

Knowledgeshare

Reviews

The Spirit Catches You and You Fall Down: A Hmong child, her American doctors, and the collision of two cultures

Anne Fadiman

Farrar, Straus and Giroux: New York,
ISBN: 0-374-26781-2, 1997, 341 pp

In *The Spirit Catches You and You Fall Down*, American journalist Anne Fadiman examines the intense collision between American and Hmong cultures through the case of Lia Lee, a Hmong child, who is too young and too sick to speak for herself. Lia's wellbeing is inextricably bound up in the pursuit of 'best interest standards' by all those around her. Fadiman reports on the complicated interactions between them all and uncovers the deep-rooted struggles of power relationships.

During infancy, after a number of seizures and visits to the accident and emergency department at Merced's county hospital, Lia's American doctors eventually diagnosed her with epilepsy, for which they prescribed regular dose medicines for her treatment. Lia's immigrant parents, on the other hand, called the condition 'quag dab peg' from which the book's title is literally translated. They understood the condition as more to do with soul loss, which began occurring when Lia's sister slammed their apartment door and frightened Lia's spirit away. Rather than seeing it as disabling, they saw it as an illness of some distinction and were ambivalent about treatment. Although the parents irregularly administered some of the prescribed medicines, their preferred method of treating Lia was with their own traditional herbal remedies, shamanism and animal sacrifices.

This was why the 'collision' of the two cultures began. Lia's parents were convinced that the directed Western medicines were making the seizures worse. Whereas the hospital medics offended the parents by accusing them of incompetence, non-compliance and even intended harm. Over several years the battle between the two sides continued, until finally, Lia suffered the 'big one'. This referred to an intractable grand mal fit. I'm stopping here, before I give too much away.

What I can tell you, though, is that the intensive, face to face method of ethnography study helped build

up and contextualise the overall holistic nature of epilepsy, from both emic and etic viewpoints. According to Taylor (2003), this story was amongst the saddest that was ever possible to tell. However, Fadiman managed to narrate this most difficult story with the most immense sensitivity, intimate familiarity, powerfulness and admirable skill. Fadiman uncovered and showed the humility and frailty of both sides (Selzer, 1998), a family stigmatized, discriminated against and deemed culturally inferior alongside behaviour by doctors in hospitals that is not always as rational and scientific as it would seem. This was not done coldly, but with constant genuine interest, admiration and fondness for all.

To me, this book was gripping, dramatic, enlightening and informative but there was no doubt that learning takes place as well. Fadiman combined real experience with generalised facts well in an unusual structure. Hmong history and war experiences were told in the even chapters interspersed by Lia's story in the odd numbered. Suspense was created and forced me to make assumptions and take sides in the early chapters. It also provided fresh insight into cross-cultural concerns and forced migration and gave another dimension to conventional thinking. It raised questions about the dominant view of the Western medical model and a clear critique of a failed system. However, at the same time it informed and stimulated me in my nursing practice and lecturing of health professionals towards cultural competence in the classroom. These were additional and unexpected gains and indicated why this book has been so widely used as a training resource in medical and anthropology schools, and journalism and writing colleges across the USA since its publication. It was illuminating to compare one's own customs and medical practices with the cultural logic and practices of those defined 'as other or different'. It gave meaning to behaviours often perceived by outsiders to be illogical, irrational and obstinate and showed that these difficulties are often merely down to cultural miscommunications rather than non-mediation (Moran, 2006). My current paperback edition even includes a 'reader's guide' at the end, which is designed to facilitate discussion and could as easily be used here in the UK in the same way.

The world certainly does look different from different cultures. One cannot help but wonder whether the outcome of this book really was inevitable, or whether it could have ended differently or was it simply just meant to be? This book has been described

as a story, an essay, a controversial medical and legal debate and even a tragedy – to me it was all of them.

