Virtual Mentor	
<b>American Medical</b>	<b>Association Journal of Ethics</b>

# April 2012, Volume 14, Number 4: 297-361. Foreignness in Medicine

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 299-300.

## FROM THE EDITORS **Coping with Unfamiliarity in Medicine**

When a "foreign" element is introduced into the medical context, it can challenge expectations, assumptions, and even procedures. That element can be a patient or doctor from another country or culture, a foreign language, or even a medical condition that is alien to traditional medical approaches. And for patients, of course, the very experience of being ill can be utterly foreign and destabilizing. This month's issue of Virtual Mentor explores what happens when these unfamiliar elements appear on the medical scene.

The most obvious "foreigner" is the foreign patient. Even more uninitiated in the ways of our health care system than the average American, this person may have different expectations of medicine than native-born patients or no language in common with the health care team. As Kirk L. Smith, MD, PhD, points out in his case commentary, many of the shared assumptions that ease communication and interaction between health care professionals and patients who "belong" to the same country cannot be counted upon in an encounter between people from different countries.

Those who are not native-born but are no longer mere visitors are immigrants. Tension can surround the degree to which immigrants belong in their chosen countries. In the American medical system, much of that tension manifests itself in debates about whether and when citizens of other countries become entitled to publicly funded medical care in the United States. In the health law section, legal editor Valarie Blake, JD, MA, discusses recent controversies over the citizenship requirements for Medicaid. Arturo Vargas Bustamante, PhD, and Philip J. Van der Wees, PhD, review current and needed efforts to integrate immigrants, both documented and undocumented, into U.S. health care, with compassion and cultural sensitivity. This month's excerpt from the AMA Code of Medical Ethics gives further guidance on bridging culture- and race-based care disparities.

Of course, patients aren't the only immigrants involved in the medical system. International medical graduates play important roles in American health care, particularly in underserved areas, but immigration policies hamper their ability to do so, Nyapati R. Rao, MD, MS, argues in his policy forum essay. Even when they're employed in the U.S., foreign doctors may have to contend with the assumptions, fears, and prejudices of patients who are uncomfortable with them. Amit Chakrabarty, MD, MS, FRCS, recommends actions physicians can take to assure patients can listen and participate effectively when communicating with health care professionals who have a different first language or ethnic background than they do.

Moreover, while making assumptions may be natural and understandable, it is still often counterproductive. In his medicine and society essay, Jing-Bao Nie, BMed, MMed, MA, PhD, exposes the fallacy of dichotomizing disparate cultures, when in fact they may have more in common than meets the eye.

Less obviously "foreign," but still very much so, are medical conditions that confound ingrained ways of thinking about and responding to illness. David Edelberg, MD, describes the ways in which the symptoms, test results, and patient behavior that accompany fibromyalgia challenge medicine's standard operating procedure and urges openness toward types of illness that don't gratify normal medical expectations.

The most unfamiliar, alienating element of all is the experience of being sick. Managing editor Faith L. Lagay, PhD, and digital media editor Todd Ferguson, PhD, explore the experience of being ill through philosophy and literature. This, above all, urges compassion for all patients and conditions, whether they subvert expectations or not.

Virtual Mentor Editors

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 301-304.

#### **ETHICS CASE**

**Language Barriers in the Emergency Room** 

Commentary by Kirk L. Smith, MD, PhD

Dr. Willis was chief resident in emergency medicine at an inner city hospital. Late one afternoon a young woman was escorted to the emergency department by her brother. They told the admission clerk that they had come to the U.S. from Brazil to visit family members who lived in the city. With the help of an emergency department aide, they listed the young woman's name as Bianca, her age as 18, stomachache as the reason for the visit, their relative's city address, and the number for the cell phone the young man carried. That was all that was on the form.

Bianca was bent over with both hands pressed against her lower belly. Her brother, Elias, who looked to be slightly older than she, said that he would translate for his sister because his English was better than hers. He said that he was very worried because Bianca was usually tough and rarely complained. Today she had pleaded with him to take her to see a doctor.

Dr. Willis started by asking questions about the pain: when had it started; did it seem to be located in one spot; was it a constant pain like a headache, or a sharp intermittent pain; had she ever had pain like this in the same place before? Without asking his sister, Elias answered that the pain had started early that morning. Then he began to translate Dr. Willis's other questions to his sister in Portuguese. Bianca pointed to the lower right quadrant of her stomach, but Dr. Willis got no answers to his questions. Bianca did not seem to understand what Dr. Willis wanted to know, even though Elias repeated the questions several times, using what sounded to Dr. Willis (who understood no Portuguese) like different words.

Dr. Willis asked whether Bianca had vomited or had diarrhea, and Elias said no. The medical record started by the emergency department nurse noted that Bianca's temperature and blood pressure were normal. When Dr. Willis asked when Bianca had had her last menstrual period, Elias seemed unable to interpret the question for his sister. "Could she be pregnant?" Dr. Willis asked. "No, she is not," Elias said.

Dr. Willis asked Elias to translate the questions about Bianca's menstrual periods and the possibility of pregnancy so that Bianca could reply, but Elias shook his head and said, "She is not pregnant. No."

Finally, Dr. Willis suggested using the hospital's telephone interpreting service so that he could get more information about Bianca's pain and its possible cause, but Elias said that the service was not necessary. He could answer the questions. Dr.

Willis responded, "I believe an interpreter would help us take better care of your sister and assist with technical questions." Dr. Willis explained that he would need Bianca's consent to the tests he would have to perform to establish the cause of her pain. "First, I want a urine sample and a blood sample that, together, will give me information about pregnancy and infection. While we wait for the interpreter, please explain that to your sister and ask for her consent."

## **Commentary**

The case is not uncommon, especially in cities that host large numbers of foreign visitors. While clinicians can identify with Dr. Willis, sympathy should be reserved primarily for patients like Bianca, whose anxiety is compounded by being ill far from home, in a strange environment, among people who do not speak her language or know her culture. In this case, Dr. Willis must be wary of false assumptions, realizing that communication depends on shared premises, often implicit, and in this encounter shared premises may be lacking.

The communication gulf is not only one of language, but also of culture—with culture understood very broadly. Bianca is from another country; her gender is different from that both of the doctor and her brother; she is younger than they are; pain has likely put her in an existential state not only distinct from that of healthy others, but also from her normal self; she is part of a family dynamic to which Dr. Willis is not privy; and the encounter is further conditioned by socioeconomic, educational, and other circumstances at which the physician can only guess. The potential for embarrassment, misunderstood social cues, and other factors that complicate communication are multiple. For example, Bianca is a woman responding to a male questioner and a male interlocutor. Are issues of gender and sexism playing into this dynamic? Does Elias discount his sister's ability, as a female, to speak for herself? Is Dr. Willis's acceptance of Elias's responses on his sister's behalf related to gender? Of course, every medical encounter is conditioned by like factors, but the present case features them to a heightened degree. In these heightened circumstances, dealing with a painful medical emergency and gaining informed consent are immediate issues.

This is first and foremost a medical case. The legal requirement to obtain consent, while critical, is secondary to responding to Bianca's medical need with appropriate care. The handling of the case is dictated by its setting in an emergency room: obtaining consent is desirable, but not if delaying treatment poses dire risk to the patient (life, limb, or major organ)—a contingency well-established by legal precedent, particularly with respect to emergency medicine. In this, the provider must rely on clinical judgment. If the patient's condition is sufficiently urgent (advancing infection, blood loss, shock, etc.) or mental state sufficiently impaired, then consent ought to be deferred so that treatment can proceed.

In this particular case, the clinician must judge whether there is sufficient time to obtain interpretive services (the availability of such services, particularly for less widely spoken languages can range from in-house translators immediately available

to outsourced telephone services that can be complicated to access) and consider whether her pain and general psychological state preclude informed consent. Pain is a powerful inducement to signing documents, whether or not those documents are understood by the signer. It should go without saying that, if medication is administered to alleviate Bianca's pain and anxious state, it should be administered as medically indicated—not simply in order to facilitate the giving of consent.

Moreover, as presented, the case introduces a raft of other concerns about Bianca's decision-making capacity: Is she in fact 18 and an adult? Is her mental capacity impaired? Is she literate? For that matter, is Elias in fact her brother? Dr. Willis has no independent corroboration or evidence to indicate an affirmative answer to any of these questions. If Bianca, for any of the above or other reasons, is not giving truly informed consent, then obtaining a signature on a piece of paper is merely a bureaucratic gesture that observes neither the spirit nor the letter of the law and probably would not withstand serious legal challenge.

Despite the priority of medical concerns, every effort should be made to obtain consent consistent with appropriate care. Though often framed as merely a legal requirement, obtaining consent is a moral act that affirms the physician's core obligation to put the patient's interests first. The process of seeking informed consent makes those interests, and the doctor's commitment to them, explicit. If the patient declines, then the exercise affirms the provider's respect for the right of patients to define their own interests.

In the present case, the medical encounter is compromised not only with respect to obtaining consent, but also with respect to providing appropriate care, for example, soliciting an adequate history and performing a physical. It is not clear that the physician has established communication with the patient. An exchange has been established with Elias, but is Elias more bridge or barrier? In this, the need to avoid assumptions is clear.

Any number of scenarios can be imagined regarding Elias and his relationship with Bianca. At face value, one may assume that he is a well-meaning and loving brother eager to see his sister cared for, whose quickness to respond to questions on his sister's behalf and decline an interpreter is intended to speed treatment, and who wishes to spare his sister embarrassing questions about sexual activity—and himself the embarrassment of asking them. For all we know, Elias's refusal of interpretive services could stem from fear of being billed for such services.

On the other hand, the story told the admission clerk could be false. The relationship between Elias and Bianca could be other than that of brother and sister; their purpose in the U.S. other than that reported. Elias's unreliability as interlocutor for his sister could be purposefully misleading.

But before indulging flights of fancy, the paramount need to avoid assumptions must be met. The physician's primary task is to provide care. Dr. Willis is obliged to

pursue only those lines of inquiry that will facilitate that—to clarify communication to the extent needed for him to proceed with an adequate history and physical and initiate diagnostic tests and procedures. The factors mediating communication in this case (e.g., language, culture, social cues, attributes of personality and psyche, etc.) affect every medical encounter to some degree. Every clinician must be vigilant to their effects and be able to respond accordingly to ensure a level of communication appropriate to the need at hand, commensurate with his or her fiduciary duty to act in the patient's best interests. The scope of that duty is illustrated by the fact that, should a clinician discover evidence of, for example, abuse, he or she would pass that information along to appropriate authorities, rather than acting on it him- or herself.

