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# Fadiman and Beyond – The Dangers of Extrapolation

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*Cross-cultural patient care is an issue that challenges healthcare providers. Caring for patients who reject some biomedical treatments because of religious or cultural reasons requires knowledge of that person's beliefs for effective treatment. This essay looks at several case studies involving Hmong patients and the way the medical staff reacted to treatment difficulties because of cultural and religious conflicts with surgery. The dangers of universalizing communication methods are stressed.*

In January 2001, a fifty-seven-year-old Hmong gentleman arrived at the emergency room with progressive nausea and vomiting. Laboratory tests indicated kidney failure and a life-threatening serum potassium level.

The medical resident in charge told the patient that he was being admitted for dialysis. Alarmed by the proposed intervention, the man refused. The resident tried vociferously to change the patient's mind but when the patient still refused, he called security, had the patient placed in four-point restraint, and sent him to the medical ward.

The resident overrode the patient's wishes because he deemed the patient incompetent to make a decision. The written diagnosis in the chart was "renal failure and hyperkalemia"; the unwritten diagnosis was "patient decision-making incompetence." Cultural difference and patient incompetence had, in this case, been construed as synonyms.

When the attending nephrologist met the patient, she was alarmed by what the resident had

done. She explained to the patient that because his condition was serious, people were concerned and reacted in an extreme manner. A culture-based value had, in this case, been treated as an obstruction to a value the staff deemed more important — the provision of life-saving biomedical therapy. The resident involved acted in good faith in relation to this goal, and motivated by systemic pressures to manage the situation efficiently. Nevertheless, the assumption that cultural difference can be overcome to secure patient compliance was forcefully conveyed.

In 2001, cultural difference should not be seen as a problem to be subdued. Anne Fadiman clearly articulates this message in her case study *The Spirit Catches You and You Fall Down*. This book offers a humane depiction of a Hmong family's epileptic child and the pediatricians who treated her. Its tale of repeated failures of communication and the medical team's perception that cultural values are obstacles to their ability to provide the highest standard of care, has become a classic object lesson on the imperative of developing "cultural competence." Since its publication in

1997, numerous journal articles, curricula, and workshops have emerged to train medical staff in cross-cultural issues in patient care. Fadiman's book is frequently invoked as depicting a worst-case scenario of cultural incompetence.

The growing cultural diversity of the United States further persuades clinicians of the imperative of cross-cultural understanding in medical care. But such understanding is not acquired overnight. Rather, it involves visiting and revisiting the same questions and issues, bringing them into dialogue with experience to arrive at knowledge grounded in theory and in practice. Cross-cultural awareness is more accurately described as something that one can only develop in stages.

At each stage, we are tempted to find patterns from which we can generalize responses. This tendency is similar to the way scientific researchers extrapolate generalizations from their data. Likewise, to make things simple, clinicians may extrapolate from a case study and universalize the cultural characteristics it presents. Ironically, even Fadiman's work can be turned to such ends. One might conclude, for example, that Hmong are animists who resort to shamans, and that most biomedical caregivers are clueless in relation to cultural difference.

Neither, in fact, is the case. Just as research scientists recognize the danger of over-generalization from their extrapolations, so must clinicians in relation to cultural data. What is true in one situation may not be true in a similar case, for reasons that may not be apparent. The challenge is to develop a nuanced understanding from case studies and case experience, without reducing the most complex of these into stereotypes camouflaged under the heading of "cultural competence."

The four fictionalized scenarios that follow are based on actual cases and further demonstrate the complexity of patient care. These cases point to several dangers in patient care beyond those found in Fadiman's case study. As in *The Spirit Catches You and You Fall Down*, these cases

show how patient values and intentions can be misunderstood. They also demonstrate challenges posed by every patient's and every family's uniqueness. The cases reinforce the importance of interviewing individuals to discover the meanings, beliefs, and interpretations that each patient and family bring to their experience of illness.

### Concepts of Culture

By culture, we mean the codes that given societies, groups, or subgroups convey to their members, teaching them "how to view the world, how to experience it emotionally, and behave in relation to other people, to supernatural gods, and the natural environment" (Helman 1994). The term "beliefs" is sometimes used in relation

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to culture or understandings of health, as in "health beliefs." However, as Smith has noted in relation to the study of religious traditions, "belief" characterizes some Western traditions better than it does other world traditions. It has also taken on an air of doubt, as in, "I believe so (but am not entirely sure)" (Smith 1998, Good 1994). We prefer the notion of "world views," to indicate the interconnectedness of perceptions, values, and related behaviors expressive of a given cultural formation.