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Medical Apartheid: the dark history of medical experimentation on black Americans from colonial times to the present

Harriet Washington

Random House: London, ISBN: 978-0-385-50993-0, 2007, hardcover, 512 pp

According to the blurb this is the first and only comprehensive history of the medical experimentation on African Americans. Starting with the earliest encounters between Africans and Western medical researchers and the racist pseudoscience that resulted, it details the way both slaves and freedmen were used in hospitals for experiments conducted without a hint of informed consent – a tradition that continues today within some black populations. It shows how blacks have historically been prey to grave-robbing as well as unauthorized autopsies and dissections. Moving into the 20th century, it shows how the pseudoscience of eugenics and social Darwinism was used to justify experimental exploitation and shoddy medical treatment of blacks and a view that they were biologically inferior, oversexed, and unfit for adult responsibilities. Shocking new details about the government's Tuskegee experiment are revealed, as are similar, less well-known medical atrocities conducted by the government, the armed forces, and private institutions. This book reveals the hidden underbelly of scientific research and makes possible, for the first time, an understanding of the roots of the African American health deficit.

Paula McGee

Editor, Diversity in Health and Social Care

Reports

A new kid on the library block – Specialist Library for Ethnicity and Health

SLEH (the Specialist Library for Ethnicity and Health) is the newest addition to the family of the NHS Knowledge Service's 'specialist libraries'. The electronic resource was officially launched on 23 October 2006 at a formal event in the magnificent setting of one of Parliament's committee rooms, with its leads (Professors Mark Johnson and Ala Szczepura) seated below a room-sized picture of King Alfred encouraging the Saxons to resist the latest wave of would-be immigrants to the shores of the British Isles! The audience, however, demonstrated quite clearly that British society has become truly multicultural, with Lords, MPs and current and former NHS chief officers from a variety of ethnic backgrounds offering their support.

Patricia Hewitt, Secretary of State for Health (who is also a Leicester MP), welcomed the team and its guests to the august surroundings of the House of Commons, and spoke with feeling about the need for multicultural competence and care in the NHS. As she observed, 'We know not just from experience in Leicester but from experience from around the country, that in far too many cases, our black and minority ethnic communities find it more difficult to access support from the NHS, particularly if they are on lower incomes'. She went on to hope that the SLEH would help to spread 'some of the superb innovation and new good practice that exists, where many clinicians and other frontline staff are really reaching out to reach grass-roots'. As she noted, the electronic resources, accessible to everyone with an internet connection, will help practitioners from all communities, and also organisations who are working within the community, to find what they need to understand health challenges and build on best practice. As she concluded, 'Sharing this sort of information and evidence can help ensure that we really do work together to improve the health of the nation and help services support some of our most vulnerable fellow citizens'.

The message was also reinforced by Surinder Sharma, NHS National Director for Equalities and Diversity, who noted that minority communities were making a very significant contribution to the success of the National Health Service. As he observed, '14% of the overall NHS employee population comes from black and Asian backgrounds. Indeed, at least 5–7% in the ambulance services, 16.4% of our qualified nurses and midwives and health visitors, 42% of our doctors, and 23% of our consultants are from black and Asian backgrounds – and the next generation are also involved: 30% of today's medical students come from BME

backgrounds'. However, as he reiterated, the health needs of the minority communities remain poorly served and often problems arise because of ignorance or lack of cultural sensitivity on the part of the 'mainstream practitioner'. In his opinion, it is only by sharing and using best evidence regarding minority health issues that this state of affairs can be remedied, and he reminded listeners that this is what current legislation requires.

Furthermore, it was stated, 'If we did things better, if we had more information, if we had systematic information about cultural and ethnic-specific needs right across the health service, then we would actually have a better patient pathway all the way through the services that we offer. But also we would save money and improve people's health'.

The electronic library, created by researchers at Mary Seacole Research Centre at De Montfort University in Leicester and from Warwick Medical School at the University of Warwick, will provide the first such resource in Europe. It will bring together quality assured research from around the world to help professionals and the public access the very best available medical evidence relevant to minority ethnic groups and cultures. The library also collates patient information in minority languages, and in future, the team hopes to look at how this can be quality assured by working with different minority communities.