By coming to the emergency room, Bianca has given tacit consent to a history taking and physical and urgent diagnostic maneuvers. Dr. Willis would be well advised to call upon interpretive services immediately, invite Elias to wait in the waiting room, get a female chaperone and, while translation is being secured, proceed with a physical examination as well as those labs he judges clinically urgent. If Bianca objects, he can await access to translation in order to address that, but only if waiting does not impose undue risk. Even if Bianca should appear amenable to proceeding without interpretive services, Dr. Willis should defer any nonurgent actions until translation is available in order to ensure that, as far as possible, Bianca is an active, willing, and informed participant in her own treatment.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 305-309.

#### **ETHICS CASE**

## Fibromyalgia Confounds Allopathic Habits of Mind

Commentary by David Edelberg, MD

Dr. Foote has been seeing Ms. Kirk, now in her forties, for years. She is overweight and depressed, with a history of migraines and irritable bowel syndrome. Dr. Foote is aware that her marriage has been going badly—her husband is unemployed and losing hope, her son is in drug and alcohol rehab. She once saw a psychiatrist who diagnosed her with depression; Dr. Foote has been renewing her SSRI prescription for years, and she reminds Dr. Foote at every visit that she is no better.

For the last few years, she has been particularly bothered by fatigue and constant, persistent joint pain that just won't let up. She can't remember the last time she had a good night's sleep or a day without pain.

Dr. Foote has ordered the usual blood work. The tests have come back negative, and Dr. Foote feels ever more convinced that Ms. Kirk's symptoms are caused by depression. Perhaps a different SSRI would help.

But Ms. Kirk turns up for another appointment sooner than expected. When Dr. Foote asks her how she's doing, she pushes a printout of a web page across the table and says, "Read this. I think I have fibromyalgia."

#### **Commentary**

Fibromyalgia, the chronic muscular pain syndrome estimated to affect approximately 12 million Americans, 96 percent of them female—more women, in fact, than have diabetes—stands out as example of an ailment that is *foreign* to medical thinking. Physicians' attitudes toward fibromyalgia indicate disturbing philosophical and ethical beliefs, ranging from "no such thing" to "no pain medication, ever!" These issues surface because fibromyalgia defies what physicians absorbed in their training about the nature of illness and how far their responsibilities extend in treatment.

Conversely, surveys among fibromyalgia patients reveal a profound dissatisfaction with the medical profession. Women complain of lengthy delays in diagnosis, disrespect because their tests results are "negative," and reluctance from their physicians to provide adequate treatment [1].

Postmodern philosophers, mainly among the French, wrote much about foreignness. Modern thinking had its roots in the Enlightenment and modernism created the dominant discourses in science, medicine, law, democracy. The scientific method

and the double-blind study both had their roots in the Enlightenment and represent the pinnacle of modernism.

To the postmoderns, especially Michel Foucault, *foreignness* meant anything that lay outside the dominant realm of thought. Conventional medical thinking, for example, would be a dominant discourse. Alternative medicine, e.g., chiropractic, Chinese medicine, and so forth, were nondominant, weaker, "wrong," and *foreign*. Male = dominant, female = weak, foreign. Caucasian = dominant, people of color (Foucault's term: "colonial") = weak, foreign. The very basis of postmodernism was questioning the validity of our dominant discourses.

Fibromyalgia, with no positive tests, is a "foreigner" in the medical landscape. Its victims, mainly female, regard themselves as powerless outsiders as well, enduring endless humiliations, and, in the opinion of someone like me who has spent his professional career treating them, suboptimal medical care.

When Lyrica (pregabalin) came up for FDA approval as a treatment for fibromyalgia, dissenting votes emphasized reluctance to approve a medication for symptoms that were not caused by a "real" illness [2].

Now, mainly due to numerous articles funded by the pharmaceutical industry, plus many articles in the popular press, physicians are learning more and more about fibromyalgia, but their discomfort about diagnosis and treatment remains. In 2008, surveys showed that 75 percent of physicians did not feel confident either diagnosing or treating fibromyalgia [3].

Our collective diffidence in diagnosing fibromyalgia begins in its foreignness. We are taught in medical school that when patients come to us with symptoms, we are to look for disease. This means tissue pathology, some visible change in structure or function of an organ or organs. We look for these changes by running tests, of which we have thousands: blood, urine, joint and spinal fluid, x-rays, CT, ultrasound, MRI, and, when all else fails, we try to see changes under a microscope with biopsies.

When everything comes up "negative," and there is simply no evidence anywhere of any pathologic change, we abandon this foreigner and refer our patient to a specialist, who will order more tests. At some point, we can tell her with a good degree of confidence, "We can't find anything wrong with you. Your tests are normal." This is the mantra of physicians facing patients with fibromyalgia: "Your tests are normal."

This unfortunate woman sitting across from us, tired and in constant pain, we label "normal." Her symptoms are "functional," the contemporary term for what was "psychosomatic" 50 years ago and "hysterical" a century ago. Because the overwhelming majority of fibromyalgia patients are female, and most primary care physicians and rheumatologists are male, this dissatisfaction might stem from gender bias and spur very realistic charges of "medical sexism." No shortage of

epidemiologic data confirms that men receive superior management of chronic pain of any cause [4]. Truly, being female and entering the domain of a "modernist" and male-dominated profession, she is *foreign*. Her fibromyalgia, not following the rule of positive tests, is foreign as well.

Having treated more than 1,600 patients with fibromyalgia (fewer than 50 of them male), I've heard this story over and over again. Sadly, once we've determined that her symptoms are "functional," our entire mindset changes; we go brain-dead. There's no pathology, no disease. "There's nothing really wrong with her," we think. "And she should be grateful we didn't find anything serious."

The patient returns occasionally, still complaining she's no better. Then one day you realize she's no longer in your practice. Maybe you received a request to transfer her records and, deep inside, you're grateful. A survey revealed that 35 percent of women ultimately diagnosed with fibromyalgia had seen seven or more physicians over several years before actually learning their diagnosis; most saw three or more [5]. Along this path, their fibromyalgia progressively worsening, they reported no shortage of hostility on the part of physicians. Some denied the very existence of fibromyalgia. Some believed it was a lazy woman's excuse to avoid work.

What happens to these patients with fibromyalgia, these outliers from our system, these foreigners to our thinking? Of the 12 million estimated sufferers, only 15 percent are actually diagnosed with fibromyalgia [6], so we really don't know about most of them. Most likely they suffer in silence. The WE FEEL survey (Women Experiencing Fibromyalgia's Effect on Everyday Lives) of 500 patients with fibro reported dramatic declines in overall quality of life, interference with careers and relationships, and unsympathetic family members and physicians [1]. This is the high price of foreignness. Epidemiologic studies reveal high rates of diabetes and heart disease (from weight gain and inactivity) and an unsurprising high suicide rate among patients with fibromyalgia [7, 8].

## What We Know About Fibromyalgia

Current thinking places fibromyalgia in the spectrum of what might be termed low-serotonin stress-susceptibility disorders, if we think of the neurotransmitter serotonin as, so to speak, our factory-installed stress buffer. We're most familiar with these as the mood disorders (depression, anxiety and panic, obsessive-compulsive disorder, posttraumatic stress disorder) and know that women are more vulnerable to them than men. The physical manifestations of this stress susceptibility are nothing more than the fight-and-flight response in a constant "on" mode: tension headaches, temporomandibular joint disorder, irritable bowel syndrome, and, as the muscles progressively tighten over her body, fibromyalgia ("muscle pain" in Greek). It is almost as if a woman is unconsciously using her muscles to create a suit of armor to protect her from stress.

But if we all tighten our muscles when we're under stress, why do some women have so much pain? Here the answer lies in the pain-modulating neurotransmitters, glutamate and substance P. Patients with fibro release more of these per "noxious stimulus" than other people. Hence, fibromyalgia is termed a "pain amplification" and "pain persistence" syndrome.

Fibromyalgia virtually always begins after a period of unchecked stress in a woman's life. A perfect storm—like Ms. Kirk's unemployed husband and son in rehab. There seems to be a component of "muscle memory" as well, a controversial term from psychiatric literature of the 1920s. Almost 25 percent of fibromyalgia patients were psychologically, physically, or sexually abused as children or experienced a sexual assault as a young adult. If you envision the posture an 8-year-old girl takes when she hears her abuser's car pull into the driveway, as she attempts to protect her body by curling into a tight ball, you'll understand a lot about fibromyalgia. Four decades later, this girl is now a woman, and her muscles "remember" how to respond to stress. As a middle-aged woman in a tsunami of noxious stimuli, she develops fibromyalgia.

What these patients need more than anything is listening. To arrive at the correct diagnosis, the physician must listen to their stories without suspicion or preconceptions and probe those stories for triggering events and telltale signs (in addition to being aware of fibromyalgia's tender points and other physical indicators). To treat those who suffer from it, physicians must take it upon themselves to be informed about treating the condition and to consider it their responsibility to see the patient through to an improvement in condition. The work of treating fibromyalgia isn't over when the usual pathological causes fail to turn up. (For clinical information, see the last chapter of my book *Healing Fibromyalgia* [9].)

Ultimately, fibromyalgia demands of us to transcend our sadly limited thinking and become, as a profession, postmoderns. We need to accept outsiders, *foreigners*, women with negative tests, endlessly returning to our offices, with sad looks, their first sentence, "I'm no better..." It's us as a profession who really need to "get better."

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David Edelberg, MD, is a board-certified internist practicing in Chicago. His center, WholeHealth Chicago, was among the first in the country to combine conventional and alternative medicine. His books, The Triple Whammy Cure and Healing Fibromyalgia, are directed toward women with chronic health problems. In addition, Dr. Edelberg writes a weekly blog at www.wholehealthchicago.com covering a variety of medical, social, and political health issues.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 310-311.

#### **ETHICS CASE**

## "Don't You Have Any American Doctors?": International Medical Graduates and Patient Prejudice

Commentary by Amit Chakrabarty, MD, MS, FRCS

Dr. Mehta is a second-year resident in internal medicine at St. Elizabeth, an urban teaching hospital. He attended medical school in India and completed a residency there in radiology before coming to the United States 5 years ago. After being certified by the Educational Commission for Foreign Medical Graduates (ECFMG) and passing the U.S. Medical Licensing Exam steps 1 and 2, Dr. Mehta applied for and gained the residency he now holds.