Likewise, culture descriptions include religion as one of many variables — as another set of beliefs contributing to a broader set of "cultural beliefs." Religion is sometimes isolated under the heading of "social support" or "coping

mechanism." We take issue with both approaches and suggest, instead, that a religious tradition or world view may inform every aspect of someone's life experience. No religious or spiritual tradition ignores the meaning of affliction, suffering, illness, and healing. This perspective is often a crucial dimension permeating one's cultural formation and understanding of health and the purpose of medicine.

Enculturation, or cultural formation, is what happens when an individual internalizes the implicit or explicit guidelines of his or her social group. It takes place over a lifetime and may involve absorbing the influence of a dominant culture, or the various subcultures of which one is a part. Cultural formation influences

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one's self-understanding and behavior toward others. It shapes one's values and direction in life. It influences the social categories and frameworks in which one finds (and places) oneself and others, with or against their will (Helman 1994). Cultural formation also governs what is experienced as normative and universal, particularly on the part of dominant groups. It includes how social and economic differences structure experience. Two individuals who come from the same cultural background, for example, will experience that background in radically different ways, depending on their class position and its related benefits and pressures on their lives.

That no two individuals internalize their cultural formation in the same manner may seem little more than a truism. Yet, in the midst of

developing cross-cultural sensitivity, that truism can easily be lost, especially as we grasp for consistent guideposts with which to navigate difference. The challenge is remaining open to the differences within difference.

### **Case One: Cultural world view or Idiosyncratic Parental Position?**

Both parents of a ten-month-old Hmong girl appeared for a routine well-child check at the office of a new pediatrician. The child appeared happy and healthy with classic features for Trisomy 21 (Down's Syndrome). The parents appeared to care for their daughter and, with six children at home, demonstrated significant knowledge regarding child care.

The pediatrician examined the child and was surprised by the presence of a loud heart murmur consistent with a hole in the heart termed a ventricular septal defect (VSD). Review of medical records from the previous clinic documented the persistence of this VSD since birth. The pediatrician knew that without surgical correction by twelve months of age, this child would develop irreversible vascular changes (pulmonary hypertension) and die of congestive heart failure by the time she was six.

When asked about their knowledge of this condition, the parents stated that they had been informed at birth and left the previous pediatrician because of her continual insistence on surgery. They noted that their child was healthy, happy, and demonstrated no illness. They rejected any steps toward surgery, including noninvasive evaluations and denied any discrimination. "We know that she is a crooked cucumber, but we love her as much as every cucumber in the patch." They refused to acknowledge the existence of any illness and rejected biomedical explanations of their daughter's condition.

The challenge of finding an informed and respectful understanding of the child's best interest confronted the pediatrician. He asked himself: What is the best interest for this child? Who should define best interest? Are these parents guilty of medical neglect that would require

reporting them to the state? He was committed to resolving the conflict without appealing to the courts. Yet, cultural and religious convictions blocked several attempts to convey the severity of the child's health problem. The parents defined their child as healthy and declared that surgery was an intervention to be avoided at all costs. The pediatrician knew from Fadiman's work and from Hmong translators that this position was consistent with other Hmong parents. Illness is defined by overt dysfunction and surgery results in loss of soul. He was reminded that recently one Hmong father had burst into an operating room with a gun, determined to rescue his child from surgery.

The pediatrician knew that significant decisions in the Hmong community are frequently made in the context of a family's clan. Yet when he asked the parents if he could approach their clan leader, they refused. The pediatrician also knew that shamans address loss of soul through soul recalling ceremonies, and that it is not uncommon for parents to seek help from other kinds of healers in relation to their children's health (Barnes, Plotnikoff, Fox, and Pendleton 2000).

When he asked if he could consult with a shaman for assistance, the parents again refused. He offered to arrange a meeting with other

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Hmong parents whose children had received surgery, but they would not agree. At this point, the pediatrician concluded that the parents' refusal was based more on undisclosed personal reasons than widely held religious values. He then turned to the child protection system. The child was ordered to undergo medical evaluation and treatment at twelve months of age, but by

that time the VSD could no longer be surgically repaired.

The case illustrates the application of the cultural knowledge taught in Fadiman's study. Had the parents agreed to consult clan leaders, a shaman, or even other parents, and been seeking traditional care for their daughter, the case would seem to represent a corroboration of the object lesson deriving from Fadiman's work. Instead, the case suggests that medical staff can be culturally conscious and still have no way to anticipate the extent to which cultural knowledge forms the basis of the family's choice. The situation was further complicated because it involved a critical, time-specific condition.

