Reading guide for

*The Spirit Catches You and You Fall Down*

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The Noonday Press, New York, 1997

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*The Spirit Catches You and You Fall Down* is a profound and lovely book that should be read on several levels. It is, of course, the story of the illness of one Hmong patient who has been inserted into the American medical culture. Illness aside, it is the story also of the cultural clash and the consequences of that clash for her care and the care of her family. Interspersed with these stories are chapters of Hmong history, ancient and contemporary, particularly of the Hmong during the last few decades.

Beyond all of these dimensions, read the book as a metaphor for the care of all patients, for the lessons of Lia’s story apply, in many ways, to every patient.

Broadly speaking, *The Spirit Catches You And You Fall Down* tells a great deal about what it’s like to be a patient and what it’s like to be a physician, the physician-patient relationship, language and communication, uncertainty, personal and professional values, and what can go wrong in the medical transaction. As you read the book, think about a series of five steps which characterize each medical encounter as an opportunity to learn and to add to one’s experience:

- **the story**—what really happened and how the patient experienced it;
- **the medical history**, the abbreviated, edited and reshaped version of the story, what physicians use to deliberate, reason and communicate;
- **the issues**, critical diagnostic and treatment questions raised by the story and the history;
- **the doctor-patient relationship**, which becomes the vehicle for care; and
- **the question, “What did I learn?”** the most important step in the physician’s professional growth.

The questions raised in this *Guide* should help you to focus your reading.

Chapter 1

Chapter 2

Chapter 3

p. 37: “…because they considered the relationship one-sided, with the Westerners holding all the knowledge.”

Question: What are the qualities of any worthwhile relationship? Make some general observations about relationships, which, in order to be successful, must be reciprocal.
Chapter 4

Chapter 5
p. 57  “‘Some of the anger came from that. From our own fear.’…It was hard to work so hard and not receive a single word of thanks—in fact, to have their efforts invariably greeted with resentment.”
Q: Part of this course is learning about what it’s like to be a physician. What are some of your additional insights about what it’s like to be a physician?

Chapter 6
p. 61  “…freighted as they were with negative expectations accumulated before they came to America,…”
Q. Part of this course is also learning what it’s like to be a patient. Starting with a patient from an obviously different culture, such as the Hmong, what can we learn about what it’s like from the story in The Spirit Catches You? What are some of your insights about what it’s like to be any patient?

p. 62  “‘The doctor is very busy. He takes people that are sick, he produces people that are healthy. If he do not produce, his economic will be deficit. But the Hmong, he will want the doctor to calmly explain and comfort him. That does not happen. I do not blame the doctor. It is the system in America.’” [italics mine]
Q. How high the stakes must be if one makes a tactical error, that is, an error in communication, in dealing with the Hmong. What are the communication errors in dealing with any patient?

p. 65  “…by their propensities for introducing themselves by their first names, wearing blue jeans under their white coats…drinking their coffee…”
Q. First impressions are important. One of the qualities of a physician is that of being a professional. What are some of qualities of any professional? What’s unprofessional about the above behavior?

p. 75  “It is when…the beliefs and customs of the family seem to be going against what you believe is in the fetus’s best interest, that you have the worst conflict…what you think is necessary happens to be exactly the opposite of what they think is appropriate.”
Q. What do you do when the patient’s wishes conflict with your view of optimal care? How do you negotiate? What do you say?

Chapter 7
p. 78  “Might Neil actually have compromised Lia’s health by being so uncompromising?”
Q. What are the issues?
Chapter 8
p. 95 “…I also believe that the long way around is often the shortest way from point A to point B and I’m not very interested in what is generally called the truth. In my opinion, consensual reality is better than facts.”
Q. An axiom from the social work profession is, “Feelings are facts.” What does this mean? How does this apply to the drama you are reading about?

p. 97 “Within thirty seconds, I could see I was dealing with a family that bore little resemblance to the one the doctors had described.”
Q. What does this reflection tell you about the writer? What does this reflection tell you about “the doctors”? What do you learn from your answers?

p. 105 “‘I miss having something that really belongs to me.’
Q. The concept of loss is a useful one in any of the caring professions. What does this statement tell you about loss? How might loss contribute to how the patient and the patient’s family experience illness?