Dr. Mehta is doing well in the program. He is about 5 years older than most of his colleagues, due to the many years of training, and most patients seem comfortable with him, eager to talk and listen to him.

As Dr. Mehta approaches Mr. Hannigan's room, hand already raised to knock on the half-opened door, he hears Mr. Hannigan's grown daughter, who has been by her father's side during his 2-day stay for diagnostic testing.

"Don't you have any American doctors? I can't understand all these foreign doctors," she says.

Dr. Mehta steps back for a minute and walks down the hall. Having visited with Mr. Hannigan and his daughter yesterday, he assumes he is one of the foreign doctors she is speaking of. Today, Dr. Mehta has serious and, therefore, unwelcome news to communicate to Mr. Hannigan and his daughter—Mr. Hannigan has a malignant tumor in his colon. Dr. Mehta wonders how to establish the proper conditions for the exchange of difficult information, given what he has just heard.

## **Commentary**

When we took the Hippocratic oath we swore to treat patients equally despite their beliefs. That means that we should be aware that people have biases and prejudices, just as we ourselves do, and should tolerate them. It does not mean, however, that we must continue to treat openly hostile or rude patients or family members.

The comment made by Mr. Hannigan's daughter was one that is, unfortunately, common in society today. Perhaps the opinion is not shared by her father. We all make remarks that are not politically correct, especially in times of stress. Mr. Hannigan's daughter is probably frightened and finds herself in a situation that is alien to her, has its own culture, even. She would like to learn about her father's illness from someone who looks and sounds like her. When we are frightened, we all

would prefer that. She did not expect to be overheard and would probably be embarrassed to learn that she had offended Dr. Mehta.

In this situation I would advise Dr. Mehta to do the following. First, he should ignore the fact that he heard the daughter's comment. He should greet Mr. Hannigan and his daughter warmly and tell the patient that he has some important news about his test results to convey.

At this stage, if Mr. Hannigan's daughter says that she cannot understand Dr. Mehta, he should offer to get a nurse or reliable member of the staff (if possible, a patient relations advocate) to join them. If there are no objections, however, from Mr. Hannigan or his daughter, Dr. Mehta should continue with his discussion, taking time, showing compassion, and stopping frequently to ask whether Mr. Hannigan has any questions.

I believe this approach would ease the situation and lead to a successful exchange of information. As Dr. Mehta explains the findings and answers questions from the patient and his daughter, they will learn that he is knowledgeable and well trained and has his patient's best interest at heart.

After moving from Detroit to rural Decatur, Alabama, in the 1990s I frequently encountered situations like that of Dr. Mehta. As I matured, both as an individual and a doctor, I learned to take the approach described above with patients. It is rewarding and gratifying when I watch a patient's skepticism and even suspicion about "foreign doctors" dissolve and I earn their confidence and trust.

If Dr. Mehta does not think he can take the approach described above, an alternate and perfectly professional action would be to talk with the division chief about the situation and suggest that another resident carry on with this patient's care.

Amit Chakrabarty, MD, MS, FRCS, is chair of the Ethics and Grievances Committee of the American Association of Physicians of Indian Origin, director of the Comprehensive Continence Center in North Alabama, an adult and pediatric urologist at the Urologic Clinics of North Alabama in Decatur, president of the Medical Executive Committee of the Decatur Ambulatory Surgery Center, and past president of the Indian American Urological Association.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 312-313.

#### THE CODE SAYS

American Medical Association *Code of Medical Ethics'* Opinion on Cultural Sensitivity and Ethnic Disparities in Care

## **Opinion 9.121 - Racial and Ethnic Health Care Disparities**

Differences in treatment that are not directly attributable to variances in clinical needs or patient preferences constitute disparities in health care. Among racial and ethnic minority populations, such disparities may contribute to health outcomes that are considerably worse than those of majority populations. This represents a significant challenge for physicians who ethically are called upon to serve patients without regard to medically irrelevant personal characteristics. The following guidelines are intended to help reduce racial and ethnic disparities in health care.

- (1) Physicians must strive to offer the same quality of care to all their patients irrespective of personal characteristics such as race or ethnicity. The provision of care should be customized to meet patient needs and preferences.
- (2) Physicians must learn to recognize racial and ethnic health care disparities and should examine their own practices to ensure that inappropriate considerations do not affect clinical judgment.
- (3) Physicians should work to eliminate biased behavior toward patients by other health care professionals and staff who come into contact with patients. Inappropriate discrimination toward any patient or group of patients must not be permitted.
- (4) Participatory decision making should be encouraged with all patients. This requires trust, which in turn requires effective communication. Physicians should seek to gain greater understanding of cultural or ethnic characteristics that can influence patients' health care decisions. Physicians should not rely upon stereotypes; they should customize care to meet the needs and preferences of individual patients.
- (5) Physicians should recognize and take into account linguistic factors that affect patients' understanding of medical information. In particular, language barriers should be minimized so that information is exchanged in a manner that both parties can understand.
- (6) Increasing the diversity of the physician workforce may be an important step in reducing racial and ethnic health care disparities. Physicians should therefore participate in efforts to encourage diversity in the profession.

(7) Physicians should help increase awareness of health care disparities by engaging in open and broad discussions about the issue in medical school curricula, in medical journals, at professional conferences, and as part of professional peer review activities. Research should continue to investigate health care disparities, including the development of quality measures.

Adopted June 2005, based on the report "Racial and Ethnic Health Care Disparities."

#### Related in VM

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 314-317.

## **JOURNAL DISCUSSION**

I Am Not Myself: Understanding Illness as Unhomelike Being-in-the-World Todd Ferguson, PhD

Svenaeus F. Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Med Health Care and Philos*. 2011;14:333-343.

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place [1].

When I am sick I don't feel "like myself." I feel *different*; my body feels foreign to me; my normal life is invaded by a virus or disease that interrupts my daily routine; and there is a disillusioning disjunction between my mind and body. Illness simply makes me feel *other than* who I am. As Hans-Georg Gadamer suggests, illness "affects [one's] life as a whole" and causes one to feel a disorienting "absence" within oneself [2].

Indeed, being sick or having a specific illness directly affects how we view and understand ourselves, how we interact with others, and how we engage with, and act in, the world around us. In "Illness as Unhomelike Being-in-the-World: Heidegger and the Phenomenology of Medicine," Fredrik Svenaeus uses the philosophy of Martin Heidegger to establish a "phenomenology of illness" that works to understand illness, or "unhealth," as a rupture in the meaningful organization, temporality, and narrative of one's life [3].

## **Towards a Phenomenology of Illness**

Svenaeus's starting point is the phenomenological method used by Heidegger to establish an existential philosophy that centers on the nature and meaning of "being"—what it means to exist, how we create meaning, and how we exist as active, intentional agents in the world.

As Svenaeus explains, phenomenology can be understood "as the attempt to found a conceptual apparatus based on lived experience—the first-person perspective—in contrast to the theories and investigations of empirical science—the third-person perspective" [5]. Phenomenology is a method by which an individual engages with, interprets, and conceptualizes the world based on his own perspective and lived experience. It also represents an "attempt to spell out meaning structures that are common" to all beings [6].

What distinguishes phenomenology from traditional science is the "meaning of experience":

Science, a human activity that strives to solve puzzles and produce results, is no doubt meaningful, but the manner of explanation particular to science, with its focus on causal relations in nature, is only indirectly tied to the everyday world [7].

In contrast, phenomenology is a human activity that is directly tied to an individual's everyday world—"the phenomenologist wants to begin with the relationship between subject and object, in the patterns of meaning that bind them together and make the object appear to the subject in a certain way" [4]. And while illness has been—and continues to be—rigorously studied from the perspective of science and organized medicine, Svenaeus believes it is also important to analyze illness phenomenologically in order to understand how it affects and fundamentally alters a subject's perception and understanding of herself and her engagement with the world, i.e., her "being-in-the world" [4].

## Being-in-the-World: Health, Illness, and "Home"

The concept of "being-in-the-world" is an important cornerstone of Heidegger's philosophy. As Heidegger writes in *Being and Time*, his most important philosophical work, being-in-the-world "stands for a *unitary* phenomenon" [8]. According to George Steiner, Heidegger, in his concept of being-in-the-world, "is saying that the notion of existential identity [being] and that of the world are completely wedded. To be at all is to be worldly" [9]. For example, every human being enacts his or her own "being-in-the-world" through his or her own intentional activities—thus, being-in-the-world "refers to the way human beings (Dasein) inhabit the world as a pattern of significance" [10].

In setting up his phenomenological understanding of illness Svenaeus first establishes the metaphor of being healthy as a state of homelike being-in-the-world. In this way, "health is a non-apparent attunement, a rhythmic, balancing mood that supports our understanding in a homelike way without calling for our attention" [11]. In other words, and as one of Svenaeus's commentators, Rolf Ahlzen notes, "being at home...is compared with being healthy" [12]. In this sense the state of being healthy represents a neutral state or the status quo—it is the normal state of affairs for my being-in-the-world: "The phenomenology of homelikeness is supposed to catch the character of the normal, unapparent, things-as-usual ways of everyday life" [13]. Things get interesting, however, when I become ill and my homelike being-inthe-world becomes compromised.

When I become sick the "unapparent, things-as-usual" character of my being-in-theworld fades away and, in its place, the "otherness" of my own body "comes to the fore" [13]. The illness that now affects me and overcomes my body corrodes how I see and understand myself and how I interact with others and the world around meand this displaces me from the homelike being-in-the-world that I tend to take for granted. "In illness," Svenaeus argues, "the body shows up as an alien being (being me, yet not me) and this obstruction attunes the entire being-in-the-world of the ill person in an unhomelike way" [13]. The shift from a homelike to an unhomelike being-in-the-world fundamentally ruptures the way I live in and experience the world: I see, hear, smell, and taste—and thus *understand*—objects differently; the ways I interact with others and act or behave in the world changes; and, of course, my perception and understanding of myself is distorted. Consequently, due to the unhomelikeness of my illness the meanings I ascribe to things—and myself—are radically altered (and not in an altogether positive way).

