

# Take Only as Directed

When medicine butts up against traditional belief, tragedy ensues.

## THE SPIRIT CATCHES YOU AND YOU FALL DOWN

A Hmong Child, Her American Doctors, and the Collision of Two Cultures.

By Anne Fadiman.

339 pp. New York:

Farrar, Straus & Giroux. \$24.

By Melvin Konner

IF tragedy is a conflict of two goods, if it entails the unfolding of deep human tendencies in a cultural context that makes the outcome seem inevitable, if it moves us more than melodrama, then this fine book recounts a poignant tragedy. It is the tale of an immigrant child whose family went in one generation from traditional tribal life in the war-torn mountains of Laos to a bustling existence in the town of Merced in the fertile San Joaquin Valley of California. This was a historic transition, and this child's story is in many ways her people's tale in microcosm — and taken to an extreme. It is a tale of culture clashes, fear and grief in the face of change, parental love, her doctors' sense of duty, and misperceptions compounded daily until they became colossal misunderstandings. It has no heroes or villains, but it has an abundance of innocent suffering, and it most certainly does have a moral.

The story told in "The Spirit Catches You and You Fall Down," by Anne Fadiman, a freelance journalist and the newly named editor of *The American Scholar*, is that of Lia Lee, born on July 19, 1982, in the Merced Community Medical Center. At the age of three months, Lia Lee had an epileptic seizure. She had about 20 more over the next few months, and three emergency room visits. They were generalized grand mal seizures, and like most cases of epilepsy were of unknown cause. At first, the parents behaved as cooperatively as most parents do in such cases. The doctors acted competently and humanely, doing appropriate tests and prescribing standard medication.

But over the next few years, Lia had many more seizures. It became clear that the parents were not following the doctors' orders about medication, though they did give her some; this is not unusual for relatively uneducated parents, regardless of ethnic background. It was also clear that they loved their child, were anguished over her illness and did not agree with the treatment plan. Eventually, when the parents refused to give a drug they thought was harming their daughter, phenobarbital, one of Lia's doctors got a court order taking her away from them. The resulting year's separation was devastatingly stressful to the child, as the staff notes show: "Lia crying four days straight. Smearing feces," and "Intense crying again. Stripped herself ... went on a wave of destruction. Had to sedate her."

When the parents finally got Lia back, they complied more rigorously with doctors' directions about medications, but Lia went on having seizures. Eventually, one afternoon she went into status epilepticus, a seizure that doesn't stop. Her parents took her to the hospital, where she was also found to be in septic shock, a life-threatening result of certain bacterial infections. The seizure and septic shock eventually were con-

trolled, but not before Lia lost all higher brain functions. Her doctors frequently refer to these events as her "death." But she didn't die. Released from the hospital in her parents' care, she remained in a persistent vegetative state, but she no longer suffered seizures (they had been "cured" by her brain damage), and she confounded her doctors by staying alive. In the doctors' view, the disastrous chain of events was started by parents who did not understand how medicine works.

Now consider these events from what anthropologists call the folk view — in this case that of Lia's parents. Lia's seizures were, in their view, the result of their daughter's being both burdened and blessed by a condition known as *qaug dab peg* (pronounced "kow da pay") — "the spirit catches you and you fall down." Lia would suffer, but she would also be spiritually gifted — a view that should shock no one who knows how contemporaries saw Julius Caesar or Fyodor Dostoyevsky. She should be protected from injury during seizures, and should get the attentions of a *txiv neeb* (pronounced "tsi neng"), or Hmong healer. Western doctors with their medications were fine; a little science and a little *neeb* together would create a balance between the spiritual good and ill that can come from *qaug dab peg*. She needed some medication, but she also needed the chants, amulets and chicken and pig sacrifices that make up effective *neeb*. She would do well in this world and the next.

But soon the parents thought that Lia was getting too much of doctors and hospitals; the excess was doing her more harm than good. They decided not to give her the drug they thought was doing the most harm, the phenobarbital. Then the doctors did what every parent most fears: they took Lia away, destroying her mental and spiritual health. Desperate to keep her when they finally got her back, the parents followed the hospital orders but, predictably, the spirit caught Lia again and again. Finally, her soul left her body. The *txiv neeb* came to the hospital bed where Lia lay comatose. Surrounded by her relatives, he sacrificed a chicken and a pig, using their blood and sacred chants to call her soul back. He recited a sevenfold repetition of the phrase "Come home." Lia survived, and her parents took her home to care for her in their own way.

**M**AXIMUM possible misunderstanding would be a pretty fair description of this sequence of events. Lia's parents, who greatly loved her, had a clear and time-honored concept of what should be done for an epileptic child. Lia's doctors were decent, well-trained people; they even went to the library to read up on Hmong beliefs. But they saw only one way to take care of Lia's illness. And despite their care, Lia still had what some might consider the worst possible outcome.

Anne Fadiman, in the course of her research, went to see the pediatric neurologist who had cared for Lia in this last emergency, which occurred at a different hospital from Merced, where she had received most of her prior care. In his view, the terrible progression of Lia's condition had nothing to do with her parents' noncompliance. He thought it likely that her infection, a typical hospital bacterium, was acquired during a hospital stay. He also thought that she might have had too much anti-epileptic medication; one of these drugs is known to reduce resistance to

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THE NEW YORK TIMES BOOK REVIEW  
OCTOBER 19, 1997



bacteria. "Go back to Merced," he said to Fadiman, "and tell all those people ... that the family didn't do this to the kid. We did."

Many in the medical profession would like to find ways to make the power of modern medicine more available to people who do want healing but who do not see illness in the same way doctors do. They might do well to emulate a family physician Fadiman interviews named Roger Fife. Not much admired by his high-powered colleagues ("He's a little thick," one said), he had many more Hmong in his practice than they did, and was better liked by them. Why? All Dr. Fife had to offer in explanation was, "Maybe I talk slower than the other doctors." But the Hmong showed a consensus: "Dr. Fife doesn't cut," a reference to his effort to avoid Caesarean section and episiotomy in delivering Hmong babies. Dr. Fife is not on some sort of mission,

nor is he the product of anthropology course work; although he gives Hmong mothers their placentas to take home, he has no idea what they do with them. His philosophy? "It's their body." While this cannot serve in all situations, it is a good guideline and is usually the law.

THE most hopeful episode in this often discouraging story is not an anthropological insight or even a family doctor's respect for his patients' rights. It occurs when the child of one of Lia's doctors becomes ill with leukemia, and Lia's mother's heart goes out to the other mother. "There was very genuine concern expressed by her questions and facial expression," the child's father, also a doctor, wrote to Fadiman. "At the end of the visit Mrs. Lee was hugging Peggy and they were both shedding a few tears. Sorrows of motherhood cut through all

cultural barriers." In this keen observation we find something that makes human life possible even in a world where cultures constantly clash. Although anthropologists sometimes deny it, there is such a thing as human nature, and it works for good as well as for ill. In this case it led two women to mutual understanding in one of the greatest of all possible sufferings: to be the mother of a very sick child.

That one was born onto the floor of a mud hut in a Laotian mountain village, that the other had years of scientific training that led her, however inadvertently, to cause pain to the first — these facts were almost irrelevant. Human nature, along with a bit of ethnological knowledge, allowed them to transcend ethnocentrism, one of the main threats to human welfare. And it allows the reader to appreciate stories like the one told in this sad, excellent book. □