

## THE SPIRIT CATCHES YOU AND YOU FALL DOWN: A BOOK REVIEW

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In The Spirit Catches You and You Fall Down: a Hmong child, her American doctors and the collision of two cultures, literary journalist Anne Fadiman presents the true story of Lia Lee and her family who migrated from Laos to California following devastating war in Southeast Asia. At three months, Lia first showed signs of having what the Hmong know as *qaug dab peg* (the spirit catches you and you fall down), otherwise known as epilepsy in the West. While Lia's doctors considered the best treatment to be an array of medications, her parents preferred a combination of Western medicine and folk remedies designed to coax her wandering soul back to her body. Over the next four years, profound cultural differences and linguistic miscommunication exacerbated the rift between Lia's loving parents and well-intentioned doctors, eventually resulting in a severe seizure and the loss of all her higher brain functions.

The chapters gradually reveal Lia's story by providing alternating narratives from the Western medical model and the Hmong culture and history. This approach facilitates readers' understanding of the two divergent worldviews and elicits empathy for both. Because Fadiman presents the perspectives and intentions of both cultures with empathy, clarity and respect, this makes their ultimate clash all the more tragic.

The Spirit Catches You and You Fall Down highlights fundamental differences in how the two cultures understood Lia's condition and how both groups (family and healthcare professionals) genuinely endeavoured to provide her with the best possible care. The story outlines how the woefully inadequate interpreting services, cultural misunderstandings, power inequalities, and

<sup>&</sup>lt;sup>1</sup> Lia Lee dies [online image]. Retrieved August 24, 2018 from: <a href="https://static01.nyt.com/images/2012/09/15/us/LEE/LEE-superJumbo.ipg">https://static01.nyt.com/images/2012/09/15/us/LEE/LEE-superJumbo.ipg</a>

fundamentally different philosophies, all profoundly and irrevocably compromised Lia's health care. Lia's family felt that her doctors were well-intentioned but untrustworthy, patronising, intrusive and misguided, administering treatments that worsened her condition and caused her pain and distress. The healthcare team considered Lia's family to be ignorant, chaotic, ungrateful, non-compliant and even neglectful. These misunderstandings eventually led to the doctors arranging for Lia to be removed from her parents by child protection authorities, following which she spent six months in foster care.

In preparation for the book, Fadiman spent many hours with Lia's family and Hmong community leaders, exploring their rich traditions and guiding values. This allowed her to provide readers with a rare insight into the depth and sophistication of Hmong culture, albeit from her North American viewpoint. Against this background knowledge of Hmong history, culture and spirituality, Lia's family's actions and beliefs become more logical and recognisable to Western readers, and the portrayal of their experiences in the US healthcare and child welfare systems evokes both concern and empathy.

This book provides valuable insights about culture. It facilitates an empathic understanding of another culture (Hmong), but also holds a mirror to the Western culture (consumerist, secular, individualist), and to the culture of Western medicine and healthcare. It gently challenges the assumption that high-tech, scientific, evidence-based approaches are always superior and infallible.

## **DISCUSSION/REFLECTION QUESTIONS**

- This book engenders empathy for the Lee family both as healthcare consumers and as members of a misunderstood ethnic minority. This allows readers to recognise and respond to the needs and experiences of the family, despite, and perhaps because of, their differing cultural practices and beliefs.
  - Discuss the elements of the Lee family's healthcare journey that are common to all healthcare consumers and which feelings might be universal to all (e.g. fear, shame, exhaustion, vulnerability, frustration etc).
- 2. Despite what might seem to be the appearance of adopting the dominant culture (e.g. wearing Western clothes, driving cars), many people from culturally and linguistically diverse (CALD) communities have deeply held cultural beliefs, values and worldviews that influence their healthcare experiences and practices.
  - How can healthcare professionals look beneath the exterior façade to gain deeper insights into people's cultural needs and values (e.g. by undertaking a cultural assessment)?
  - How did you feel when Child Protective Services took Lia away from her parents? Do you believe it was the right decision? Was any other solution possible in the situation?
- 3. Lia's family frequently signed consent forms for treatments they clearly did not understand. Hmong, as well as people from other CALD backgrounds, may state 'yes' to indicate that they are listening, not that they agree (or even understand) what is being presented to them. This book also illustrates the elaborate system of approval that should have been followed for Hmong people, such as seeking consent from male family members/ senior family members or clan leaders etc.
  - What types of 'risk' are presented when consent is obtained in the manner described in 'The Spirit Catches You and You Fall Down'?
  - The book contains many Hmong phrases and many medical phrases, both unfamiliar to most readers. Why do you think the author included them?

- 4. Fadiman said in the book that she '... was struck . . . by the staggering toll of stress that the Hmong exacted from the people who took care of them, particularly the ones who were young, idealistic, and meticulous' (p. 75). Why do you think the healthcare professionals felt such significant stress?
- 5. How do you think the healthcare providers in the book would respond to the suggestion that their cultural insensitivity compromised Lia's care?
- 6. Did you feel empathy for Lia's healthcare providers? Did you experience it in a different way from your empathy for her family? Why?
- 7. It is clear that many of Lia's doctors, most notably Neil Ernst and Peggy Philp, were heroic in their efforts to help Lia, and that her parents cared for her deeply, yet this arguably preventable tragedy still occurred. Can you think of anything that might have prevented it?
- 8. Chapter 17 of The Spirit Catches You and You Fall Down presents eight questions from Arthur Kleinman's (1978) Patient Explanatory Model, designed to help healthcare professionals who work in cross-cultural settings. How might these questions be used to as a guide for clinicians to explore consumers' (and families') understanding of their health problems?
  - What do you think has caused your problem?
  - Why do you think it started when it did?
  - What do you think your problem does inside your body?
  - How severe is your problem? Will it have a short or long course?
  - What kind of treatment do you think you should receive?
  - What are the most important results you hope to receive from this treatment?
  - What are the chief problems your illness is causing you?
  - What do you fear most about your illness/treatment?
- 9. In a diverse society like Australia, it is not possible to understand the background of people from so many different cultures. How then is it possible to practise with cultural empathy?
- 10. In Chapter 18 Fadiman writes, 'As William Osler said—or is said to have said—Ask not what disease the person has, but rather what person the disease has'. How might have the events of this book have unfolded if Osler's dictum were universally followed by the healthcare professionals?

## **LINKS**

A conversation and reading with Anne Fadiman: <a href="https://www.youtube.com/watch?v=C8J7JxVp1Rs">https://www.youtube.com/watch?v=C8J7JxVp1Rs</a> Interview with Anne Fadiman: <a href="https://youtu.be/ihYD57hpQ04">https://youtu.be/ihYD57hpQ04</a>

## REFERENCES

Fadiman, A. (1997). *The Spirit Catches You and You Fall Down*. New York: Farrar, Straus and Giroux.

Kleinman, A., Eisenberg, L. and Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, pp 251-258.

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