Chapter 9
p. 106 “…a period that seemed uneventful from the doctors’ perspective was revealed, from the Lees’ perspective, to be one of the richest in her life.”
Q. What do you learn from this observation about the transaction between the physician and the patient? As a physician, how would you inquire about the interval between the last transaction between you and the patient and the current transaction?

p. 112 “Neil and Peggy had no idea what the Lees were doing to heal Lia because they never thought to ask.”
Q. What sorts of questions would you ask? What questions can one use to open up any inquiry? What are “open-ended questions”?

p. 113 “Jeannine’s [the social worker] empathy for the Lees may have been deepened by two factors: she understood what it was like to live with a chronic illness, because she had severe asthma herself; and she admired the closeness of Hmong families, because her relations with her own family, who were fundamentalist Christians, had been strained for many years, ever since they had learned she lived with a lesbian partner.”
Q. What is the meaning of “empathy”? Look to your own personal experience. Are there any personal dramas upon which you can draw to give you further insight and empathy into responding to someone’s need?

Chapter 10
p. 119 and following The chapter entitled “War.”
Q. In caring for a Hmong patient, why is it important to know about the war and the context of living? What is the application of your response to this question to the care of any patient? How would you open that inquiry?
“In fact, the parents understood an entirely different version of reality from the one Neil intended to convey. When I asked them why they thought Lia had been sent to Fresno, Nao Kao said, ‘Her doctor was going on vacation, so there wasn’t any doctor here, so they sent her away.’ Foua said, ‘Lia’s doctor was good at taking care of Lia. Sometimes when she was very, very sick, we would take her to him and he would make her better in a couple of days and she would be bouncing around and walking around. But that time he went to play, so they had to send Lia to someone else.’ In other words, the Lees believed their daughter was transferred not because of her critical condition but because of Neil’s vacation plans, and that if she had stayed at MCMC, he would have restored her to health, just as he had on every other occasion.”

Q. From this excerpt, what do you learn about the difference between patients’ perceptions and those of physicians? Is awareness of this difference important? How would you inquire about patients’ perceptions?

“ ‘It was awful,’ Dee recalled. ‘The doctors wouldn’t even look at Foua and Nao Kao. They’d only look at us and Jeanine. They saw us as smart and white, and as far as they were concerned the Lees were neither.’ ”

Q. What are your reflections on this moment? What do you suppose it was like for the Lees? What do you suppose it was like for the doctors? What do you learn from these reflections?

Chapter 12

“Instead of seeing the Hmong as struggling within a constraining context of historical, political, and economic forces that have reduced them from proud, independent, mountain people to landless refugees, the Hmong are blamed for their miserable condition.” [italics mine]

Q. Context is important in practicing medicine, making a diagnosis and addressing the psychosocial dimensions of any illness. How does the above passage apply to the care of any patient?

“A meaning-packed word heard about the Hmong almost every day was ‘difficult,’ and its ramified derivatives: ‘difficult to work with,’ ‘the most difficult group,’ ‘set in their ways,’ ‘rigid,’ ‘stubborn,’ ‘you cannot get through to them,’ ‘backward.’ ”

Q. How do you use the word, “difficult,” as in “He is a difficult person,” in your everyday discourse? What other words carry meaning that is pejorative and may obscure creative thinking for a physician?

“… ‘The first spontaneous reaction with regard to the stranger is to imagine him as inferior, since he is different from us.’”

Q. Does someone have to be of a different ethnic group for you to consider him “different”? What can you do to neutralize your reaction to someone who is “different” from you?
p. 171 “Violence, starvation, destitution, exile, and death were, however horrific, within the sphere of known, or at least conceivable, tragedies. What had happened to Lia was outside the sphere.”
Q. Beyond the pain or other symptoms of any illness, “uncertainty” is one of its major dimensions. Often it needs to be acknowledged to the patient and the patient’s family. How would you open this discussion?

p. 172 “‘I didn’t know the family very well, but I’d heard that they were noncompliant and difficult.’”
Q. Put yourself in the physician’s position. How would you react? How would you approach this family? What application do your reflections have on the care of any patient?

p. 175 “Though some nurses did their best to be sympathetic, most were exasperated by the unremitting commotion.”
Q. What’s going on? What are the issues?

p. 176 “In fact, though the Lees believed Lia was so sick she might die, they wanted to stop treatment because they thought it was the medicines that were killing her…. ‘I was sure she was dying,’ [the physician] recalled, ‘but that’s the quandary of Western medicine, that you can’t let people die.’”
Q. Two issues are present:
1. The different views of the same event by the physician and the patient’s family.
2. The point of view that “you can’t let people die.”
What do you learn as you examine these issues? Do you buy point 2? Why or why not?

p. 180 “She had too much medicine and her body just gave way.”
Q. Among the important concepts in medicine is that of “drug-induced illness.” Think of some examples from your own experience. How would you instruct a patient about a new medicine which you are prescribing?