## The Lived Experience of Illness

In his sympathetic analysis of Svenaeus's phenomenology of illness, Rolf Ahlzen argues that Svenaeus's theory "gives access to an epistemology within which certain of the riddles and enigmas of clinical everyday life are better understood and handled" [14]. In a clinical world where doctors' objective scientific analyses and diagnoses often eclipse or ignore a patient's subjective experience and struggle with illness, and how the illness completely transforms being-in-the-world (i.e., the core of a person's existence), Svenaeus's theory restores an essential first-person perspective regarding the lived experience of illness. It also, as Ahlzen suggests, "complement[s] the predominantly scientific modes of understanding ill persons" [14].

The stories patients tell about how disease or illness *change* them and make them feel *other* than who they *really are* are invaluable; they indicate what an illness means to a patient and how an illness alters "the lived body in its being-in-theworld" [15]. When we are beset by an illness, our bodies are out of synch with the world around us as we struggle to make sense of the objects and events that now seem alien to us, and as we seem alien to ourselves.

Of course, it is difficult to imagine that health care professionals will engage with their patients in a discourse about illness as an unhomelike being-in the-world. We consult our doctors for expert medical advice, not phenomenological analysis. But perhaps a wide gulf ought not separate empirical science and research from phenomenological reflection and analysis. Not only do such methods complement each other, as Ahlzen suggests, but together they provide a holistic view of how illnesses affect us physiologically and psychically—both as an object of medical science and as an existential subject of lived experience.

While a phenomenological analysis of illness—of understanding illness as unhomelike being-in-the-world—will never treat an illness or cure a disease, it can help us better understand how illness disrupts "the lived body and the way it inhabits the world" [16]. It also goes a long way toward suggesting how we might rebuild our homelike being-in-the-world and live a meaningful life, despite our "dual citizenship" in the "kingdom of the well" and the "kingdom of the sick."

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 318-323.

## STATE OF THE ART AND SCIENCE

## **Integrating Immigrants into the U.S. Health System**

Arturo Vargas Bustamante, PhD, and Philip J. Van der Wees, PhD

## **U.S. Immigrants: Current Number and Projections**

According to the American Community Survey and U.S. Census, the immigrant population in the U.S. increased by almost 24 percent between 2000 and 2010 [1]. In 2010, approximately 40 million foreign-born individuals resided in the U.S. [1], 53 percent from Latin America (including Mexico and the Caribbean), 28 percent from Asia, 12.5 percent from Europe, 4 percent from Africa, 2 percent from Canada, and 0.5 percent from Oceania. Approximately 44 percent of these immigrants were naturalized U.S. citizens, 26 percent were documented, and 30 percent were undocumented [2]. If present trends continue, there will be approximately 83 million foreign-born people in the U.S. in 2050, representing an increase from 12.5 percent in 2010 to 20 percent in 2050 [3]. In other words, the number of immigrants living in the U.S. is expected to double in size in the next 30 years.

## The ACA and Health Care for Immigrants

Immigrants comprise almost 30 percent of the uninsured in the U.S. [1]. Within the foreign-born population, according to 2009 data from the Migration Policy Institute, 52 percent had private health insurance, 15 percent had public health insurance coverage (i.e. Medicare, Medicaid, Children's Health Insurance Program), and 33 percent were uninsured [4]. By contrast, only 12.5 percent of the native-born population was uninsured in the same year. It is estimated that approximately half of the 33 percent of immigrants who are uninsured are undocumented [2].

The Patient Protection and Affordable Care Act (ACA) will give U.S.-born people and documented immigrants similar entitlements. These policies, however, will benefit those who have been here longer—there will be a 5-year waiting period to receive some benefits [5]. Documented immigrants who have resided in the U.S. for 5 years or less will be subject to the health insurance mandate but will remain ineligible for Medicaid; they are, however, eligible for subsidized participation in the state health insurance exchanges [6]. Undocumented immigrants are excluded from all provisions of the ACA.

The clear beneficiaries of the ACA are the approximately 7 million low- and middle-income documented immigrants who are currently uninsured and have been in the U.S. for more than 5 years [7]. The overall effect of the ACA on newly arrived documented immigrants and undocumented immigrants is currently uncertain. The ACA is more likely to impact undocumented immigrants who currently have health insurance coverage (31 percent of children and 40 percent of the adult (18-64)

undocumented immigrant population have employer-provided health coverage [4]) who face the risk of losing it if their employers decide to start providing health insurance through the exchanges, where legal status could be scrutinized more closely. In addition, undocumented immigrants who pay income taxes (using taxpayer identification numbers or false social security numbers) but do not have coverage through their employers may still choose to pay the penalty for not purchasing health insurance coverage, even if they are exempt from the health insurance mandate. They may not want to signal their legal status to the federal government through the Internal Revenue Service, the agency in charge of enforcing the health insurance mandate. Recently arrived documented immigrants and undocumented immigrants who would remain uninsured, however, could potentially benefit from the positive spillover effects of better health care delivery in community clinics and health centers that will receive increased funding through the ACA [6].

## **Health Care Utilization Among Immigrants**

Overall, immigrants are less likely to access, use, and spend on health care than the U.S. native-born population [8-10]. While this can partly be explained by socioeconomic and demographic differences, experts in the field also attribute low health care utilization among immigrants to a phenomenon known as immigrant selfselection [7], one of the most obvious examples of which is the "healthy immigrant effect" [11]: immigrants need to be relatively healthy to leave their countries of origin. Consequently, they are on average healthier than nonimmigrants [11].

Low health care utilization among immigrants can also be related to legal status. One of the main factors that delays seeking care among the undocumented is fear that their legal status will be uncovered if they access the health system [12, 13]. A recent study that compared health care access and utilization among Mexican immigrants found that the undocumented were 27 percent less likely than documented immigrants to have a doctor visit in the previous year and 35 percent less likely to have a usual source of care [5].

## Familiarity With the U.S. Health System

Even if immigrants are covered by public or private health plans, coverage does not automatically translate into access. Recently arrived immigrants are often used to health systems that are differently organized and administrated than the U.S. health care system. Differences in care quality, prices, methods of payment, patient expectations, or patient-physician relationship are some of the aspects that immigrants have to become familiar with. Lack of familiarity with the system may contribute to low health care use among the foreign-born. Of the U.S. foreign-born population in 2010, it was estimated that approximately 40 percent entered the country by 1989, 27 percent between 1990 and 1999, and 33 percent in 2000 or later. It is reasonable to expect that immigrants' experiences in the U.S. health care system differ based on the length of time of U.S. residence, their English proficiency, their knowledge of the American health care system, and similar factors.

## What Physicians Should Do to Help

Cultural competency. With the increased diversity of the U.S. population, physicians and other health care professionals have been encouraged to develop competence in providing culturally sensitive care to people with backgrounds other than their own [14, 15].

Cultural competence goes beyond cultural awareness or sensitivity and requires the effective use of skills in cross-cultural situations and community-based health management. Culturally and linguistically appropriate services (CLAS) should be employed to reach out to immigrants and facilitate their integration into the U.S. health care system [16]. Health care professionals, however, need to be careful about not stereotyping and relying on broad generalizations. Cultural competence is by no means a matter of one-size-fits-all treatment.

Physicians and health care personnel should participate actively and regularly in training programs designed to increase cultural awareness, knowledge and skills. This training should start in medical school and continue throughout their careers. For instance, the UCLA health system's PRIME program trains physicians particularly devoted to serving disadvantaged populations on ways to provide high-quality, culturally sensitive care. Such training models should become more widespread.

Culturally sensitive care and the immigrant integration process are interlinked. Situations can easily arise in which immigrants' cultural health beliefs and practices clash with the standard of care. Indeed, some health-related beliefs and practices can lead to unhealthy, even fatal, outcomes. This can make care provision difficult. Physicians and other health care personnel should learn how to handle these cases and talk to immigrants about the benefits of high quality care. Healthy behaviors should be encouraged and reinforced to take advantage of the "healthy immigrant effect," not only in the short term when immigrants arrive in the U.S., but also in the long term.

Language assistance and health information. Language services for immigrants with poor English proficiency should be offered at any point at which they may access the health care system. Health information materials and utilization-related documentation should also be tailored to populations with different levels of English proficiency and cultural approaches to health and health care utilization. Also key for the continual improvement of culturally sensitive quality care standards is the collection and analysis of better data on immigrants' socioeconomic, epidemiological, and assimilation (e.g., years in the U.S. and English fluency) characteristics. Health care professionals should ensure that this information is consistently collected in health records and management information systems. More important would be to use this information to improve outcomes and health care delivery methods especially tailored to immigrants.

Organizational openness to cultural diversity. A culturally diverse workforce can also facilitate the administration of quality and culturally sensitive care to immigrants. Recruiting, retaining, and promoting a culturally diverse workforce can encourage the dissemination of open, multicultural approaches to delivering health care. The best way of approaching this goal is continued support and expansion of residency and fellowship programs for and mentorship of members of groups historically underrepresented in health care.

Health care organizations should also develop effective outreach approaches to integrate immigrants into the U.S. health care system. Developing partnerships with organizations in the communities they serve and engaging with hometown associations (i.e., those organizations formed in the U.S. by immigrants from the same towns or regions) represent effective ways of facilitating this process. Coordination with traditional healers and other alternative practitioners should be considered to ensure continuity of care and avoid complications.

**Conclusions: The Role of Health Care Providers in Immigrant Assimilation** The increased diversity of the immigrant population in the U.S. in terms of countries of origin, length of stay, and legal status emphasizes the need for cross-cultural adaptation of care and the role of health care providers in facilitating the integration of the foreign-born population to the U.S. health care system. "Integration" is generally described as a process that helps immigrants achieve self-sufficiency, political and civic involvement, and social inclusion in their new countries [17].

Immigrants are self-selected, but the longer they stay in the U.S. the more they start to resemble the U.S. native population in several measures ranging from income to health expenditures and utilization [7]. Most immigrants assimilate after a few generations. Evidence shows that recently arrived immigrants to the U.S. will not be the exception [18]. Physicians and other health care professionals should become more knowledgeable about the different stages of this transition process so they can facilitate better integration of immigrants into the health care system.

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## Acknowledgements

Dr. Vargas Bustamante is grateful to his HS200B Health Care Financing and Organizations students' comments for this article.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 324-328.