### **Case Two: Misconstruing a Family's Explanatory Model**

A married, forty-seven-year-old Hmong mother of eight arrived at an emergency room complaining of severe right upper quadrant pain, fever, nausea, and vomiting. Ultrasound evaluation demonstrated significant gallbladder disease with signs of advanced infection.

She was intubated and underwent an emergency Endoscopic Retrograde Cholangio-pancreatography (ERCP) to drain pus from her gallbladder. Blood cultures quickly grew three strains of bacteria. Her blood pressure dropped and she was taken to the intensive care unit with a diagnosis of acute cholecystitis, ascending cholangitis and bacterial sepsis. The preferred treatment for this possibly fatal condition was emergency surgery. The family refused and the surgical and medical residents were stunned.

The case immediately raised two issues. First, who makes the decision in such a case; and second, what constitutes a legitimate decision? At stake was the question of competency. The residents wanted to involve the legal system, to force a ruling.

In this situation, however, the attending physician refused to support it. She argued that the family's choice was reasonable, and that they were acting according to their values and presumably,

as competent surrogates, by the woman's own wishes. To the medical staff, the family appeared concerned and wanted what was best for her. "They have no reason to want her to die," the attending physician said, "and we'll respect them by abiding by their wishes." In this case, she was able to accept this family's choice because she understood the Hmong world view and, in particular, the way decisions are made as a family process. The example appears to be a good illustration of lessons learned from Fadiman; however, the story has a twist.

The woman remained in intensive care and was treated aggressively with high-dose antibiotics and supportive care. Nevertheless, her condition grew progressively worse. The family watched what was happening, and became more and more distressed. Finally, they asked the medical team to turn off the ventilator. Without the ventilator, the staff believed that the patient would die and they also believed her case to be futile without surgery. They knew that the family had every

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right to decline an invasive or burdensome intervention, even if it resulted in death. However, several members of the medical team disagreed with withdrawal of care. Some felt conflicted about withdrawing support from a young mother of eight with a reversible disease. They were uncomfortable not knowing the patient's actual wishes. The team tried to persuade the family to continue the ventilatory support.

What was unclear to the medical team was that the family wanted the patient to live. In the family's understanding of disease, wind brings and induces illness. The ventilator — as a wind machine — was bringing the patient wind that

was responsible for her critical condition. Their request to turn off the ventilator was not a wish for a peaceful death in a situation of medical futility. Rather, it arose from their wish to protect her and to do everything in their power to keep her alive. They had brought her to the hospital with the expectation that, while certain courses of action might not be acceptable to them, others would be available that could still save her life.

Recognizing that there are cultural roots to the rejection of surgery among Hmong patients, the medical team was able to respond to the no surgery decision within a cultural framework. However, because they addressed "culture" as a piecemeal set of "beliefs" about surgery, they did not think to look for its influence in other aspects of the case. They assumed that their values were at work in the family's request to shut off the ventilator, and came close to shutting down the case prematurely.

They were, in fact, jumping to conclusions based on a resemblance between what in reality, were two radically different decisions. Soon however, it became clear to them that the family members wanted the woman to live as much as they did. To the medical staff's surprise, the antibiotic treatment proved successful and the woman walked out of the hospital one week after her admission.

### **Case Three: Conflicting Intergenerational Understandings of Decision Making**

A nineteen-year-old, English-speaking Hmong college student, born and raised in the United States to Hmong immigrant parents, developed progressive liver failure requiring a liver transplant. He agreed to be placed on the transplant waiting list, but his family members, when presented with this information, rejected it, saying, "If you have this transplant, you will no longer be our son!" To the medical team, their response sounded like a harsh threat. It triggered criticisms and once again, culture became an obstacle to care.

Two issues emerged. First, the team failed to understand that from a Hmong animist religious

perspective, the liver is the seat of the soul. To remove the liver was not only to risk the loss of this particular soul; the very act of replacing it meant that an entirely different soul would come to reside in their son's body (assuming that it had, too, not been lost in the course of the surgery). The family was making a descriptive statement, not issuing a threat. With a new liver, their son's identity would undergo a change that could mean, quite literally, that he would no longer be the person they knew. They feared that his identity was at stake. To resolve this dilemma would have required in-depth consultations with both the clan and a trusted shaman, neither of which took place.