Chapter 14
p. 185 “The proselytizing backfired. According to a study of Hmong mental health problems, refugees sponsored by the this pastor’s religious organization were significantly more likely, when compared to other refugees, to require psychiatric treatment.”
Q. What does this observation teach you about the dangers of unrecognized clashes of cultures and cultural points of view?
p. 190 “Hardly anyone knew they had a rich history, a complex culture, an efficient social system, and enviable family values. They were therefore an ideal blank surface on which to project xenophobic fantasies.”

Q. The less one knows about a person/people, the more one may be inclined to construct a story about him/them, and the more likely the story is to be inaccurate. The more professional one acts, the less likely this happens. What are ways to maintain this professional stance? What are some other qualities of a “professional?”

p. 196 “The Hmong may have been following their venerable proverb, ‘There’s always another mountain.’”

Q. One way to avoid personal and professional confinement and maintain one’s values is to declare, “There’s always the possibility of one more move.” Values are important in maintaining one’s balance. What are some of your personal and professional values?

p. 203 “According to a Minnesota study, Hmong refugees who had lived in the United States for a year and a half had ‘very high levels of depression, anxiety, hostility, phobia, paranoid ideation, obsessive compulsiveness and feelings of inadequacy.’”

Q. Are these terms names of symptoms, diseases, parts of a larger psychosocial context, or what? Are these helpful concepts?

p. 203-204 “Loss of family, status, home, …etc.”

Q. Note the prominence of the concept of “loss.” Apply this to an illness from your own or your family’s experience.

p. 205-206 “Their memories of wartime Laos are almost unrelievably traumatic: a ‘bereavement overload’ that critically magnifies all their other stresses…As the family reshuffled, I realized that its power structure had turned completely upside down, with the youngest girl now occupying the head of the line and the grandfather standing forlornly at the tail… Of himself and his fellow leaders, [the former battalion commader] said, ‘We have become children in this country.’”

Q. These are “psychosocial” data. Are they important to recognize in the care of a Hmong patient? Any patient? Why? What are the losses?

p. 208 “Even more crucially, the essential Hmong temperament— independent, insular, anti-authoritarian, suspicious, stubborn, proud, choleric, energetic, vehement, loquacious, humorous, hospitable, generous—has so far been ineradicable… [T]he French missionary attributed their ethnic durability to six factors: religion; love of liberty; traditional customs; refusal to marry outside their race; life in cold, dry, mountainous areas; and the toughening effects of war.”

Q. If all the physicians see is the medical problem, these strengths can be overlooked. Why is it important to know about a patient’s and a family’s strengths? How would you begin that inquiry? How would it help you to care for a Hmong patient by having read this book and this chapter (“The Melting Pot”) of the book?
p. 211-212 “…her doctors attributed these improvements to reduced swelling in the medulla and hypothalamus. Her parents attributed them to the herbal infusion with which they had bathed their daughter when she first came home, and for many days thereafter.”
Q. What does this passage tell you about perceptions and ways of looking at the same event? Why is your answer important? How would you open this inquiry with a patient?

p. 212 “Some all-powerful doctor in the regional bureau said the Hmong sleep on the floor anyway so they don’t need it [the hospital bed]…”
Q. Why is it important to have an advocate in the medical system? Who should be the patient’s advocate?

p. 213 “The first time Lia returned to the clinic for a checkup, Neil was on duty… That first visit was a very significant visit for me,’ he said. ‘It was very emotional…”
Q. Reflect further on what it must have been like for him and what it’s like to be a physician, addressing in particular: mistakes, forgiveness, the role of reflection itself, the potential for isolation.

p. 213-214 “As months passed, Lia became, in some cockeyed sense, a rational vital child.”

p. 216 “Now, constantly attended by her parents and siblings, she had assumed a position in the family that was, if anything, even more regal. She was a central stillness around which the life of the family condenses.”
Q. Take note of the different views of the physicians, the nurses, and the author in viewing Lia. Compare this situation with that of a demented, elderly, nursing-home resident whose daughter comes every day to feed her. What are the similarities? What do you learn from this comparison?

