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Doctors Within Borders

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In 1982, a tiny baby girl was brought to a Merced, California emergency room with a murky complaint. Her parents spoke no English and no hospital staff spoke their language, Hmong. Not much seemed to be wrong with her except congestion, for which the resident on duty prescribed antibiotics and told the parents to bring her back in ten days for a follow-up appointment. They didn't, as they had no idea they had been asked to do so; but in nineteen days, they were back in the ER with a similarly urgent but unknown concern, and the whole scenario played out again.

The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures
By Anne Fadiman
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On their third such visit, the problem crystallized—the child arrived still in the throes of a grand mal seizure. The doctors sprang into action, as doctors do, to control the seizing (which they did), determine the cause (which they didn't), and provide her family with anticonvulsants to prevent it from happening again (which they tried).

It happened again, dozens of times. With every new seizure there was an increased risk of progressive damage to the brain, as the critical flow of oxygen was impeded.

After a few months of treatment and multiple adjustments to the prescription, the doctors realized to their dismay that the patient was not responding to the medication *because she was not taking it.* How could this be? Her parents were clearly devoted to her, but perhaps they did not understand. A fleet of nurses, social workers, and other liaisons was dispatched to the family home to draw up charts and schedules, stick little suns and moons on pill bottles to indicate the time to be administered, mark liquid dispensers with the proper dosage, divvy out the medication day by day, tape samples to a calendar to show what had to happen when, and explain a hundred times the utmost importance all this had to restoring their daughter's health.

Though a translator had not been present at the family's first few encounters with American medicine, by this point there was usually a cousin or older sibling or interpreter provided by the county, which ostensibly

was to allow for all parties to make themselves perfectly clear, and, presumably, arrive on the same page as to the care of the patient, whose best interests everybody had at heart. But it turned out that the lack of a translator was the least of their problems. For reasons of their own, which health care providers vaguely sensed related somehow to "spirits," the parents balked at many therapies no matter how carefully, repeatedly, or urgently they were explained, preferring to sacrifice a cow or rub coins on the baby's body than to give her Western medicines with their disturbing side effects.

Over the next few years, the confrontations darkened as the disorder grew more severe. At one point, a pediatrician called in Child Protective Services to remove the girl from her adoring family so that her medications could be administered correctly. At another, her father tried to abduct her from the hospital, believing a form he had been asked to sign scheduled her imminent death. But from the doctors' perspective, the mounting frustration and hostilities paled next to their dread of "the big one" that everybody knew was coming.

It came in 1986, the day before Thanksgiving. The patient went into prolonged status epilepticus, seizing for two hours, flailing and jumping straight off the table even in restraints. When she was stabilized and transferred to a larger hospital she seized again, finally obliterating all higher brain activity. Though biologically she survived, everything about her personality and all hope of a normal life was gone.

Every doctor has defeats—the cases he can't stop thinking about and wishing he could do over, or the ones he wants never to think about again, knowing the grim outcome was essentially ordained. This was not the first patient her doctors failed to save; nor the first with whom there was a language and cultural difficulty; nor the first who (or whose parents) did not take totally to heart every word of their hard-earned, well-intended, desperately needed expert medical advice. These tragedies, major and minor, happen in hospitals every day; and though this one was more harrowing than most, it was a sadly ordinary part of their vocation.

In an effort to scrutinize mistakes and improve future care, most medical practices regularly hold "Morbidity and Mortality" conferences, where they can put their heads together and determine What Went Wrong. In the matter of this patient, Lia Lee, her exceptionally conscientious doctors held such reviews at the time; but the real breakthrough would come a few years later, when Anne Fadiman, a journalist staying with a friend in town, caught wind of some discord between local Hmong refugees and their health care providers.

