Director's Corner

Lessons from *The Spirit Catches You and You Fall Down*: Moving To and Through Cultural Competence in Healthcare

By Adina Kalet, MD, MPH

When, in 1997, American essayist and reporter Anne Fadiman, published *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, she could not have known how profoundly her award-winning work would impact medical education. Considered by some to be among the best narrative nonfiction books of the twentieth century, it reads like a novel. The book tells the story of Lia Lee, the American-born child of Laotian Hmong refugees, Nao Kao Lee and Foua Yang. Lia develops a severe form of epilepsy as an infant. In alternating chapters from the points of view of Lia's family and the health care professionals in Merced, California, we experience the culture clash and deepening void as they try—and sometimes spectacularly fail—to save Lia's life.

I need to re-read *The Spirit Catches You* yearly in preparation to teach a medical student seminar on Medicine and Culture. These cycles of reading, thinking, and teaching have introduced me to the Hmong people—a group with which I have had very little direct contact—but have also opened my eyes to our gaps in understanding the "culture of medicine."

Some students believe they have no cultural heritage

To set the stage, I start each seminar by asking the small group of first-year medical students to introduce themselves culturally. A few offer harrowing, heartwarming, or detailed stories about their family migrations, multigenerational homes, special religious holidays, food particularities, strict gender roles, or the challenges of speaking less-than-fluently with their non-English-speaking grandparents. Invariably, though, half the group says something along the lines of, "I don't really have a culture," or "I grew up in the suburbs," or "my family story is nothing special." They believe themselves to be culturally normative and, therefore, not in need of consideration or explanation.

Yale Professor of Surgery and author, Sherwin B. Nuland, wrote a review of Fadiman's book that includes his commentary on the noxious impact of denying one's culture. Nuland, the son of Jewish immigrants, explains that, "in [the 1950s], the whole thing was to assimilate, to look and act like a WASP. We could have provided so much comfort to patients who looked like our

parents. And we just didn't. … Suddenly you read a book like this, and you say to yourself, 'Oh, my God; what have I been doing?'"

Nuland goes on to connect how this pervasive lack of recognition limits our empathy and blunts our effectiveness in easing patients' suffering.

"A great beast"

In my seminar, we discuss the collision of health beliefs illustrated throughout the book. Lia's pediatricians, Doctors Neil Ernst and Peggy Phillip, a couple in a modern egalitarian marriage, are highly respected for their devotion to their work and their commitment to providing the best care for all their patients. To them, Lia's life and future are constantly threatened by her dangerous seizure disorder. The seizures, therefore, require aggressive pharmacological suppression despite the significant side effects of treatment. To the Lee family, Lia's predicament is *quag dab peg, or,* "the spirit catches you and you fall down," and is caused by her soul leaving her body after hearing very loud noises. This existential crisis requires intercession by a Hmong shaman.

Both groups want the same thing for Lia but understand both the problem and the solution very differently. This does not go or end well. Dr. Ernst finally reports the family to Child Protective Services for not complying with the medication regimen. Lia is removed from her home and spends a devastating year in foster care and, possibly due to undermedication, ultimately experiences hypoxic brain damage from prolonged *status epilepticus*. She is left in a persistent vegetative state.

After extensive conversations with experts, Fadiman concludes that no one person was to blame for this outcome. "Neil and Peggy were excellent physicians, but ... imperfect healers," she writes. There was simply a "great beast of cross-cultural misunderstanding."

Although its impact is unknowable, I suspect that hundreds of thousands of American medical, nursing, and journalism students have been introduced to importance of cultural competence by reading the Fadiman's book (Uy and Dimaano, 2019).

