease or injury, attempt to secure official action, anger at government’s failure to act...and appeal to right-minded citizens for immediate action and for reform of government” [3]. An example of this type of cartoon, entitled “Our Honored Guest,” was drawn by Frank Bellow and appeared in *Harper’s Weekly* in 1871 [4]. In this image the Grim Reaper carries a doctor’s bag labeled “cholera” and “Asia” through dirty streets in a U.S. town and is greeted by disheveled governmental officials. The caption of the illustration reads, “We bid you welcome believing that you will find the condition of our streets to suit you as well as anything in Asia” [4].

This particularly striking cartoon took aim at local community conditions, government officials, physicians, and immigrants. It reflected the common perception of physicians as more likely to be responsible for death than for its prevention, and it depicts the disdain that many citizens felt toward the national governments of both the United States and the country or area where a disease originated, believing that capitalist greed resulted in worse health for Americans.

It is interesting to consider how this cartoon might be re-drawn in 2007, given that the national attitude towards immigrants is particularly contentious. It should be noted that in the caption the cartoon did not address individual *people*, but rather geographical regions, choosing to comment implicitly about the type of people who lived in these areas. Given the political correctness of today's society, this cartoon would probably be found to be in poor taste, since purposefully portraying specific countries in a blanket, negative way is now frowned upon. In addition, doctors' skills are generally held in higher esteem today than they were 150 years ago.

Using Images to Educate the American Public

The use of images to draw society's attention to health and medicine moved away from the politically provocative newspaper cartoons and towards government-issued visuals during the first half of the 20th century. Between 1920 and the 1960s the United States government forwarded its public health agenda with the help of animated movies. These reels featured the work of Theodore Geisel, better known as Dr. Seuss, who led the animation unit of the U.S. military during World War II; Walt Disney; and the creators of Popeye, to depict the dangers of stomach cancer, tooth decay, and tuberculosis among others [5]. Many of these short movies were aimed at soldiers who were being taught how to

keep their mess gear clean, avoid fear of battle, and properly use the bathroom at base camp. ... in *Enemy Bacteria* a melodramatic 1945 saga commissioned by the US Navy [the story is] told from the point of view of a germ that has gotten past a surgeon and into a patient's body [5].

Soldiers, however, weren't the only intended audience. Immediately after World War II, messages about health matters peaked and "animation became the main medium for public health education" [5].

Despite the many benefits of this medium, it was not without problems. Public health images were often sexist or laden with stereotypical racial caricatures. For example, "in a 1942 film titled *Use Your Head* a marine in the South Pacific named Private McGuillicuddy defecates in the woods instead of a prescribed latrine. A fly with thick glasses and buck teeth spots the infraction and rings a triangle dinner bell shouting 'Come and get it' in a caricatured Japanese accent" [5]. These movies, outdated by advances in medical prevention and treatment, described disease in alarmist tones. Donald Crafton, an animation historian, reflected that these older films "...tended to provoke anxiety about the body and its susceptibility to

illness...But they also sought to reassure people that with proper vigilance—as well as the help of an expert doctor and new medical technology—dread disease could be averted” [5].

It is during this era of animated public health movies that one can most clearly see the shift from blaming the government and its policies for disease as it did in the 1870s to a more friendly view of government, in part, of course, because the government was responsible for creating these cartoons. Still the depiction of non-traditional Americans in unfriendly terms persisted and these films continued to rely on stereotypes and stigmatization.

21st Century Use of Images

In the 21st century, images have moved beyond paper and film and onto the Internet. No longer are public health messages packaged for young adults or soldiers but for children and those with low health literacy. Today’s images are culturally diverse, and this diversity is portrayed as a positive asset.

An example of a modern, culturally sensitive visual that can help children and those with low health literacy can be found at www.bam.gov [6]. BAM!, which stands for body and mind, is a government-sponsored web site that utilizes images, games, and words to increase knowledge about health and wellness.

This web site, unlike the aforementioned media, is interactive and features characters that have as much racial variety as those viewing the site. BAM! was created by the Centers for Disease Control and features a diverse group of superheroes (known as the Immune Platoon) who ward off diseases, a black tween (that is, a young person between the ages of nine and 13 years old) named Kendra who is the xpert [sic] on food and nutrition; Michael, a black tween and xpert on physical activity; Elli, a young skateboarding female with dyed hair and of ambiguous heritage is the safety xpert; Matt, the blond haired, blue-eyed xpert on “Your Life”; and Kristi, a young blonde female who is the xpert on “Your Body.” Each character has its own page and gives advice using kid-friendly slang, visuals, and interactive games to convey specific messages to help members of the youngest generation improve their health literacy.

This web site also demonstrates how far the message of public health has come. These types of media address physical health, as well as concerns about peer pressure, safety, and stress. Modern-day cartoons are not being used to insult those of various races and ethnicities; minorities are now being portrayed as educated and friendly.