p. 218 “But whenever I began to be lulled by this relatively rosy picture, I was drawn up short by an explosion of rage from Nao Kao (‘My child is lost because of those doctors!’) or, more frequently, by a sudden seepage of grief from Foua.”
Q. In dealing with patients, a physician will sometimes encounter unexplained anger. How does this passage help to explain those moments? As a physician, how would you handle that inquiry with a patient?

p. 224 “I gave them my full shot,” [Martin, the nurse] said. “You saw how patient I explained things to them.”
Q. The nurse thought he had done well, the best that he could do. What’s your view? Comment on the importance of talking over “difficult” cases or patients with a trusted peer or teacher.
Q. The issue, in other words, is “values,” both the patient’s and the physician’s. A value-based professional career provides the opportunity for consistent and thoughtful practice and promotes the highest level of professional service. A value-based career helps to insure personal professional satisfaction and avoid ethical drift. Change is a reality of our personal and professional lives. How we cope with change affects our level of satisfaction. Having a set of values against which to measure important choices provides a framework for those decisions. Values guide decisions and validate positions. Unless you are aware of a conflict of values, you cannot deal with the conflict.

As a physician, how would you examine the patient’s values? How would you examine your own values? How would you resolve a conflict between your values and those of the patient?

244 “‘Does money mean more or does the family mean more?’”
Q. This is another statement of values. How do you think such an issue enters into choice of medicine as a profession, choice of specialty, and choice of a situation in which to practice medicine?

Chapter 17
p. 253 Dan Murphy, who became the director of MCMC’s Family Practice Residency Program, once told me that when you fail one Hmong patient, you fail the whole community….Lia’s case had confirmed the Hmong community’s worst prejudices about the medical profession and the medical community’s worst prejudices about the Hmong.”
Q. What does this passage tell you about (1) professional reputation and (2) prejudice? What steps would you take as a physician to avoid such pitfalls?

p. 253 “At the family practice clinic, the staff continued to marvel at the quality of care the Lees provided to their clean, sweet-smelling, well-groomed child. But at the hospital next door, where the nurses had had no contact with Lia since 1986, the case metastasized into a mass of complaints that grew angrier with each passing year.”
Q. When we don’t know details, we tend to fill in the skeleton of a story with our own guesses about the details, and then we regard those details as facts. This passage and the rest of the paragraph describe some of the stories which the staff had constructed about Lia’s family. What are the dangers of such “stories.” What steps would you take to avoid such pitfalls?
p. 256 “I asked...whether he thought Neil had made a mistake in not recognizing and treating Lia’s sepsis... ‘If Neil made a mistake, it’s because every physician makes mistakes. If it had been a brand-new kid walking off the street, I guarantee you Neil would have done a septic workup and he would have caught it. But this was Lia. No one at MCMC would have noticed anything but her seizures. Lia was her seizures.’”

Q. The clinical context—long-standing seizure disorder—obscured the acute problem—sepsis. Whenever a problem appears, always consider the possibility that it’s an entirely new event before assuming that it’s the continuation of a long-standing chronic illness. There are many such examples in medicine. How would you construct a ‘fail-safe’ model of reasoning to prevent such an error?

p. 257 “Once I asked Neil if he wished he had done anything differently... ‘Do you wish you had never met Lia?’ [He answered], ‘Once I might have said yes, but not in retrospect. Lia taught me that when there is a very dense cultural barrier, you do the best you can, and if something happens despite that, you have to be satisfied with little successes instead of total successes. You have to give up total control. That is very hard for me, but I do try. I think Lia made me into a less rigid person.’”

Q. One of the most important questions one can ask after each transaction, successful or not, is “What did I learn?” Such a question is crucial for professional growth. What else could Neil have learned from Lia’s story? What more could he have said about the psychosocial issues? What did you learn from this saga?

p. 258 “American medicine had both preserved her life and compromised it. I was unsure what had hurt her family more.”

Q. What do you think?

p. 259 “‘Until I met Lia..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...and they would still think their way was right and our way was wrong.’”

Q. Granted, some problems are simply not solvable, but what’s missing in this formulation of what went wrong?

p. 259 “Was the gulf unbridgeable?”