What she found when she set out to learn more is in a sense the keenest and most thoroughgoing specimen of the M&M genre ever, encompassing Hmong history and ethnography, the recondite world of modern medicine, and a *Rashomon*-style report on the view of every single person involved with the case (except the one at the center of it, who could no longer speak for herself). On top of all that, it's damn good storytelling. *The Spirit Catches You and You Fall Down*, published in 1997 and re-released with an updated afterword in 2012, is a work of breathtaking intelligence and sympathetic insight. The title comes from the Hmong explanation for epilepsy, *qaug dab peg*, wherein the soul is frightened from the body or stolen by a spirit and gets lost (occurrences of which Lia's doctors and nurses were, to a fault, uninformed). Where do these *dabs* come from, what does one do about them, and what role might American medical authorities have to play in all of this? You would have to go back to the second beginning of the world, in Hmong time, to find out, or perhaps the first. Early on, Fadiman tells of a Hmong student in Lia's town assigned to give a five-minute oral report in French. He chose to describe the recipe for *la soupe de poisson*, Fish Soup. To make Fish Soup, of course you need a fish; to catch a fish, you need the proper hook; to select your hook, you must know something about the fish's habitat, anatomy, and feeding habits. For the next forty-five minutes, the student helpfully explained all these things, as well as how to clean and gut and chop the fish and finally to season and cook it, with the aid of diagrams and decision trees for the different kinds of fish and flavors desired, including many of his own fishing memories as illustrations. "When the class period ended, he told the other students that he hoped he had provided enough information, and he wished them good luck in preparing Fish Soup in the Hmong manner."

The Hmong phrase for "once upon a time" translates as "to speak of all kinds of things." "You can miss a lot by sticking to the point," it implies. "No event occurs in isolation." Most importantly, "the world is full of things that may not seem to be connected but actually are."

Lia's family landed in Merced in 1980 along with 10,000 other Hmong displaced by war in Southeast Asia. The Hmong, a fiercely independent ethnic minority living in the mountains of Laos where all they wanted was to be left alone, had been forced to choose a side in a lengthy civil conflict that erupted after the Second World War. Most of them wound up allied with the Royal Lao against the communist Pathet Lao. Whereas next-door Vietnam became a prominent proxy theater for the two great powers in the global referendum on communism, those powers were

covertly involved in Laos as well, in what the CIA called the "Secret War." Hmong guerrillas thus found themselves conscripted, supported, and directed by U.S. agencies—which, when they pulled out in 1973, left the Hmong to their fate: face reprisals or seek escape. Some were captured and interned in reeducation camps. Some live on the run in the jungle to this day. Some made the perilous trek over the border to Thailand on foot; those who survived starvation, exhaustion, disease, and genocidal attacks* eventually arrived at semi-permanent refugee camps with no electricity, running water, or sewage, where they remained for years. Despite initial resistance, the United States eventually opened its doors to many of these refugees (ultimately 150,000), though they did not particularly want to come here, having heard that American doctors like to eat Hmong brains and other insalubrious details of foreign life. But by then, there were few other places for them to go, and so they came.

Thus washed up from the wreckage of a clash between all-embracing ideologies, the Lees soon found themselves swept into another one. By and large, hostility was not a major factor; apart from one unabashedly racist obstetrician who pops up here and there throughout the book to offer his opinion on welfare, immigration, and ethnic cuisine, most local medical personnel wanted nothing more than to help the Hmong, choosing careers at a public hospital that served a large refugee population out of a strong sense of purpose. Thinking that Merced "might be sort of like the Peace Corps (but with good hamburgers)," as Fadiman surmises, they were baffled by frequent standoffs over very basic care.

On the other side of this same reality, the Hmong felt assaulted by their contact with U.S. institutions. In a medical setting, procedures such as spinal taps or any kind of surgery so violated bodily integrity as to endanger them spiritually, and yet the doctors insisted on these things. Sometimes, especially in pediatric cases, the power of the state became involved. One Hmong subjected to a court order surely spoke for many when he said he found this more oppressive than communism. The Lees would later say that the events surrounding Lia's illness were worse

* A longstanding controversy over Yellow Rain, putatively a chemical weapon used by the Soviets against the Hmong, was revived in a recent episode of WNYC's science show *Radiolab*. Some studies have indicated that what the fleeing Hmong perceived as a toxin being dropped on them from planes was no more than—of all things—bee droppings from a passing swarm. This unexpected finding runs so counter to eyewitness experience that, barring further explanation, the issue must be considered unresolved. It is indisputable that the Hmong were targeted and killed or injured greatly by conventional weapons.

than their entire ordeal in Laos and Thailand, even though they had lost other children there.