The question of who had the decision-making authority in this case superceded consultation. From the perspective of the medical team it was the patient himself. Assuming that a person's humanity is defined by independence and choice making, with volition and autonomy as key criteria, the team took for granted that a patient who is of age should make his own medical decisions. They viewed themselves as his advocates, responsible only to him, as their patient.

He, in turn, as a young man accustomed to some of the dominant cultural values concerning individual identity, gave every appearance of concurring with the team's orientation, particularly when he said, "It's my life, and I should be allowed to decide." Because of his age, the issue of child best interest was not at stake. He had agreed to the prospect of surgery, and appeared to present no cultural challenge to the medical team. To them, he seemed the model of acculturation — the patient who accepts the ethos of biomedicine and is correspondingly compliant.

What the team did not grasp, however, was the complex network of loyalties pulling at this young man about the way a healthcare decision should be made. From his family's perspective, he was ill, and should not be making any such decisions. Instead, these decisions should properly be made through the network of the family. From the family's point of view, their son did not even have the right to make this choice, particularly

because it would affect the entire family. Rather than basing their position on the model of an individually oriented, choice-making self, the family instead was drawing on an understanding of the self as a network of relationships.

This model is not uncommon in a number of Asian systems (Tu 1985) as well as in various African systems, in which such a network may include not only the living but also the dead, through connections with ancestors (Ephirim-Donker 1997). Informal surveys conducted by

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Barnes with multiple audiences of medical students, residents and medical faculty show that at least half the audience acknowledges having had a direct experience of a ghost, or knowing someone else who reports such experiences and whose judgment in all other matters is considered reliable. Yet these same groups frequently dismiss the ancestor traditions of other cultural groups as phenomena not to be taken seriously.

Within such contexts, decision making is a collective process. Only a decision arrived at through this process is seen as legitimate, because competence resides in the group. The case illustrates the complexities introduced by the possibility for intergenerational differences, varying degrees of acculturation, and multiple allegiances, all within a single family. One cannot assume that all members will adhere equally to the same values and loyalties.

#### **Case Four: Culture as Predictive Factor or Confounding Variable?**

A fifty-four-year-old Hmong gentleman was hospitalized for symptomatic bradycardia with a heart rate of approximately thirty beats per minute. The diagnosis was third degree heart block. The treatment of choice was implantation of a cardiac pacemaker – a common and relatively benign procedure that would cure this condition. He refused the operation.

The cardiology team tried repeatedly to change his mind. They reiterated the biomedical reasons supporting their recommendation, and became increasingly frustrated by his resistance. At the same time, they told themselves persuading him was fruitless. As an older non-English speaking Hmong immigrant, he appeared to be refusing surgery for traditional reasons. Increasingly, they found themselves writing him off, seeing his cultural background as a predictive factor. For the medical staff, to be Hmong was to reject surgery.

Because the patient refused care, the staff called for an ethics consultant. The consultant sat down with the patient and asked whether he had worked with a shaman or an herbalist for his condition prior to coming to the hospital. He expected the patient to say yes.

“Oh no,” said the patient, smiling. “I’m part of the New Culture.”

The patient was not animist; he was Christian. He had converted from his animist upbringing, and had become a member of an evangelical Christian church, often referred to in Hmong communities as “New Culture,” or “New Religion.” Because of difficulties with carrying out their old traditions, the conversion to Christianity is not uncommon for many Hmong who relocate to the United States.

When asked to describe the meaning of Christian faith in his life, the patient disclosed that he refused the pacemaker because he worried that

accepting it would be equivalent to denying the power of an all-powerful God and the healing power of prayer. He feared that reliance on a medical procedure would reveal the failure of his own faith and constitute a major hypocrisy. The consulting physician explored the patient’s concerns over several visits to better understand the patient’s beliefs. The patient noted that after being in the hospital for a week, no one had ever asked him about what was important to him about his faith. He said that the medical staff did insist on telling him what was important to them. The threat of soul loss from surgery was not what was at stake for him; rather, it was the wish to embody his new faith congruently throughout the different areas of his life. When this patient reached an understanding of faith and health that he was comfortable with, he requested that a pacemaker be implanted.

The case illustrates how care can be inefficient and ineffective when patient beliefs are not explored. For some people, medical decisions are based on biomedical rationality. For others, spiritual rationality guides these decisions. In any case, medical staff cannot know patient decision-

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making factors unless they ask. Universalizing Fadiman’s portrayal of Hmong people in the *Spirit Catches You and You Fall Down* misses her message, and universalizing one’s own perceptions is not an ethical approach. These approaches misinterpret the book and create a standardized Hmong patient. Every clinician must interview the patient to understand his or her uniqueness.