Q. Well, was it? What if the communication pattern had been different? What do you understand now about the concept of the “difficult patient?” How do your reflections on these questions apply to the care of any patient?

p. 259 “Trying to understand Lia and her family by reading her medical chart...was like deconstructing a love sonnet by reducing it to a series of syllogisms.... Every one of those words reflected its author’s intelligence, training, and good intentions, but not a single one dealt with the Lees’ perception of their daughter’s illness.”

Q. The medical record is not the whole story. What does this passage tell you about what it’s like to be a patient and what it’s like to be a physician?

p. 260-261 the “explanatory model” of Arthur Kleinman. See also the Kleinman references on p. 319.
Q. How do the eight questions he poses apply to the care of all patients?

p. 261 “‘First, get rid of the term ‘compliance.’”
Q. “Compliant” and “non-compliant,” when used to describe a patient or a family can be pejorative and not useful. They hamper communication between physician and patient and between physicians. Are there other words that are equally useless?

Chapter 18
p. 262 “I have come to believe that her life was ruined not by septic shock or noncompliant parents but by cross-cultural misunderstanding.”
Q. How is this statement a potential metaphor for any patient?

p. 264 “Farr told the husband she wished that his children would never be sick, that their rice bowls would never be empty, that his family would stay together, and that his people would never be in another war.”
Q. In a sense these are blessings and have impact. What other words can a physician say to any patient which is like a blessing?

p. 264-265 “This last case warrants particular scrutiny, because Francesca Farr did a number of things that generally weren’t done at MCMC, and certainly weren’t done with Lia. She made a house call. She took along a capable and assertive interpreter whom she treated as a cultural broker (by definition her equal, and in this case her superior), not a translator (her inferior). She worked within the family’s belief system. She did not carry her belief system—which included a feminist distaste for being forced to deal with the husband instead of the wife—into the negotiations. She never threatened, criticized, or patronized. She said hardly anything about Western medicine. She flew completely by the seat of her pants…Also Francesca Farr liked the Hmong.”
Q. How would these qualities of a good transaction and relationship apply to all patients?

p. 265 “Neil and Peggy were excellent physicians, but by Kleinman’s definition—a concern for the psychosocial and cultural facets that give illness context and meaning—they were, at least during their early years with Lia, imperfect healers.”
Q. Is it reasonable for a patient to expect both technical excellence and “psychosocial and cultural” excellence in a physician?

p. 265 “But love…cannot be taught.”
Q. Do you buy this premise? Can one teach the “human part” of medicine?

p. 266 “To improve Hmong health care in general,…”
Q. This paragraph is a prescription for the care of the Hmong. How do the elements of it apply to the care of any patient?
p. 266 “...practice conjoint treatment...because illness is so profoundly affected by psychosocial factors, it actually improves the outcome.”
Q. What are some examples from what you have read and from your own experience which validate this statement?

p. 267 “‘Since Hmong health treatments never hurt anyone, but could possibly help a patient, [they] should be seriously considered as part of a client’s course of treatment.’”
Q. Notice the phrase “as part of.” What are the potential dangers of relying solely on “Hmong health treatments”? What are the potential dangers of relying solely on any single point of view?

p. 267 “Shamans are, first and foremost, quintessential mediators.”
Q. Who are other potential mediators in the physician-patient relationship? How would you enlist their help?

p. 268 “…I thought of how often the Hmong react to threat or blame by fighting or fleeing, which in the medical arena translate to various forms of noncompliance. The txiv neeb’s exclusion of guilt from the transaction dovetails perfectly with the Hmong temperament.”
Q. Can you think of ways in which physicians and other healthcare professionals deliberately or inadvertently invoke guilt and what impact this maneuver has on the patient or the patient’s family?

p. 270 “...since 1990, more than half the population growth in the United States has come from immigrants and their children—and...many of these immigrants...may find mainstream health care culturally inaccessible. [italics mine]
Q. What are ways in which any patient may find mainstream health care “culturally inaccessible?” Think of language barriers (such as medical jargon), inadvertent prejudice and other factors.

And finally...

pp. 273-276. These pages describe how medicine is taught and how it should be taught. “…a Hmong patient, ...referred to a specialist for further treatment, did not ask the referring physician to find someone skilled or famous. He asked, ‘Do you know someone would care for me and love me?’”
Q. What are your views of what the ideal education of a physician should entail?

Chapter 19