Though the hospital staff wondered why Hmong parents didn't care enough about their children to accept and follow through on free medical care (valued at upwards of a quarter million dollars in Lia's case, all told) and the government considered the most recalcitrant to be child abusers, in fact they were very concerned with their children's health, saving up their small public-assistance checks for months on end in order to administer the type of treatments they had relied on at home. Lia's mother spent the better part of every day caring for her, preparing and administering salves and potions from plants she grew, like other Hmong women, in buckets in the parking lot of the apartment building, an inventive substitute for the mountain fields they used to manage. From time to time, Lia was provided with a large pig or other animal to be spiritually wedded to so that after being sacrificed its soul would look after her errant one, an event that involved the whole community. Shamans were consulted—who in Hmong culture often were epileptic themselves, given to states of otherworldly perception. A vast knowledge of herbs and *dabs* and ceremonies and taboos was brought to bear on any given ailment, a knowledge passed down through tradition, loyalty, and affection since time immemorial—surely more trustworthy criteria than the Americans' blunt, abstract, and often contradictory authority (an authority that had betrayed them on the other side of the Pacific).

This was not a case, as media outlets into the 1980s and even 90s were wont to intone, of a "primitive," "extremely simplistic," "Stone Age" tribe "emerging from the mists of time," but of a transplanted people with a sophisticated culture that just so happened to be at complete odds with the dominant one. Fadiman hilariously pegs the difference to two representative examples: "The Hmong Way," a county health report on an exorcism of offended spirits from a swollen penis—an apparently successful procedure in which a shaman spit water on the infected area and supplicated to the spirits with incense; and "The American Way," an excerpt from an article in the *Journal of the American Medical Association* entitled "Doctors Have Feelings Too." Authored by William M. Zinn of Harvard Medical School, it cautions that doctors may neglect their feelings while "doing multiple other tasks," "maintaining a clinical distance," and so forth. "So, if you're a doctor," Fadiman asks, "how can you recognize that you're having a feeling? Some tips from Dr. Zinn: 'Most emotions have physical counterparts. Anxiety may be associated with a tightness of the abdomen or excessive diaphoresis; anger may be

manifested by a generalized muscle tightness or a clenching of the jaw; sexual arousal may be noted by a tingling of the loins or piloerection; and sadness may be felt by conjunctival injection or a heaviness of the chest.'" Fadiman reflects that "if any of my Hmong friends heard that American doctors had to read an article in order to learn how to tell if they were angry," they would never darken the doors of a hospital again.

This medical culture has its own Fish Soup, which she does not assemble for readers in the same comprehensive way as she does the Hmong historiography. We already know it, more or less. We know the line-up of philosophers and probers who established the scientific method in modern Europe and cleared out the *dabs* creeping around their own societies. We know those *dabs* did not want to go away, but verifiable results eventually speak for themselves. We know the kind of truth discovered this way does not belong to a "culture" but to everyone, and thus to relativize or confine it would be not only condescending but a weird act of bamboozlement, particularly if the information can potentially save lives.

Because of this record of success, it follows that *all* knowledge is to be approached in provable and quantifiable terms, reducing layered reality to data bits and isolating variables to the point where nothing is connected. Even if it does sometimes constrain common-sense insights to a preposterous lexicon, this excessive self-examination is understandable. How many important discoveries have been made by some plucky questioner overturning what "everyone knew" since time immemorial? Better to cover all the bases.

At the same time, the world of evidence-based medicine suffers from a lack of self-examination in another way. With the analytical mentality surrounding the discipline, and most discussions framed in these terms, it becomes difficult or impossible to talk about the values embedded in it, as opposed to the best way of achieving a predetermined aim.