As in this case, attempts to simplify patient care may result in unnecessarily difficult patient care.

Sometimes clinicians reduce the failure to accept a biomedical therapy or procedure for religious reasons to a tension between truth and superstition, thereby making it easier to dismiss. A more accurate and productive way to interpret the situation is to appreciate the painful choice confronting patients, who may experience themselves as caught in a no win situation, facing a difficult judgment no matter what they choose. The case is also a reminder that cultural background is not inevitably predictive of a particular religious orientation. The consultant couldn't have helped the patient if he hadn't discovered his true fear.

### Meeting the Challenge

Even when one increases one's understanding of cultural diversity, there is still the risk of falling into a patterned mindset rather than eliciting the patient's and family's actual understanding of the situation. The core issue involves the art of questioning, listening, and going beyond answers to what the person is really saying. To this end, the classic questions of Kleinman, Eisenberg, and Good (1978) continue to be effective, with the caveat that the potential influence of religious world views should also be more comprehensively incorporated in every question that medical professionals ask their patients the more complex and critical the case becomes.

As Kleinman notes in a conversation cited by Fadiman, a core problem resides in the very notion of patient compliance, which Kleinman characterizes as "a lousy term [because it] implies moral hegemony. You don't want a command from a general, you want a colloquy" (Fadiman 1997). The patient and family must be invited to present information concerning how they make decisions. In this process, the patient or family participates in defining the role of the clinician. The model is one of negotiation, in which the parties involved may be dealing with competing moral worlds.

For this reason, teaching cases that present these dilemmas can be an effective pedagogical strategy in training clinicians in the arts of mediation, negotiation, and compromise (Carillo 1999). One must learn to step back and discern what is most vital to each party, and locate the compromise that will leave each party feeling that the resolution addresses what is most at stake for those involved. One must learn how to talk across difference at the same time that one remains aware and accepting of it, and one must be willing to adapt his or her practice to fit the cultural context of the patient.

Cultural awareness also requires that clinicians recognize the multiple cultural orientations present during the clinical encounter—that of the patient, of different family members, of clinicians themselves, *and* of the culture of biomedicine. (Clinicians already operate across a field of internal cultural differences, since one is only socialized into biomedical culture as an adult.)

Cultural awareness also means remembering that cultural diversity is operative among ostensibly "white" or "Caucasian" groups, not only because of differences in social class, but also to national origins that inform one's experience of "whiteness." Even though individuals may refer to themselves simply as "Americans," differences of origin persist in action and practice. Finally, clinicians cannot negotiate effectively unless they become aware of the various influences that constitute their own cultural formation, particularly with regard to the way they were taught to perceive and assess various kinds of difference.

No one's culture is homogeneous or static. How a given individual experiences it will be shaped by variables such as gender, sexual orientation, social class and access to resources, racial-ethnic identity (both by self and others), and the access to or exclusion from power. One may live in a cultural environment and be part of a minority group with its own cultural orientations that are subject to the pressures of a dominant culture. In the United States, subcultures may exist in tension in the context of larger social pressures



of institutionalized racism. In practice, this means that each person is part of "a plurality of subgroups that exert a multiplicity of influences depending on the degree of contact with each subcultural context" (Helman 1994).

The model we propose requires clinicians to recognize that all patients and their families compose their own healthcare systems, which involve the biomedical clinician as one among multiple players — and not necessarily the most important one. To understand how the patient and family view biomedical intervention involves discovering the multiple components of their system. Frequently, one learns that the different parts of the system come into play as different aspects of affliction need to be addressed. Recent studies of complementary and alternative therapies in the United States show that it is not uncommon for people to pursue multiple modalities simultaneously in the effort to address multiple aspects of the problem (Eisenberg et al. 1998).

Such complexities are no less true of Hmong patients and their families who have lived in the United States since the 1970s than they are of Anglo-American patients and families whose ancestors arrived in the 1600s. While Fadiman and other similar accounts are superb in their own right, and have made a powerful case for the imperative of cross-cultural understanding, it is a reality that any narrative can be reduced to an essentializing template.

When this happens, the cultural knowledge extrapolated from the case is no longer a learning tool, but a mechanism that closes off the connection with the patient. But as Llerena-Quinn notes, each patient is like every other patient, and like no other patient. The art of cultural care lies in learning to balance *possible* cultural characteristics with their idiosyncratic application in the lives of patients and their families.

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