However, the library will be just as important for the gaps it highlights as it is for its actual content. As Sir Muir Gray, Director of Knowledge Process and Safety for NHS Connecting for Health, observed in an innovative electronic presentation (while simultaneously flying to California to talk to the Google organisation about the future of electronic health information): 'The Warwick and De Montfort team have managed to take an area of terrific complexity and developed an electronic library which makes sense and is clear and easy to use'. He also noted the challenges facing the team and all practitioners and researchers in the field. Firstly, unlike the other medical libraries, a great deal of important material in this area is to be found outside medical journals in a very diverse range of detailed reports by various public sector organisations. Locating, accessing and quality checking this material are vital but difficult. Secondly, helping users to search the library has required careful thought as to the range of terms they might employ to look for evidence on different ethnic minorities – there is still much confusion and a lack of consistency in the terms used both in science and in the way people talk about migration and ethnic diversity.

In Muir Gray's own words, 'This library will not only be an invaluable tool bringing together the very best in current research evidence on ethnicity and health: it will also highlight the significant gaps in our knowledge of how a range of treatments impact on

ethnic minorities. This I hope will inspire new research and clinical trials that will help to close these gaps and provide even more high quality content for this new library'.

The team responsible for the development of the project modestly believe that their pioneering work in constructing the Specialist Library for Ethnicity and Health for the NHS will become a benchmark that will assist other countries in their construction of their own electronic libraries of information in this field. It is clear that with growing ethnic minority populations in most countries, this form of free, easy-access, one-stop shop will be essential for good medical care in the 21st century.

Access to the resource is free, although some journals will only allow access to abstracts unless the user works for an organisation with a subscription or 'Athens' password. Some sections are designed for use by clinicians while others contain materials specifically intended for use by patients and carers. Guidance is given on the website in using the search facilities and resources. Suggestions and questions can be posted using the 'Contact Us' facility provided on the website www.library.nhs.uk/ethnicity

Mark Johnson

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Report of the 32nd Annual Conference of the Transcultural Nursing Society, 1–4 November 2006, Annapolis, USA

The conference was held in Annapolis, a small town lying on Chesapeake Bay, Maryland, on the east coast of the USA. The theme of the conference was 'Enhancing Health Care through Transcultural Nursing'. There were four programme objectives:

- 1 describe implementation initiatives that enhance the provision of culturally congruent care
- 2 examine various methods for educating students and staff to provide transcultural healthcare
- 3 differentiate the role of administration in fostering transcultural nursing to enhance healthcare
- 4 analyse the contributions of transcultural nursing theory and research in enhancing healthcare.

This was a very busy but fruitful conference. The keynote speakers were challenging and excellent in engaging their audience. Particularly enjoyable was Josepha Campinha-Bacote's presentation on 'Can you paint with all the colors of the wind? using the paintbrushes of cultural desire, cultural humility and sacred encounters'. Her notion of cultural desire is already known but cultural humility she describes as 'a

life-long commitment to self-evaluation and self-critique, of finding the greatness in others and thinking less of yourself.' Equally challenging but in a very different way was Carol Picard's presentation on 'Energising nursing practice: keep the passion in compassion'. She spoke of art and healing being sisters 'tied together by a silver thread'. Both these presenters used the arts to produce a memorable climax to their presentation. Josepha played the flute and Carol both sang and danced, but it was the dancing which was most effective.

There was also a very thoughtful presentation from Carol Taylor who is Director of the Centre for Clinical Bioethics at Georgetown University, Washington. Her topic was 'Care and justice'. Her research suggests that females develop a *morality of response and care* whereas males develop a *morality of justice*. She went on to compare and contrast justice and care as distinct moral orientations.

There was also a huge variety of concurrent sessions. Presentations ranged from caring for people devastated by hurricane Katrina to problems of the 'lost boys' of Sudan and type 2 diabetes amongst First Nation peoples in Canada. There were also two Education Panels where the first dealt with 'Approaches to building cultural competence in nursing programmes' and the second with 'Enhancing cultural understanding for practising nurses and students in diverse settings and programmes'. Some interesting ideas were put forward including distance learning while others used short immersion measures both overseas and at home. These latter were the more interesting as they gave accounts of caring for homeless families in shelters where cultural encounters allowed students to describe their experience as 'being in another world'.