For example: Lia's pediatrician Neil Ernst refused to simplify her cocktail of prescriptions, even if doing so would have meant a greater likelihood that her parents would consent to administer them, because to him that meant giving her a lower "standard of care"; Lia ought to have access to the same level of therapy that a daughter of a middle-class American family would. Implicit in this stance and other aspects of the story are a number of assumptions about the morals and purpose of medicine that are entirely independent from the scientific facts themselves. These are all excellent things, but do the rationalists in health care realize them for what they are, or do they vanish into self-evidence?

What brings change to a culture that has so little awareness that it even is one?

The Spirit Catches You and You Fall Down, which surprised everyone with its popularity, has been one such agent of change. (Hmong culture, too, has naturally been influenced by decades of immersion in the United States; the bittersweetness of assimilation is a story for another time.) Originally, Fadiman's project was commissioned as an essay for *The New Yorker*, but a changing of the guard at that fine publication somehow resulted in its getting spiked. Fadiman was so chagrined at the prospect of telling the many people who had kindly opened up to her that it was all for nothing that she turned around and spent several years writing a book instead, while expecting that "the story of an epileptic Hmong toddler would attract about seventeen readers." There have been a few more than that. It has become a classic in specialty fields such as medical anthropology and cross-cultural medicine, and has nudged those fields much further into the mainstream; the book is now required reading for all students at many medical and nursing schools.

To anyone concerned with the way that valuable training-time is spent, given the enormous volume of material to master (which with the progress of research is growing all the time), these subjects may sound, at best, like a boutique concern. Fadiman hints at this potential skepticism in the afterword to the fifteenth-anniversary edition, where she walks us through some of the evolving schools of thought in cross-cultural health care: "cultural competence" (familiarity with patients' beliefs and traditions as they may affect their care, freighted by the critiques that this stereotypes individuals by their backgrounds and that one cannot really achieve "competence" in a whole other culture anyway) giving way to "cultural humility" (a doctor's awareness of his own ethnocentric paradigm and the limitations that it brings) and onward to "cultural responsiveness" (a grab bag of all of the above, culminating in the basic responsibility to treat people with respect—always a good idea). If you blink, she writes, you might miss the latest iteration.

To be fair, this jargonology reflects an admirable effort to convey with precision, if not much grace, the most dignifying way for doctors to approach their patients in an uncertain but common situation. And "if this all sounds like a Yertle-the-Turtle-like scramble for the slippery pinnacle of political correctness, remember how difficult life used to be for Hmong patients—and patients from many other backgrounds—before doctors started thinking about why so many cross-cultural cases ended badly.... Whatever you choose to call it, the ability to deal with patients from unfamiliar cultures shouldn't be a political stance but a *human* stance, as well as a strategy that saves lives."

Strategically, that is, man cannot heal by science alone. At a purely

pragmatic level, where the sole concern is delivering effective treatment, treatment will *be* more effective if doctors can secure patients' cooperation. If the fluffy assignment of developing a culturally sensitive bedside manner is just as crucial to this task as a hard rational grounding in physiology, so be it.

The greater importance of all this, though, lies much deeper. It is often pointed out that these are necessary skills for American health care providers in this day and age because so many of their patients hail from other backgrounds. But of course. Our immigrant history is a defining national feature—a central element of our identity and something we rightly take pride in. It runs through our earliest stories of people who fled here to live freely according to their religious convictions; through the founding documents that established that liberty in law; through the poem engraved on the "Mother of Exiles" shining her torch over the port of entry at Ellis Island, promising refuge and freedom; and through the constantly renewed waves of migration—including those who did not come chasing the American Dream but because our military took their destiny into its hands—and the sacred obligation to welcome them.

In fact, America's first hospital, co-founded by Benjamin Franklin in 1751, served a large population of immigrants arrived via the port at Philadelphia, which as historian Richard Harrison Shryock puts it was "a melting pot for diseases… [where] Europeans, Africans and Indians engaged in free exchange of their respective infections." Standards for how to treat such varied patient populations have naturally developed over time, but as Dan Murphy, a physician close to Lia's case, notes, there have long been any number of health care providers and other public caretakers who "deeply understood the essential nature of being sensitive, responsive, and respectful of other cultures," though none managed to articulate it in quite the way *The Spirit Catches You* does, or with the same impact.