#### **HEALTH LAW**

## Citizenship Requirements for Medicaid Coverage

Valarie Blake, JD, MA

Social policies that allocate health care resources to the poor have long been a controversial issue for politicians, lawmakers, and activists alike. States clash with the federal government over how to spend Medicaid dollars and politicians question the very worth of social welfare and equitable health care access; federal health reform legislation in 2010 further entrenched these debates. Always an undercurrent in these debates is the matter of health care coverage and access for immigrants, particularly low-income and undocumented ones. In the last 5 years, new Medicaid rules have been promulgated to ensure the exclusion of this population and some states have drafted broad, sweeping reforms to laws that affect how physicians respond to their immigrant patients. This article will explore the current health status of low-income immigrants and then turn to some of the latest and most controversial regulations occurring in this area.

## **Insurance Coverage and Access to Health Care**

As of February 2012, 38 million immigrants resided in the United States, making up 12.5 percent of its population [1]. Immigrants residing here both legally and illegally are more likely to be uninsured than American citizens, accounting for 20 percent of those uninsured [1]. Their children are also less likely to have health insurance, with more than one-third lacking coverage [1].

The gap in health care insurance coverage between immigrants and legal citizens has been attributed to a number of factors, including socioeconomic factors and Medicaid eligibility. Many immigrants work in jobs that do not provide health insurance, and they may make too much money to qualify for Medicaid [1, 2]. Immigrants who legally reside in the U.S. must wait 5 years before becoming eligible for Medicaid and the Children's Health Insurance Program (CHIP) [3]. The latest reform to CHIP, in 2009, permitted states to waive this 5-year requirement for children and pregnant women [3]. As of January 2012, 24 states have done so for children and 18 for pregnant women, but a large portion of lawfully residing immigrants still remain uninsured or awaiting insurance [1]. Illegal immigrants are ineligible for Medicaid and CHIP with the exception of prenatal care for pregnant women, because the law permits coverage of the unborn child [1]. Emergency care may also be covered under Medicaid and CHIP [1].

The Patient Protection and Affordable Care Act will expand health coverage options for legal immigrants beginning in 2014. Nearly all persons with incomes up to 133 percent of the poverty level (up to \$14,484 for the individual or \$24,645 for a family

of three in 2011) will be covered under Medicaid, thus widening the net of coverage to higher incomes [4]. Persons with incomes up to 400 percent of the poverty level (\$74,120 for a family of three) will receive tax credits for purchasing insurance [4]. This expansion will eventually lead to coverage for many lawfully residing immigrants, but the 5-year waiting period will remain, and undocumented immigrants will still be ineligible for Medicaid or for tax credits.

## **Proof of Citizenship Regulations**

Battles about allocating Medicaid resources are not only about immigration. They stem from Medicaid's being a federally funded but state-implemented program with limited resources. In the context of a federal budget resolution to reduce Medicaid spending by \$10 billion over the next 5 years, the Deficit Reduction Act was born in 2005 [5]. Despite a July 2005 report by the Health and Human Services Office of Inspector General (OIG) finding that widespread citizenship fraud did not exist [5] and another finding that "virtually no ineligible immigrants [were] applying for or receiving Medicaid" [6], two Republican Congressmen from Georgia with the intention of preventing illegal immigrants from defrauding Medicaid proposed the requirement that anyone applying for Medicaid provide evidence of U.S. citizenship, such as a passport or birth certificate.

At the time of the passage of the law, legal immigrants who applied for Medicaid were already required to provide documentation, illegal immigrants were forbidden from receiving benefits, and citizens were asked to sign statements of citizenship under penalty of perjury. Specific cases of suspected fraud were investigated by the states.

The proof-of-citizenship requirement generated considerable backlash. States that tracked its effect in 2006 found that many eligible U.S. citizens who simply lacked the necessary documents were denied coverage or had to wait significant periods without insurance or pay fees to obtain proper documentation [7].

In 2009, CHIP reform created a new option for states determining Medicaid and CHIP eligibility [6]. Now states can verify citizenship within 24 hours by checking for a valid social security number. If there is not a match in the Social Security Administration's database, the applicant has 90 days to prove citizenship in some other manner, such as presenting a birth certificate [6]. As of January 2012, 40 states and the District of Columbia have all elected the new option of matching social security numbers for Medicaid, and 31 states have done so for CHIP [8].

Pressure around the proof-of-citizenship requirement has lessened with the social security solution, but the procedural change does not address the fact that the citizenship requirement remains on the books, even though it proved ineffective at identifying fraudulent applicants and even though immigrant fraud appears virtually nonexistent. The citizenship requirement also presumes wrongdoing on the part of immigrants and may encourage public opinion that immigrants are scamming Medicaid.

## **Transport and Reporting Laws: New Movements in the States**

Access to care can be affected by other elements too, in addition to access to health insurance. The latest state regulations aimed at broader immigration reform may indirectly affect health care access for immigrants. In South Carolina, legislation was passed that would make it illegal to transport undocumented immigrants, even to a hospital [9, 10]. These provisions were blocked by the Federal District Court in December 2011 [11]. That same year, Arizona's legislature passed a bill making it a fineable misdemeanor to harbor or conceal illegal immigrants, which many feared could force doctors to report illegal immigrants to the authorities when they seek treatment [12, 13]. Naturally, if this were the case, one end result could be immigrants' avoiding hospitals for fear of deportation. The federal government challenged the constitutionality of the bill, and the 9th Circuit Court of Appeals has held it unconstitutional and blocked it from going into action [14]. The case, which has implications for many broad regulatory efforts at immigration control, has been brought before the Supreme Court, which will hear arguments on April 25, 2012 [15]. Recently, the American College of Physicians decried any law that requires physicians to report the citizenship status of their patients as incompatible with their professional, ethical, and traditional obligations [16].

Whether more direct (like the Medicaid requirements) or more indirect (like the transport and reporting laws), the legal barriers to health care for immigrants are great. The issue is poised for change in the near future as the federal government, states, medical societies, and courts weigh in on both sides, but whether change will be for the better for immigrant health is yet unknown.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 329-337.

#### **POLICY FORUM**

"A Little More than Kin, and Less than Kind": U.S. Immigration Policy on **International Medical Graduates** 

Nyapati R. Rao, MD, MS

"IMGs work where there are poor people, people of color and few doctors in proportion to the population." Kristen Harris [1]

The quote above captures an essential aspect of international medical graduates' (IMG) contributions to American society. Foreign international medical graduates (FIMGs) play important roles in American medicine, but their position, both social and legal, remains tenuous. Despite their high levels of performance and contribution to alleviating the American physician shortage, they seem to be viewed, as Claudius was by Hamlet, as "more than kin, and less than kind" [2]. This piece argues that because of FIMGs' substantial contributions, they should be not only allowed but encouraged to live and work in the United States and recognized as a vital part of the American health care system. The accompanying flow chart illustrates the obstacles commonly encountered by FIMGs in their quest to find a place in the permanent physician workforce in the United States.

#### **IMG Demographics**

IMGs are physicians who have graduated from medical schools outside of the U.S. and Canada that lack accreditation by the Liaison Committee on Medical Education (LCME) [3]. IMGs are a heterogeneous group with widely varying cultural, educational, and linguistic backgrounds. Included in this group, but distinct from FIMGs, are USIMGs, who are U.S.-born or naturalized citizens who have obtained their medical education abroad. USIMGs, some of whom are second-generation Americans, tend to be graduates of Caribbean medical schools whose native language is English, are younger, more likely to be male, and more likely to practice in primary care specialties than FIMGs [4]. Though studies indicate that they perform less well than FIMGs on certifying [4], training [5], and specialty board examinations [6], they have less difficulty in entering the workforce in the United States [4].

In 2009, USIMGs and FIMGs accounted for one-fourth of the licensed physicians in the U.S. and 29.2 percent of physicians in residency/fellowship training [7]. The top five countries in which IMGs practicing in the U.S. obtained their medical degrees are India (20.7 percent), the Philippines (8.3 percent), Mexico (5.6 percent), Pakistan (4.9 percent), and the Dominican Republic (3.2 percent) [3]. New York, California, Florida, Texas, and Illinois are favorite destinations for all IMGs in the U.S. [7].

Internal medicine (24.6 percent), pediatrics (8.2 percent), family practice (7.9 percent), psychiatry (5.2 percent) and anesthesiology (4.5 percent) are the top specialty choices for IMGs [7]. About three-quarters (76.9 percent) of IMGs (including those in residency/fellowship training) are mainly engaged in clinical care, with minor representations in medical education (0.7 percent), research (1 percent) and administration (0.7 percent) [7].

## Weaving IMGs into the Safety Net

Studies have found that IMGs tend to practice in physician shortage areas characterized by high rates of infant mortality and below-average physician-to-population ratio [8]. They are also believed to take care of more minority patients [9], accept more Medicare and Medicaid patients, and work more hours [10] than U.S. medical graduates (USMGs). In addition, FIMGs have tended to work in primary care medical specialties that are less popular with USMGs, such as internal medicine, pediatrics, psychiatry and ob/gyn [11]. This issue of specialty choice by IMGs is highly controversial: some believe that by choosing such specialties, IMGs correct physician maldistribution [9], while others contend that IMGs do not substantially differ from USMGs in specialty choice [12].

As for the quality of care rendered, in a large retrospective analysis FIMGs performed better than USMGs and USIMGs in, for example, the care of congestive heart failure [13]. In addition, IMGs seem to have greater ability to tolerate stress and higher self-esteem than USMGs and USIMGs [14]. The performance of IMGs on the U.S. Medical Licensing Examination (USMLE) is better than that of USIMGs [15].

The competence of IMGs as physicians and the soundness of their educational backgrounds has long been a contentious issue. This does not mean that IMGs have any fewer or easier requirements than USMGs—in fact, they have more. To qualify for residency training in the United States, IMGs must be certified by the Education Commission for Foreign Medical Graduates [16], which requires that they pass the USMLE Steps 1 and 2, including the Clinical Skills Assessment, within a certain period of time. In addition, they must document that they have studied for 4 years at, graduated from, and received a diploma from a school listed in the *International Medical Education Directory* [17] To obtain a license to practice medicine in the United States, IMGs are required not only to pass the USMLE Step 3, but, in most states, to undergo more residency training than USMGs, e.g. complete 2-3 rather than 1 year [18] (see figure 1).