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Notices

Delivering Race Equality in Mental Health Care: Policy, Practice and Research 2nd National Conference, 21–22 February 2007, West Midlands

This two-day event will focus on the progress that is being made since the launch of *Delivering Race Equality in Mental Healthcare Action Plan* in 2005. The conference will address key issues of concern to the community, practitioners and users of the services from the perspectives of:

- users' and carers' experience

- policy
- practice
- research.

For pre-registration or more information contact: Tel: +44 (0) 7809 413 519; email: Lynette.Ametewee@csip.org.uk; website: www.actiondre.org.uk

The 33rd Annual Conference of the Transcultural Nursing Society, 19–21 September 2007, Bournemouth University, UK

The theme of the conference is: Human Rights, Migration and Poverty; their impact on transcultural nursing. The conference objectives are to:

- explore the issue of human rights in relation to global migration and the implications for health and wellbeing with particular reference to HIV/AIDS
- examine how transcultural healthcare professionals can respond to the effects of world poverty on the health of its peoples
- analyse the impact of the migration of healthcare staff on the provision of care
- evaluate the effectiveness of research and education in improving transcultural care.

For more information and abstract submission go to: www.bournemouth.ac.uk/ihcs/tcnsabsub.html

Resources

Prostate cancer

The Prostate Cancer Equality Action Plan – tackling prostate cancer in BME groups, to combat existing inequalities.

Every year nearly 32 000 men are diagnosed with prostate cancer in the United Kingdom and 10 000 men die from it. Prostate cancer is now the most common cancer diagnosed in men in the UK – every hour at least one man dies from this disease. Men of African or African Caribbean origin are three times more likely to be diagnosed with prostate cancer than their white counterparts. However, men from black and minority ethnic communities (BME) have traditionally suffered from later diagnosis and restricted access to services, including palliative care. This new coalition aims to improve the future of BME communities in the UK and create a force for change among government and healthcare providers.

For more information about The Prostate Cancer Charity's African Caribbean Project go to www.prostate-cancer.org.uk/what/acp.asp

Learning disabilities

Under the government's Public Service Agreement Targets, Child and Adolescent Mental Health Services (CAMHS) must become fully comprehensive by the end of 2006, but less than half of services claim to have provision for children and young people with learning disabilities according to a recent report: National Child and Adolescent Mental Health Service Mapping Exercise 2005: A Summary of National Trends, Department of Health, Durham University, Department for Education and Skills, www.camhsmapping.org.uk/2005

The Foundation for People with Learning Disabilities has produced a set of guidelines to help CAMHS become more inclusive for young people with learning disabilities. The guidelines, 'This is what we want', were produced following consultations with young people with learning disabilities. The guidelines cover issues such as: referral and access to services; information and rights; care and intervention; multi-agency working.

'This is what we want' is available to download from the Foundation for People with Learning Disabilities website www.learningdisabilities.org.uk

Diversity webwatch

Cecil Helman

Many readers will be familiar with the writings of Professor Cecil Helman, who has done considerable work in the field of culture and health. We are pleased to bring to your attention his recently acquired website, www.cecilhelman.com

Intute

Intute is the new face of the Resource Discovery Network (RDN), a free national service enabling lecturers, researchers and students to discover and access quality internet resources. Intute brings together two of the Hubs of the Resource Discovery Network: Altis and SOSIG. The new service provides information and tools to help you access the best of the Web in the social sciences, including social welfare, sociology, government policy, women's studies, and law. Visit the new Intute Social Sciences service at: www.intute.ac.uk/socialsciences/

Knowledgeshare welcomes the following contributions:

- short accounts/evaluations of specific initiatives to improve practice or education in health and social care
- reviews of books, websites, games or other resources that can inform practice or education
- information about assessment tools and their applications
- conference reports
- other information that may inform the development of health and social care practice.

All contributions for this section should be sent to Lorraine Culley, email: lac@dmu.ac.uk