



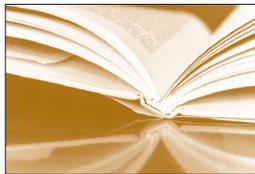
Culture collision

The spirit catches you and you fall down: a Hmong child, her American doctors, and the collision of two cultures

Anne Fadiman

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Lia Lee was three months old when the spirit first caught her. Her sister slammed a door, and then Lia rolled her eyes and went into an epileptic fit. Her family had no doubt that the door-slaming provoked an evil spirit, a *dab*, to cause the fit, and that the fit made Lia special as well as ill. Lia's parents took her to hospital. Born in Laos, Lia's parents are Hmong, members of a once-remote Indochinese hill tribe with a distinct culture that, despite persecution and repeated migrations, has been kept intact for more than 4000 years. Like most Hmong refugees in the United States, they neither spoke nor understood English. There were no interpreters at the hospital, and the fit was over by the time they arrived.

Lia's family is among the more than 10 000 Hmong who have settled in the unlikely town of Merced, a community of 61 000 in California's Central Valley that boasts the Yosemite Dental Society Smile Contest and the Romp 'n Stompers Square Dance. The cultural mismatch is apparent in all aspects of their lives, not least with respect to medical care. Health care workers have found the Hmong problematic because of communication difficulties, their lack of compliance (that awful word for an even worse concept) in taking medications and keeping follow-up appointments, and their custom of being visited in hospital by numerous wailing, chanting, gong-banging, chicken-sacrificing relatives.

When Lia was examined her lungs were found to be congested, and she was sent home with a prescription for antibiotics. In the next three months she had at least 20 more fits, and she

was still fitting the third time she was seen in hospital. On that occasion she was examined by Dr. Dan Murphy, a family practice resident who was interested in Hmong culture. He did a full work-up, which meant that Lia's parents had to consent to procedures they could not have understood. She was discharged with three prescriptions. Despite an "explanation" in sign language, her parents had no idea what the medicine was for, how much to give, or when. Lia's mother, who had learned to write her name to satisfy what she viewed as a strange American penchant for signing forms, had signed a piece of paper saying she would bring Lia for follow-up. Not having understood why she should bring Lia back, she didn't. Thus began a tragedy that reached Shakespearian proportions.

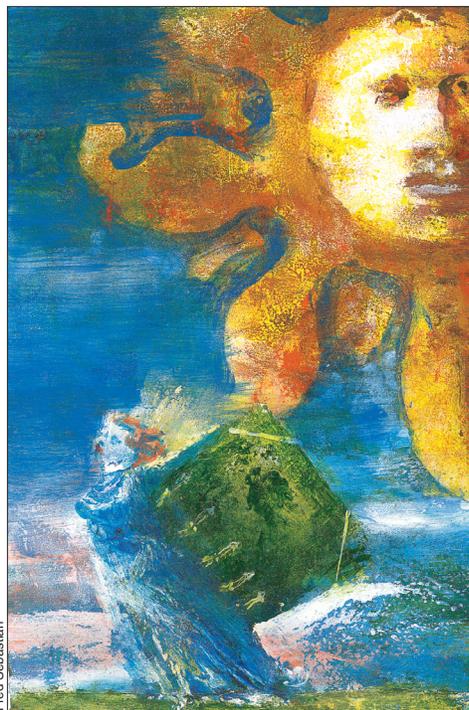
During the next three years, Lia's seizing grew far worse. She showed increasing signs of developmental delay. Tests showed that she was not being given her medications. The two pediatricians in charge of the department, Peggy Philp and Neil

Ernst, became increasingly desperate. They were, Fadiman writes, two of the most dedicated doctors you could find anywhere. Every time Lia was admitted, even at three o'clock in the morning, one of them would drive to the hospital to see her. They wanted to ensure that a language barrier would not stand in the way of Lia's care. But the problem was not just that Lia's parents did not understand English or understand the doctors. The doctors did not understand their patient or her culture.

In those three years Lia's drug regimen was changed 22 times. Lia's parents found that many of the drugs made her worse, and when that happened they discontinued them. The droves of social workers who visited their home were met with polite stonewalling. Most eventually went into

burn-out. Philp and Ernst, convinced that Lia was sliding downhill because she was not being given her medication, had her taken into care. Thus Lia's parents discovered that in the land of the free doctors can take your children away. Lia continued to get worse. While she was in care, with a wonderful family who followed doctors' orders to the letter, she still got worse.

Meanwhile, social workers and newly-recruited translators worked hard to make the Lees understand the need for giving the drugs correctly. Nearly a year later, when the Lees were deemed ready, Lia was returned home. And still



Fred Sebastian



she got worse, even when tests showed that she was receiving the proper doses of medication.

Three months later, at a respite care centre, Lia fell off a swing and went into the worst status epilepticus her doctors had ever seen. No one knows whether she was fitting because she fell, or whether she fell because she fitted. She developed a *Pseudomonas aeruginosa* bacteremia and sank into a vegetative state. Her fits had stopped forever. She was quadriplegic, incontinent and brain dead. The doctors sent her home to die in the arms of her adoring family.

That was in 1986. Lia is still alive.

Her family removed the hated nasogastric tube when she was brought home, and so they no longer qualify for free formula. Her doctors keep her supplied with free samples instead. Lia's mother spoons formula down her throat and is adept at getting her to swallow it without gagging. She grows special herbs for Lia. She has the shaman in, and sacrifices pigs and chickens on auspicious occasions. She chews food in her own mouth and then feeds it, like a mother bird, to Lia. Fadiman writes that she has seen other children in persistent vegetative states in institutions. They have pallid skin, are a bag of bones, and smell faintly of urine. In contrast, Lia

looks beautiful and smells delicious.

Read this book. It is superbly written, utterly fair-minded, impeccably researched and has the pace of a literary novel. Among the enthusiastic endorsements posted on the Amazon Web site is the following comment by Dan Murphy: "Never have I felt so fairly treated in defeat, and never have I felt so much respect for an author's skilful distillation of a tragically murky confrontation of cultures."

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One thousand words



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Bathers in High Park Sanitarium, Toronto, Ont., July 26, 1914. The sign in the background advertises "Battle Creek Sanitarium methods in the treatment of Rheumatism, [?] Anemia, [word illegible], Diabetes, Goitre, Constipation and diseases of the Heart, Kidneys and Nervous System." Founded by Adventists, the sanitarium at Battle Creek, Michigan, promoted hydrotherapy, exercise and a vegetarian diet. In 1894 its chief physician, John Harvey Kellogg, and his brother William Keith Kellogg invented corn flakes as a dietary substitute for bread.