The key is, though, that there is a reason to honor people's beliefs as intrinsic to their human dignity, one that the United States makes a special effort to recognize. Medicine tends to see itself as above all that, co-opting moral authority in any situation. It is what critical theorists like to call a hegemonic discourse—that is, a worldview of overweening power that will not even admit discussion outside its own terms. The fact that the reasons why are so palpable just goes to prove the point.

In this respect, it stands in the same basic relation to more mainstream American communities as it does to the Hmong. Other religions and subcultures may be better adapted to its standards and eager to avail themselves of its benefits; but rather than a monolith of everything American versus all Hmong, this story can be

seen as medicine versus any other value or belief—and thus is a useful primer for anybody interested in prosaic ethical questions not involving exorcisms, as well as a tour guide to the border where the Enlightenment breaks down.

"Until I met Lia," Murphy said, "I thought if you had a problem you could always settle it if you just sat and talked long enough. But we could have talked to the Lees until we were blue in the face—we could have sent the Lees to *medical school* with the world's greatest translator—and they would still think their way was right and ours was wrong." This is hardly a unique situation, and unsurprisingly not limited to health care. What kind of society can best provide for these inevitable differences—some of them quite vast?

Even more fundamentally, you don't have to belong to a shamanic religion, or any religion at all, to feel dehumanized by the medical system. Fadiman writes:

> Medicine, as it is taught in the United States, does an excellent job of separating students from their emotions. The desensitization starts on the very first day of medical school, when each student is given a scalpel with which to penetrate his or her cadaver: "the ideal patient," as it is nicknamed, since it can't be killed, never complains, and never sues. The first cut is always difficult. Three months later, the students are chucking pieces of excised human fat into a garbage can as nonchalantly as if they were steak trimmings. The emotional skin-thickening is necessary—or so goes the conventional wisdom—because without it, doctors would be overwhelmed by their chronic exposure to suffering and despair. Dissociation is part of the job. That is why doctors do not treat their own relatives (feelings would handicap their effectiveness); why, beyond routine issues of sterility, the heads of open-heart patients are screened from the surgeon's view (individuality would be a distraction)....

Fadiman mentions several methods that are employed by some medical-training programs to prevent undue callousness, calling especially on the empathy that drew students to the profession in the first place. Formal attention to such things has only increased since her book was published, which is, needless to say, all to the good. Dissociation, though, is not just a coping mechanism; it is an inadvertent revelation.

During Lia's final seizure, a critical care specialist who struggled for twelve hours to control the crisis apparently did not during that whole time notice her sex; a detailed three-page report of the patient's condition notes that "His metabolic acidosis was decreased after initial bolus of bicarbonate" and "His peripheral

perfusion improved and pulse oximetry started reading a value that correlated with saturation on the arterial blood samples." Fadiman calls this "American medicine at its worst and its best: the patient was reduced from a girl to an analyzable collection of symptoms, and the physician, thereby able to husband his energies, succeeded in keeping her alive."

In less of an emergency setting, the physical reality of Lia's sex would of course be noted. That fact, along with her metabolic acidosis, peripheral perfusion, and manifold other component parts and processes, from a scientific viewpoint all add up to "her." Even for the more qualitative aspects of her personality, some combination of chemical pathways was integral to their expression—could in a sense be said to *be* them.

It is no use finding this offensive, given that it's all perfectly true, but at the same time this method of description simply fails to capture so much of what it's like to be a living creature. No wonder, then, that people respond uneasily to definition in this way and search for other explanations. The upshot of the tradition that carries down from Hippocrates to Bacon and Descartes to Dr. William Zinn is that *every* person is unsouled. The reality is right there in the scalpel, a rationality undulled by feeling that cuts through people, not only their flesh but—as the Hmong intuited—their stories and spirits. This is the paradox of modern medicine: to save human bodies, you need to nullify part of what it means to be a human being.