## **United States Immigration Policy and FIMGs**

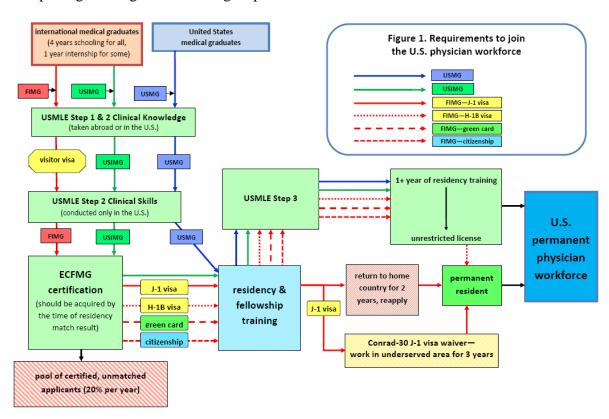
To participate in graduate medical education (GME), in addition to having ECFMG certification, FIMGs are required to obtain a visa from the immigration service. The temporary visas consist of the J-1 exchange visitor (EV) visa and the H-1B visa; the permanent category includes citizenship and permanent resident status. Permanent resident documentation, also known as a "green card" or immigrant visa, is obtained based on a preferential system that classifies an applicant as either family-sponsored

or employer-sponsored. Historically, the J-1 visa has been the dominant mode of temporary entry, and family-preference status the dominant mode of permanent entry for foreign national IMGs [3]. The visa and immigration status of those in graduate medical education programs are shown in table 1.

Table 1. Citizenship status of participants in GME programs [19]

Immigration Status	All GME participants	IMG portion of column 1 category
Native-born citizens	66.1%	7.6%
Naturalized citizens	8.1%	37.7%
Permanent residents	7.3%	67.6%
Non-immigrant H- and J-visa holders	8.9%	96.7%
Other (B-1, B-2, F-1, refugees, unknown citizenship, etc.)	9.6%	65%

The J-1 visa is for residency training, and it is sponsored by the ECFMG (see figure 1). For a graduating resident on a J-1 visa to continue to work in the U.S. after completing training, the following steps need to be taken.



Conrad-30 waivers. J-1s are waived under certain circumstances, such as when the applicant's skills are needed, the visa holder anticipates persecution in his home country, or the applicant's U.S.-citizen spouse will experience exceptional hardship if the applicant returns to his or her home country [20]. The Conrad-30 waiver program allows each state's Department of Health to sponsor up to 30 (initially 20)

international medical graduates each year for waivers of the requirement that they reside in their home countries for 2 years after their visas expire before applying to change their immigration status.

Those approved for Conrad-30 waivers are required to serve in rural or urban federally designated health professional shortage areas or medically underserved areas [21, 22]. The 1,000 waivers issued in 2010 is a tremendous increase from the 70 issued in 1990 [23], attesting to the extent to which many communities across the United States continue to face severe difficulties in attracting U.S. physicians to meet their health care needs [22] and to which IMG residents on J-1 visas contribute to the alleviation of those difficulties.

According to the U.S. Government Accountability Office [23], the J-1 visa waiver has become the major means of placing physicians in rural and other health professional shortage areas. Ninety percent of J-1 physicians complete their employment term, and 28 percent of them continue to practice in the same area up to 4 years later [3].

*H-1B visa*. The H-1B visa is for temporary workers in specialty occupations holding professional-level degrees, including graduates of foreign medical schools. Unlike the J-1 visa, the H-1B visa does not have a 2-year home residence requirement; it allows a foreign national to remain in the United States for professional-level employment for up to 6 years, and it does not prohibit "immigrant intent." H-1B visas require the prospective employer to attest to the Department of Labor that the candidate will be paid the same salary that is paid to a citizen [24] and the candidate to pass USMLE Step 3. Physicians who complete 6 years of employment on H-1B visas usually seek permanent resident status.

*Immigrant visa (green card)*. IMGs may qualify for an immigrant visa (also known as a green card), which permits foreign citizens to remain permanently in the United States if they are immediate relatives of a U.S. citizen or lawful permanent resident, employees of a sponsoring employer or prospective employer, or "diversity immigrants" chosen by lottery.

#### **Effects of Immigration Policies on IMGs**

There has been considerable ambivalence, inconsistency, and arbitrariness in U.S. immigration policies towards FIMGs. A few little known and potentially serious obstacles that immigration policy presents for IMGs will be discussed and their implications for the U.S. health care system will be considered. A brief discussion of remedies to address these problems will conclude the paper.

*Treatment of J-1 visa holders*. J-1 visas have one of the most exacting sets of requirements. The United States Citizenship and Immigration Service (USCIS) prohibits J-1 visa holders from having current or possible future "immigrant intent," and they are subject to suspicion on that front. In this regard one major policy-related issue for IMGs, which is little-known outside of the IMG community and some

training programs, is USCIS's preventing IMGs on J-1 visas from reentering the U.S. after visiting their home countries.

This policy is randomly enforced, however, creating considerable uncertainty for IMGs, as well as distraction from learning and enormous stress and worry. One program alone saw one of its residents on a J-1 visa and the family of another resident on a J-1 visa unable to return from their home countries after their visas were rejected by U.S. consulates. They were able to reenter the U.S. much later, only after frantic activity on the part of elected officials in the U.S. In the process, both patient care and residency training for the residents were interrupted, not to mention the extreme degree of personal anxiety the forced separation from their families caused. Incidents such as these are not infrequent among IMGs on J-1 visas.

Denial of visas for the Step 2 Clinical Skills exam. The second issue concerns the experience of foreign medical students seeking visas to enter the U.S. to take the Clinical Skills (Step 2 CS) exam. Obtaining ECFMG certification is a drawn-out and expensive process that requires FIMGs to pass USMLE Step 1 and Step 2 CK (Clinical Knowledge) examinations in their native country and travel to the US to take the Step 2 CS (Clinical Skills) examination, which is administered at only a handful of centers in the U.S. After passing the Step 1 and Step 2 CK exams, however, some applicants find that their applications for visas to take the CS exam are rejected (unpublished data). The effort and resources they put into passing the first two steps is thus wasted.

Brain drain. Concerned about possible deleterious effects of physician emigration on IMGs' home nations, also called "brain drain," policy makers have been advocating that the United States depend on itself to address the physician shortage [25]. Such a stance is paternalistic, and immigration is not necessarily incompatible with one's responsibility to the home country and its needs. While an emigrating physician might deprive his or her home country of the knowledge and skills of a medical professional, he or she may contribute to the native economy in other, perhaps more important, ways, such as sending money home, taking much-needed skills back, and building hospitals.

To try to address its physician shortage, the United States has embarked on an expansion of its internal educational capabilities by 30 percent by adding new medical schools and expanding the class sizes of existing schools [26]. However, this expansion will not fix the shortage unless it is coupled with a correlative expansion in GME slots (and since, as the number of USMGs increases, the number of FIMGs in GME decreases [27], so it appears that this will prevent IMGs from being able to become licensed in the U.S.). The primary source of GME funding—from the Centers for Medicare and Medicaid Services—is frozen at 1997 levels [28] and is threatened with significant reductions due to the current budget crisis. Meanwhile, the demand for physician services will increase enormously with the addition of 32 million currently uninsured people who will become insured under the recent health care reforms and aging baby boomers' need for medical services.

Therefore, due to the inherent impossibility of expanding both USMG slots and GME slots quickly enough to enable an entirely domestic solution to the physician shortage, serious consideration should be given to a role for IMGs.

#### Remedies

- 1. *Address the inconsistencies*. To prevent disruption of patient care, IMGs on temporary visas should be allowed the freedom to travel out of the country and return unfettered.
- 2. Address unemployed IMGs. To avoid putting examinees through the expensive USMLE process fruitlessly, the ECFMG should limit the number of examinees based on GME slots in a given year and ensure that all the candidates who pass USMLE Step 2 CK get visas to enter the U.S.
- 3. *Fund more GME*. If the number of GME slots were determined by the needs of the system, the physician shortage could more realistically be addressed.
- 4. Redesign immigration visa categories by permitting dual intent for people on temporary visas or doing away with temporary visas altogether. A new visa type similar to category O (a temporary visa for "aliens of extraordinary ability") should be created for physicians to allow flexibility during the various phases of their training and careers.
- 5. *Plan for the long term*. If the current physician shortage is not addressed by the measures suggested, one might consider the following long-range solutions.
  - a) Undertake active recruitment of foreign physicians. This is a radical idea that would allow IMGs with postgraduate degrees from certain English-speaking countries to enter the U.S. and start practicing right away. (The requirement is that any foreign physician, no matter how senior, who wishes to obtain a license to practice medicine in the United States must complete a residency program here.) Active recruitment was used by the United Kingdom to recruit a large number of senior physicians from India and South Africa to run its national health service [29, 30]. However, one must keep in mind that it is unethical for the recruiter to rescind these physicians' employment when the native physician supply improves.
  - b) Develop a truly global medical education system in which the United States' undergraduate and graduate medical education standards shape medical education abroad. This would allow professionals to move back and forth between the United States and their countries of origin as people are able to move within countries and Euro-zone countries. Recently, the ACGME accredited Singapore's GME [31], and many U.S. medical schools have established satellite campuses abroad [32]. The ECFMG will require international accreditation of foreign medical schools starting in 2023 [16].

In conclusion, high-performing doctors willing to work to alleviate the shortage of medical care in the United States should not be barred from doing so because of their foreign medical education. Allowing and encouraging international medical graduates to work in the U.S. will benefit those who need care here, the IMGs themselves, and the global economy.

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## Acknowledgments

The author thanks Chella Kamarajan, PhD, and Rahul Kodali, MD, MPH, for their able assistance in preparing this article.

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# Virtual Mentor

American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 338-343.

#### MEDICINE AND SOCIETY

The Fallacy and Danger of Dichotomizing Cultural Differences: The Truth about Medical Truth Telling in China

Jing-Bao Nie, BMed, MMed, MA, PhD

In this age of globalization and multiculturalism, how cultural differences should be respected and addressed poses a persistent challenge for health care practitioners as well as for society at large. In medical education, the question has long since shifted from whether or not cultural differences on illness, health, and healing should be a part of curriculum to *how* these differences can best be taught. But the existence, sociohistorical roots, moral meanings, and political implications of cultural differences are rarely as straightforward as they appear. As a result, empirically dubious statements, ethically problematic judgments, and practically contentious proposals can become entangled in thinking about and dealing with cultural differences in health care, as they can in wider sociopolitical domains.