Arthur Kleinman's Eight Questions: Exploring the patient's explanatory model of illness

In her research looking for solutions, Fadiman introduces psychiatrist and anthropologist Arthur Kleinman's "Eight Questions to Ask of Patients." By distinguishing between *disease* as seen from the point of view of the doctor, and *illness* as seen from the point of view of the person who is sick, Kleinman's framework enables healthcare professionals to step back from seeing patients' predicaments in narrow biological terms and encourages empathic, respectful discussions and negotiations built around health belief models. The questions are:

- What do you call your problem?
- What do you think has caused it?
- Why did it start when it did?
- What does your sickness do to your body?
- How severe is it?
- What do you fear most about your sickness?
- What are the chief problems your sickness has caused for you (personally, family, work, etc.)?
- What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?

In our seminars, I have the students embody a story crafted from their own experiences (or we provide a scenario). Through role play with peers, we use the "Kleinman Questions" to gain insight into the worldview, culture, social context, and spirituality of "the other" as well as of ourselves. The information gained, in combination with our own biomedical "health belief model," encourages more trusting relationships and lays the groundwork for durable and flexible patient centered plans. We work to address both the patient's disease and their illness in ways that are consistent with their cultural understanding.

With discussions like these, medical education can help prepare students and residents to address the ubiquitous cultural awkwardness and frank incompetence of our practice and systems. Step One is to be both humble and curious. While all physicians do not need to have an anthropologist's deep knowledge of specifics of cultural practices, we *do* need to develop the practical wisdom, curiosity, and skills that push us to instinctively ask the right questions, listen to the answers, and utilize the information to collaboratively create workable plans.

Cultural humility is our superpower. Read this issue of the *Transformational Times* to learn more.

At its most basic, cultural competence in healthcare teaches that sets of communication skills, attitudes, and characteristics allow providers to explore each patient's own cultural interpretation of their illness, thus preventing medical misdiagnoses and allowing for collaborative approaches to wellness. But a much more robust approach is also needed. *Cultural humility*, the next step up, is our superpower. It requires us to be curious, mindful, flexible, respectful, and empathic to the cultural identity that is most important to that other person and their family, even when those concepts are very strange to us. To cultivate this kind of humility requires self-reflection and lifelong learning.

Here is where our students come in. Many, like those who share their lives with us in this issue of the *Transformational Times*, are exquisitely sophisticated in this domain. Not surprisingly, it is those who have had a "transcultural" experience—migrating or growing up with immigrants or refuges (as did I)—that can, if nurtured to do so, translate that experience into empathy and advocacy for others. Simply *having* these life experiences does not guarantee that they are on

the road to wisdom; our students must learn to understand their journeys and express themselves. They must be given safe environments in which they feel valued and empowered. They must have opportunities to be powerful advocates for cultural competence.

As our student-essayists demonstrate, not only are they committed to care for their "own" communities—people with whom they share deep cultural history and identity—but they can use their life experience to teach all of us, by example, the humility and self-awareness needed to work with, and deeply understand and respect, the experience and beliefs of others.

Cultural strengths exist in all our communities

I was stunned to read Lia Lee's obituary in the *New York Times* in 2012. I had assumed, along with many others, that she had died a decade before. But she lived until the age of thirty, having spent twenty-six years in a permanent vegetative state (able to breath without assistance but with no brain activity), cared for lovingly at home by her family, with a little assistance from the health care community and occasional rituals performed by Hmong shamans. It would not surprise anyone that long term survival in this situation is an exceptionally rare occurrence in America. Clearly, we have something profound to learn about care from this Hmong community.

Further reading:

Tricia Uy and Christian Dimaano, Lessons learned from *The Spirit Catches You and You Fall Down*: Student perspectives on how cultural differences can lead to health disparities, *Health Education Journal* 2020, Vol. 79(1) 73–81.

Sherwin B. Nuland, Doctors and Deities, *The New Republic*, October 13, 1997.

Cooper, L. A. Health Inequity and Racism Affects Patients and Health Care Workers Alike, *New Engl J Med Catalyst Innovations in Care Delivery* 2021, 2(3).

Lia Lee Dies; Life Went On Around Her, Redefining Care, *New York Times,* September 14, 2012.

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