Conclusion

Cartoons and visuals about medicine have evolved greatly over the last 140 years. No longer are most still images tinged with criticism of the government, critical about the role that physicians play in disease management, and reliant on negative stereotypes to forward a public health agenda. Today’s images are diverse, facilitate

greater communication between patients and physicians, and promote health initiatives, perhaps nonverbally indicating that the importance of appealing to the society as a whole has been recognized. Similarly, public health images have come to embrace a multicultural America, showing children of different colors and ethnicities encouraging healthy everyday habits. Now, it is unacceptable for immigrants (or their home countries) to be portrayed as incubators for disease or for foreigners to be depicted in caricatured, almost-universally disparaging, stereotypic ways. Cartoons and images that portray public health messages are now inclusive of other cultures, reflecting the changing demographics of the country.

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Allison Grady is a senior research assistant and assistant editor of Virtual Mentor at the American Medical Association in Chicago.

Related in VM

[Migrating Pathogens: Imagining Health Risks in Relation to National Borders](#), June 2001

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Readings and Resources

American Institute for Research. A patient-centered guide to implementing language access services in healthcare settings.

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August Contributors

Jennifer Blanchard, MD, is an assistant clinical professor of medicine at the University of California, San Diego (UCSD). As a faculty member of the Owen Clinic, UCSD's HIV specialty clinic, she cares for patients and families with HIV, many of whom are of Mexican heritage, along with a cohort of patients from East Africa.

Romana Hasnain-Wynia, PhD, is vice president of research for the Health Research and Educational Trust, the research and educational affiliate of the American Hospital Association, and adjunct associate professor at Northwestern University's Feinberg School of Medicine in Chicago. She is the principal investigator on a number of studies that examine quality of care for diverse populations.

Adel Olshansky, MD, is in her first year of postgraduate medical training at St. Joseph's Hospital in Phoenix and will begin a neurology residency at the University of Southern California in summer 2008. She graduated from UCLA with a BS in physiologic science and received her medical degree at University of California, San Diego School of Medicine.

Yolanda Partida is director of the national program of *Hablamos Juntos*, dedicated to eliminating language barriers in health care. The program's national office is at the Center for Medical & Education Research at the University of California, San Francisco's branch campus in Fresno.

Debra Pierce is project manager of Knowledge Networks at the Health Research and Educational Trust, a research and educational affiliate of the American Hospital Association, in Chicago. The Knowledge Networks include the Center for Health Management Research and an Agency for Healthcare Research and Quality (AHRQ) ACTION Network.

Ruby Roy, MD, is a general academic pediatrician who recently joined the Neiswanger Institute for Bioethics and Health Policy and began teaching medical humanities at the Loyola University Chicago Stritch School of Medicine.

Andres Sciolla, MD, is assistant professor of psychiatry at University of California, San Diego (UCSD), where he teaches patient-physician communication to medical students. He sees patients in UCSD's Outpatient Services Clinic and at the Maria

Sardinas Center in San Ysidro, California. His research interests include medical and psychological outcomes of adult survivors of childhood trauma.

Lindia Willies-Jacobo, MD, is associate professor of pediatrics at the University of California, San Diego School of Medicine and is director of the Pediatrics Clerkship Program. She is especially interested in curriculum development and cultural competency in pediatrics.

Mara Youdelman, JD, LLM, is director of the National Language Access Advocacy Project, funded by The California Endowment, to increase awareness of language access issues at the federal level. She coordinates a national coalition to develop a consensus-driven agenda to improve policies and funding for individuals with limited English proficiency. She has worked at the National Health Law Program (NHeLP) since 2000 on problems associated with Medicaid, language access, racial, and ethnic disparities, data collection, and immigrants' issues.

Maria Luisa Zuniga, PhD, is an assistant professor and epidemiologist in the Division of International Health and Cross-Cultural Medicine at the University of California, San Diego School of Medicine (UCSD) and is also affiliated with the UCSD Division of Community Pediatrics and San Diego State University Graduate School of Public Health. She specializes in behavioral health and access to care in Latino populations living with HIV, particularly those living in the U.S.-Mexico border region.

Staff Contributors

Allison Grady is a senior research assistant and assistant editor of Virtual Mentor at the American Medical Association in Chicago.

Megan Johnson is a research assistant at the Institute for Ethics in the American Medical Association in Chicago. She assists with the Ethical Force program, an effort to develop performance measures for ethical behavior across the health care system. She is pursuing her masters degree in communication at DePaul University in Chicago.

Abigail Van Kempen is the fifth DePaul-American Medical Association Law and Medical Ethics Scholar. She recently completed her first year at DePaul University College of Law, where she is a health law fellow and member of the Health Law Institute student board of directors. She is interested in the legal and ethical aspects of end-of-life care. Abigail graduated from Hope College in Holland, Michigan, in 2006 with a BA in political science and psychology.

Matthew Wynia, MD, MPH, is the director of the Institute for Ethics at the American Medical Association in Chicago. Dr. Wynia practices internal and infectious diseases medicine at the University of Chicago Hospitals, where he is also a clinical assistant professor of medicine.

Theme Issue Editor

Robert Deiss, MD, graduated from the University of California, San Diego (UCSD) School of Medicine. Before starting a residency in internal medicine, he is pursuing cross-border research in tuberculosis epidemiology as a post-doctoral fellow at the Division of International Health and Cross-Cultural Medicine at UCSD. He has a master of arts degree in international relations from the University of Southern California. Dr Deiss's research interests include international and cross-cultural medicine, infectious disease epidemiology, and medical education. He has published and presented original research on pharmaceutical patents in Africa, HIV/STI risk behaviors, and injection drug use.

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