Dichotomizing constitutes one of the most dominant and pervasive approaches to perceiving, defining, and presenting cultural differences, especially when comparing Western and non-Western cultures. Among the widely-circulated sets of oppositions are:

- Communitarian or collectivist China vs. the individualistic West;
- Family decision making vs. the model of individual autonomy;
- The emphasis on personal virtues and obedience vs. the emphasis on individual liberty and rights;
- Moralism vs. materialism;
- A holistic mentality vs. an analytic and mechanistic mindset;
- (In the medical care context) patients' not being told of terminal illness or being told indirectly by family members in China vs. being directly told by medical professionals in the West.

Dichotomization offers neat characterizations of different cultures and appears to respect differences. It has much to do with a good-faith attempt to understand the people, practices, and values of other cultures or societies. Nevertheless, this deep-seated and still popular approach is actually a major obstacle to adequately appreciating cultural differences. Rather than enlightening us about the differences between cultural practices and norms, the dichotomizing approach often merely reinforces a variety of stereotypes—explicit or implicit, good or bad—that exist in the public mind and academic circles. Rather than promoting the intended cross-cultural understanding and dialogue, it often helps to fortify the invisible old "walls" between cultures and even creates new ones.

In the following, I will use the issue of medical truth telling about terminal illness in the Chinese cultural context as a way to illustrate briefly not only the speciousness of dichotomizing cultures but also the elements of a way to move beyond it [1].

## **Obscuring the Truth**

Medical professionals' open and honest disclosure to patients about their medical conditions, including the diagnosis and prognosis of terminal illness, has now become standard practice in most Western societies. Yet, according to an Italian physician who has written extensively on cultural differences regarding truth telling in the past two decades, variety in truth-telling practices in medicine remains throughout the world [2]. While practices and attitudes have shifted toward truth telling and disclosure of diagnosis to cancer patients, partial and full nondisclosure can still be found in many cultures that grant primacy to family and community values [3].

In sharp contrast to the West, as widely acknowledged within and outside, medical professionals in China (including Hong Kong and Taiwan) routinely withhold information about terminal illness from patients, usually inform family members only, and sometimes along with relatives even lie to patients. Based on the usual assumptions about China and the West, Chinese and non-Chinese commentators alike have presented a clear-cut cultural dichotomy between China and the West regarding the communication of a dire prognosis—a crude opposition between nondisclosure or indirect disclosure and direct disclosure. In this image, medical truth telling about terminal illness has been assumed to be unknown in the Middle Kingdom until recently.

The cultural differences at stake here are far more complex and rich, however, and thus far more intriguing and fascinating than anything implied by this crude dualistic schema. Using extensive primary historical materials in China, including the biographies of ancient medical sages and famous physicians from various dynasties, a long, although forgotten, Chinese tradition of truth telling about terminal illness that dates back at least twenty-six centuries can be recovered [4]. The traditional practice in Chinese culture and medical ethics was, in fact, for physicians to disclose diagnoses and prognoses of terminal illness truthfully and directly to patients. Important ethical rationales for doing so were offered or presumed. The Confucian moral outlook mandates truthfulness as a basic ethical principle and a cardinal social virtue that physicians ought to take as their guiding star [4, 5].

This long Chinese tradition is especially remarkable when compared to the situation in the West, where concealing the truth about terminal illness was the cultural norm historically and clearly stipulated in both ancient medical texts (including the Hippocratic writings) and modern professional codes of medicine (such as the internationally influential 1847 Code of Medical Ethics of the American Medical Association)—and where direct disclosure did not become the standard procedure until the 1960s and 1970s, or even later [6]. Interestingly and somewhat ironically, the contemporary mainstream Chinese practice of *non*disclosure is not as culturally

authentic as it appears; its origin and development might be closely connected with the then-dominant Western norm of concealment.

Also, the wide Western acceptance of generalizations about concealing or even deceiving the patient as the representative Chinese feature on the diagnosis and prognosis of terminal illness might arise from such deeply rooted stereotypes as the "untruthfulness of the Oriental mind"—designations that were in wide circulation in the West not so long ago [4].

Sociologically, numerous surveys conducted throughout mainland China, like others in Hong Kong and Taiwan, demonstrate that the great majority of Chinese patients want truthful information about their medical condition, even in terminal cases [5, 7-10]. Moreover, the great majority of medical professionals and their family members would themselves prefer to know the medical truth when they were asked to imagine that they were patients [5, 11]. A shift from current practice of avoiding direct disclosure toward honest and direct disclosure by physicians is now occurring in China, a change that is not so much an aping of Western (and thus foreign) ways as it is a return to a long-neglected indigenous Chinese tradition.

These findings provide compelling evidence that contrasting medical truth telling in China and the West in the conventional dichotomized terms—nondisclosure or indirect disclosure vs. direct disclosure—is descriptively wrong. This leads to an erroneous normative conclusion if, based on the apparent cultural difference, one argues that medical truth telling ought not to be practiced in China or with Chinese patients because it is culturally alien to China.

My intention here is not to discuss the historical, sociological, and ethical issues surrounding medical truth telling in China in detail (for such a discussion, see 4, 5). Rather, my point is about the misfortunes brought about by the age-old and still dominant habit of dichotomizing cultures. Too often, as the passage above has shown, this habit grossly distorts the historical and sociocultural realities in both China and the West (and especially in China) and oversimplifies both. Moreover, it obscures the real ethical predicaments at stake; deprives the cultures concerned of openness to new possibilities; and, finally and most dangerously, promotes defeatist beliefs about the inevitability of cultural clashes and the impossibility of creative cross-cultural dialogue.

## **Hobbling Ethical Debate and Evolution**

Dichotomizing cultures is fallacious on a purely empirical level because it assumes fundamentally (or at least largely) single, unified, homogenous Chinese or Western cultures. As a result, it downplays, if not totally ignores, the great internal plurality within every culture. Moreover, those who dichotomize deem the dominant practice or official position of a given culture on a particular issue to be the authentic representative of that culture. Other viewpoints, discourses, voices, especially dissident and marginalized ones, are generally dismissed as irrelevant or even outside the culture (e.g., "un-Chinese" in the context of China). Furthermore,

dichotomizing cultures involves what has been called "false cultural essentialism." It treats culture as an iron cage or entirely rigid structure when, in reality, culture is an open system, changeable and changing.

Describing culture as a closed system with fixed categories denies the openness of the culture concerned in a more serious sense; that is, it denies that culture constantly reforms itself not just by learning from foreign cultures but also by following moral imperatives. Hence, dichotomizing cultures is politically and normatively dangerous because it accepts as cultural norms, either tacitly or explicitly, some ethically problematic beliefs and practically contentious theses. This, in turn, diverts ethical examination from grappling with true moral dilemmas or difficulties to describing existing cultural practices. In other words, dichotomizing reinforces what can be called the tyranny of cultural practices over ethics, rather than upholding the primacy of morality.

Politically, dichotomization can create a significant barrier to cross-cultural understanding through the "assumption of radical differences" or the "assumption of incommensurability." Cultural differences are often exaggerated to reject the existence of cross-cultural similarities and commonalities or shared humanity. Dichotomization advances the "self-defeating prophecy of the clash of cultures," that is, a widespread belief that the clash, especially the violent clash, of the cultures of China and the West—or of different civilizations in general—is inevitable. The clash of cultures and civilizations, as has repeatedly occurred throughout history, is defined as a matter of our destiny, not human choice. But history has also taught us that, so long as we are willing, genuine dialogue between and among different cultures—like those that take place between diverse moral traditions and viewpoints within every culture—is not only necessary but also possible, however difficult its realization may be in practice.

It is, therefore, time to put to rest the dichotomous approach to thinking and presenting about East and West, about "them" and "us," and about cultural differences in general, however deep-seated and apparently useful the habit of thought is. It is time at least to put those conventional dichotomies in the right perspectives. In order to adequately understand and address cultural differences, alternative ways have to be explored.

#### **Beyond Dichotomies**

Originally trained in traditional Chinese medicine, I myself used to accept the dichotomization and its series of dualistic contrasts between Chinese and Western cultures, medicine included, without questioning their validity. I undertook in-depth investigations into medical ethics in China and Chinese people's views and experiences of abortion with an explicit or implicit comparative approach. Through these research projects I realized how inadequate and misleading the dichotomizing schema is. As a result, I have put forward (and am still developing) an alternative, what has been called a "transcultural" or "interpretative" approach [12, 13]. The main features of this paradigm of cross-cultural ethics and comparative studies

include resisting a variety of cultural stereotypes and stereotyping; highlighting the great internal plurality, richness, dynamism, and openness of medicine and morality in any culture; acknowledging cultural differences as well as common humanity; and searching for more appropriate methods of generating genuine and deep crosscultural dialogue.

In contrary to the clear-cut crude opposition fostered by dichotomization, a transcultural or interpretative approach pays close attention to the complexity of cultural differences and some important common features, such as the wish of most patients in both China and the West to know the truth about their medical conditions. Either of the two practices—direct and open disclosure and nondisclosure or indirect disclosure—is as Chinese as the other one, just as each is as Western as the other.

On a practical level, following the conventional approach to dichotomizing cultures, Chinese patients would be simply pigeonholed into a ready-made cultural "label" or "category": nondisclosure or indirect disclosure. But the transcultural or interpretative approach calls for medical professionals to carefully examine every individual case. Rather than just assuming China as the "radical other" of the West (and Chinese as the "radical others" of the Westerners) or stereotyping the needs of Chinese patients, the transcultural approach advocates individualized care for each patient, with family input on how medical information should be handled. And it contends that the mainstream practice in contemporary China, according to which crucial information has often been withheld from patients with terminal illness, needs to be reformed.

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#### Acknowledgment

This essay would not be possible without the kind invitation of Faith Lagay and her editorial assistance, far beyond what is usually expected from an editor.

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# Virtual Mentor

American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 344-350.

# IMAGES OF HEALING AND LEARNING "Sickness Is a Place": The Foreign Culture of Illness Faith L. Lagay, PhD

"In a sense, sickness is a place...and it's always a place where there's no company, where nobody can follow" [1].

The illness experience—time spent in the place of sickness—has been a defining topos of biomedical ethics since that discipline's birth in the early 1970s. All students of medical ethics and many preclinical medical students are assigned Tolstoy's *The Death of Ivan Ilych* as a way to begin to understand the torment of a man isolated from his family and friends by his terminal illness.

Long part of the literary canon, in part because it is a manageably short sample of Tolstoy's writing that showcases his satire of the middle class of his day, this late nineteenth-century (1886) novella was seized upon by the medical ethics community for its close look at existential suffering and the harm wrought by lying to patients about their prognoses. Ilych blames the deception for plunging him into loneliness that "could not have been more complete anywhere—either at the bottom of the sea or under the earth" [2].