Lia Lee returned from the hospital in 1986 in a vegetative state and high fever, expected to live for a few days. She did not die, but except for the fever, she did not get better. Instead, she lived at the center of her family's devoted care for many years, far surpassing the norm for someone in her condition. "Medicine couldn't have kept her alive. I'm certain love kept her alive—that sounds off the wall, but I mean it in a literal sense," Fadiman recently told the *Los Angeles Times*. Speaking with the *Sacramento Bee*, Lia's pediatrician Peggy Philp concurs: "We saw her life ending when she was five, but her mother's unconditional love taught me the value of life."

When Fadiman met her, the feisty little girl who would come to life again in her pages was already gone, replaced by a gravitational *presence* around whom all household activity revolved. Although with her level of brain damage she was not supposed to have any awareness, to her siblings and other observers, she seemed to sense when her mother was present, crying and whimpering when she was away. "When we hold her, she knows it and is smiling," her father said. Her mother's view: "Sometimes when I call her, it seems that she does recognize me, but I don't really know, because it seems that Lia cannot see

me. My baby hasn't done anything bad. She is a good girl, but because she is hurt like this it is just as if she is dead. Every day now, she cannot see me." Looking at Lia, Fadiman writes, "I could not help feeling that something was missing beyond the neurotransmissive capabilities of her cerebral cortex, and that her parents' name for it—her *plig*, or soul—was as good a term as any."

Lia passed away on August 31, 2012. Her thirtieth birthday was celebrated earlier in the summer, as all her others had been, with a cake and big family party. Her soul, restless in life, was summoned home with a traditional Hmong three-day funeral. During this event, the *plig* must travel backwards in space and time to visit each place the person ever went, culminating at the site of birth. (Lia's soul would not have had to venture across the ocean like her parents' or older siblings' would, as she was the first in her family to be born in an American hospital; apart from a road trip to visit a special healer in Minnesota, she spent most of her life in California.) It is accompanied on its journey by continuous playing of a drum and a large reedy instrument called the *qeej*. At Lia's funeral, these proceedings were paused for a few hours in the middle, where her siblings arranged for a Western-style segment with eulogies and a slideshow of her life. What was especially moving about the slideshow, notes the woman who immortalized her, was that it wasn't chronological—photographs from her whole life both before and after the crisis were mixed together. "The message was: At all times, this was our sister."

To some Americans, she was the first Hmong they ever heard of—an introduction to a people who lost everything assisting us in an overlooked military operation. To many doctors and nurses, she was a warning or a turning point, a sacrificial figure who helped them and their patients avoid a lot of heartache and perhaps some similar catastrophes. To any number of people who don't know anything about her, she was a catalyst for changes in hearts and minds and policies and institutions that affect them, contributing to one of those cultural shifts whose origin becomes more obscure the more its influence is felt. To everyone who does know her story, she was a fellow human being whose life had profound value—but who should have had a different one.

Who or what is there to blame for what should have been? Many readers of *The Spirit Catches You* have wanted to villainize either the parents for not being more open to instruction or the doctors for not being more open to difference. The way Fadiman sees it, the blame does not lie with either side but with "the unbridgeable cultural gulf" between them.

This is a tempting if tragic place to leave the question. But it suggests a false equivalence between the two sides, which, uneven as they are, will only grow more so over time. Which is the greater loss: that modern medicine will undo the tenets of tradition—albeit with respect, empathy, and practical concessions along the way—or that it will not do so soon enough to save some lives?

Meanwhile, it is still apparent that that gulf between medicine and tradition owes its existence not just to the unfinished work of reason but to the essential mystery of human life, not in *how it works* but in *what it is about*, from the sweep of geopolitical-historical forces down to a family mourning its favorite child. On this, science and medicine have little to nothing to say, and only sometimes the wherewithal to make things better. But there are other lights than the Enlightenment, which burn in individual hearts and radiate out through families, communities, institutions, and cultures, torches in the existential darkness calling home all those wandering souls.

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