In *Imagine a Woman* [3], a late twentieth-century novella by surgeon-writer Richard Selzer, the woman of the title exiles herself to a foreign land to die. If her story is as credible as that of Ivan Ilych, I wondered, would it have anything to say about the difference between the social isolation imposed by a foreign landscape and the psychological isolation induced by illness. Could the former in any way mitigate the latter?

The Internet seemed a likely place to look for a twenty-first-century description of the illness experience. I had followed Leroy Sievers' radio essays, *My Cancer*, during the 18 months before his death in August 2008 at age 53. Beginning in 2006, his audio diary on national public radio's *Morning Edition* later became a blog, and all his posts and responses to them by readers are now available on the Internet [4]. Sievers was a journalist who covered wars, genocides, and national disasters for decades. He was employed by *Nightline* for 14 years, during the last 4 of which he was its executive producer.

I have no watertight rationale for selecting these three texts as testing grounds for the hypothesis that sickness is a foreign place and culture. *The Death of Ivan Ilych* seemed an obvious starting place, given its prominence in the medical humanities literature, and the blog, a fitting twenty-first-century destination. *Imagine a Woman* 

sprang to mind because I have loved this novella for two decades, and Selzer's romance—for it is one—would have us believe that choosing a place to die can change one's last days for the better; that changing the physical place in which one is sick can change the psychological experience of sickness. We'll just see about that.

At first, the omniscient narrator in *The Death of Ivan Ilych* tells us that what torments Ivan Ilych most is the deception, "the lie which for some reason they all accepted that he was not dying but was simply ill" [5]. "This falsity around him and within him did more than anything else to poison his last days" [6]. What we learn as the last days arrive, however, is that Ivan Ilych's mental suffering and "chief torture" are far worse than and the lying of those around him. It is the lying "within him" that is most excruciating and insufferable. Ilych wonders whether he might not have spent his life as he should have and "the question suddenly occurred to him: 'What if my whole life has really been wrong"[7]? And if that is so, he reasons further, "and I am leaving this life with the consciousness that I have lost all that was given to me and it is impossible to rectify it—what then" [7]?

What comes to light finally is his unbearable existential suffering. What if my life has been wrong, false, and I am only discovering it now when it is too late to do anything about it? Indeed, as a public prosecutor and judge, Ilych was conscious of his power to imprison anyone he chose, to ruin anyone he wished to ruin, and, we are told, his success at "these things made his work still more attractive" [8]. Ivan Ilych's several fortnights on the couch in his parlor are spent in a place created by illness in the sense that, absent his sickness, Ilych would not have been removed from the camaraderie of his friends and fellow judges and would not have had the devastating thought that, possibly, his life was wrongly lived. His sickness and isolation, in truth, provide a space in which psychological investigation and disintegration can occur.

It is a long way, physically—and spiritually, one might say—from the button on the back of Ivan Ilych's sofa and the creases in its Moroccan leather at which he stares for weeks to the fragrant acacia grove that surrounds a lakeside *pension* in Veyrier, France, to which an ailing "American woman" escapes. Her story is told in letters to her husband that she has wrapped, addressed, and given to Madame Durand, the concierge, with instructions to post them a month after her death. Madame Gallant her name is pronounced once by the concierge—has AIDS. Learning that she had contracted the disease from her husband and that the child she was carrying would most likely be affected, Madame Gallant ran off and remained out of touch with her husband for nearly a year. (The inferences that an AIDS diagnosis means imminent death and that her unborn child cannot be spared the disease place the story in the late 1980s or early 1990s.) She has come with "enough money and morphine...to free myself from anxiety and discomfort" [9].

Unlike Ivan Ilych, the woman knows her diagnosis and those around her know she is dying, but there is no discussion of it at the pension or in the village. Madame Durand silently provides what is needed to support the woman in her decline; she

serves as midwife when the child is stillborn. The woman documents her failing physical state in her letters: she is losing weight, shedding her skin, her legs feel 50 years older than the rest of her body,

Parts of me are quite raw. Why do they call it shingles? I cannot bear the weight of the sheet on my chest. Once again Madame has provided: a loose, flowing white cotton gown that covers me wrist to ankle with a mantle to raise against the sun [10].

Despite the unrelenting progress toward death, the woman experiences no psychological pain or existential suffering. The lamp light hurts her eyes, causing them to water, but "I weep for no other reason," she assures Madame Durand [11]. She neither hates her husband nor condemns his secret love. "Despite all," she writes, "I continue to marvel at love however one locates it" [9]. In the earlier days of her stay, she walked to the village, visited the baker at his brick ovens, and rode up the hill in a truck to the farm of a market woman and her family.

As death approaches, the woman begins to see a diver—"a sweet water Triton"—arise from the lake [12]. They talk, and the Triton tells her to throw a stone into the water when she wants him to come, and he will carry her away. "When I am with him, he is absolutely real," she writes. "When he has left me, I wonder" [13]. And in the end, she tells the Triton she is ready: "I want to go down" [14].

For Ivan Ilych, death is not a lake and welcoming Triton but a black sack that haunts his dreams.

For three whole days...he struggled in that black sack into which he was being thrust by an invisible, resistless force. He struggled as a man condemned to death struggles in the hands of the executioner, knowing that he cannot save himself...He felt that his agony was due to his being thrust into that black hole and still more to his not being able to get right into it. He was hindered from getting into it by his conviction that his life had been a good one [15].

Is it enough to say simply that Tolstoy wrote of a man tortured by the recognition that he had lived a selfish, mean-spirited life and Selzer of a woman with no regrets? It seems not to be. Can we believe that enough morphine can free one from the anxiety and discomfort of terminal illness? Ivan Ilych had morphine, too. Can knowledge of one's diagnosis and prognosis, acknowledgement by others that one is dying and deserves respect, and planning for one's last days—can these be the difference?

Because these are fictions, we can conclude that it is a romantic idea on Selzer's part that one can elect to slip away from life as into a cool lake in the strong arms of a Triton. It is no less romantic on Tolstoy's part, however, to have us believe that, if one's life has been selfish and unexamined, the only way out is being stuffed into a

black bag against one's will. The notion that a bad death will follow a "wrong" life is neither more nor less true, empirically, than the notion that a good death will follow a good life. Both are fictions, romantic fictions.

As the twentieth century progressed, personal, *non*fiction accounts of suffering from ill health—pathographies—began to propagate. With the Internet and its blogosphere, pathographies now abound. Illness is more thought-provoking than health. It grabs the attention of its victim and screws it to the present. Ivan Ilych's waking moments are dominated by thoughts of "the kidney and the appendix that were not behaving as they ought to" [16]. The American woman's illness fixes her attention on an equally sensuous but more salubrious present.

I have become strangely receptive to the moon, the waterfall, the trees, the bread, the wine, and all the components of this magic village. As my immunity to the germs has dwindled, so has my resistance to these "influences" [17].

With the opportunity for daily blogging, those with illnesses can keep everyone informed of each passing moment—waiting for the next painful diagnostic invasion or the first sickeningly sweet rush of chemical toxins into the system. It behooves a reader to approach pathographies with aesthetic discretion. Many are poor. Leroy Sievers' My Cancer is rich.

Sievers acknowledges that, since his diagnosis he lives in a different world [18], a parallel universe. "It looks like the regular world, but it's very, very different. It's populated by other patients with whom you share war stories" [19]. Interesting to me—and more than a side note—is that Christopher Hitchens, international journalism's number one atheist and all-around "bad boy," makes a similar point in his Topic of Cancer essay for Vanity Fair. Rescued from his New York hotel by emergency services, "I had the time to wonder," he writes in typical sardonic fashion,

why they needed so many boots and helmets and so much heavy backup equipment, but now that I view the scene in retrospect I see it as a very gentle and firm deportation, taking me from the country of the well across the stark frontier that marks off the land of malady [20].

So far so good for confirming O'Connor's dictum: sickness is a place. But at this point, things change for Sievers (if not for Hitchens, who is not the fellow-blogger type of guy). Once others correspond with Sievers, "this whole blog thing" connects him to a defined subculture, those with cancer [21]. He says its members encourage and strengthen him; their e-mails are "stunning in their eloquence, their courage, their determination" [22]. Often he paraphrases from the responses he receives or retells someone's story. After a tough day in August, he asks fellow residents of his cancer world, "What gets each of you through the days? Is it food, a particular treat? I do this out of curiosity," he says, "but quite frankly, I'm sort of running out of tricks myself. I'm looking for some new ones" [23].

The Internet-facilitated interconnectivity among people with like experiences is often ridiculed for the extreme specificity of the links, e.g., a web site for red-haired second children of blended families in which the Irish biological mother is 10 or more years younger than the non-related Italian father. It seems to me now, though, that this sometimes-ridiculed interconnectivity has made possible a subculture in which those with terminal illnesses and diagnoses can escape the loneliness and isolation endured by Ivan Ilych. After sharing some of the correspondence he has received, Sievers says, "so, to all of my friends and to all of you out there who are fighting this disease along with your loved ones, thank you. Like it or not, we're all in this together" [24].

This is certainly not to say that sharing a virtual "place" and a language with others makes dying any less frightening or more welcome—Sievers *does* say, "like it or not." It is only to say that perhaps sickness has become a place where there *is* company and people *can* follow, a less isolated place. Would Ivan Ilych be likely to be a blogger were he in Sievers' shoes? Probably not.

Does the virtual community grant a greater sense of control over one's life? In a tiny way, maybe sharing loss of control with those who you know will understand counts. Sievers:

I think a lot of you will understand, those who share the journey I'm on. You lose control of so much when you're diagnosed with cancer. So you try to hold on to as much control as you can, even if it's just where you go for dinner. In so many ways, large and small, you want to show yourself—if not the world—that you haven't lost yet. You're still in charge [25].

So maybe for the large-hearted, sharing sort of twenty-first-century person, sickness is a place, but a place where one is not necessarily alone. But my appreciation for romance forces me to give the last sentence to "the American woman" who had no physicians, no treatment, no ICU, no daily medical assessment of her decline to death. Wonder what that says.

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American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 351-359.

## **Suggested Readings and Resources**

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# Virtual Mentor

American Medical Association Journal of Ethics April 2012, Volume 14, Number 4: 360-361.

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