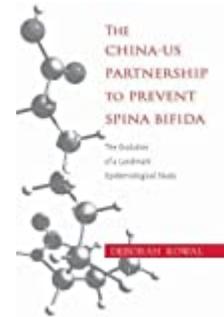


# H-Net Reviews

in the Humanities & Social Sciences

**Deborah Kowal.** *The China-US Partnership to Prevent Spina Bifida: The Evolution of a Landmark Epidemiological Study.* Nashville: Vanderbilt University Press, 2015. 256 pp. \$69.95 (cloth), ISBN 978-0-8265-2026-5; \$27.95 (paper), ISBN 978-0-8265-2027-2.



**Reviewed by** Chieko Nakajima (Assumption College)

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**Commissioned by** Seth Offenbach (Bronx Community College, The City University of New York)

*The China-US Partnership to Prevent Spina Bifida: The Evolution of a Landmark Epidemiological Study* presents a fascinating story about a China-US joint project to prevent spina bifida and other neural tube defects (NTDs). NTDs begin at an early stage of embryonic development and cause a range of disabilities. In this project, China enlisted women from local counties to take folic acid pills and track their pregnancies; the United States evaluated data and provided technical and financial help. The author describes various events and incidents Chinese and American researchers experienced to conduct this study. After overcoming many challenges, researchers in both countries eventually succeeded in monitoring some 250,000 pregnancies in China and creating a huge database to validate their hypothesis: intake of folic acid significantly reduces the risk of NTDs without adversary effects. With this result, mandatory fortification of grain products with folic acid has been implemented in the United States and other countries.

This book is pertinent to two academic fields. First, it presents a social history of NTDs. Today NTDs are relatively rare, but they were fairly common across the world as recently as the 1980s. The book describes how Chinese and American doctors and epidemiologists garnered funding, designed the entire research project, and

mastered new techniques to collect and analyze large statistical data. Numerous Chinese staff members at various local levels—including county leaders, township health workers, village doctors, and obstetricians—also participated in this project and made significant contributions. The author gives a vivid description of the dynamics involved in the epidemiological study of NTDs. Studying NTDs is not just doing experiments in a scientific lab; it involves individuals, families, and local communities.

Second, this book is also about US-China relations in the post-Mao era. In the early 1980s, China had begun to open up to the outside world. This NTD study was one of the first successful academic collaborations between China and the United State. The book covers the 1980s to the 2010s and the author observes changes in mutual perceptions of the two countries. When researchers launched this project, many Americans regarded Chinese society as “primitive” and technologically backward (p. 51). Likewise many Chinese people were suspicious of America’s hidden motives for this study. After the Tiananmen Square incident in 1989 and the US bombing of the Chinese embassy in Yugoslavia in 1999, relations between the two countries became tense and strained. In spite of such initial reservations, researchers were able to establish a reliable partnership.

The author provides a comprehensive picture of this collaborative project in an accessible manner. The book is highly readable to lay readers with little knowledge of epidemiological studies or Chinese studies. The book begins with a conversation between Yan Renying from the Beijing Medical University (BMU) and Godfrey Oakley from the Birth Defects Branch at the US Centers for Disease Control (CDC). Yan and her colleagues found an unusually high occurrence of NTDs among newborns in northern China's rural areas. The death rate of babies with NTDs is high, and many people with NTDs need special equipment and medical treatment. China in the 1980s was a poor country and isolated from the Western medical world. Yan sought international consultations and technical support to reduce these defects. On the other side of the earth, Oakley and American epidemiologists were also working on the prevention of NTDs. They were aware of correlations between the birth of babies with NTDs and insufficient levels of folate acid of mothers. Yet available data was small; results were suggestive, not decisive. Researchers needed to study a large number of women to reach a definite conclusion. China's size and high NTD rate provided an ideal venue to amass sufficient statistical data. It would take less time and be less costly to obtain statistically meaningful samples in China than in the United States. The BMU and the CDC shared a mutual interest in finding the cause of NTDs and preventing them. The idea of forming a China-US research collaboration grew out of this discussion.

Transforming such an ambitious idea into a realistic plan that could be implemented is never easy. At every stage of the project, Chinese and American researchers encountered various political problems, scientific and technical challenges, and cultural differences. They negotiated with each other, convinced their governments and bureaucrats of the importance of the work, created and modified their project design several times, and recruited and trained local personnel.

To begin, researchers from the BMU and the CDC had to solidify their plan and make it technologically and financially sound. They also had to convince their governments to give them support and funding. In spite of their dedication and enthusiasm, throughout the entire process, both sides expressed concerns and reservations. Some Americans were skeptical of Chinese capability to use state-of-the-art technology. Some were displeased that the United States was giving money to a communist nation. The greatest concern for Americans was about informed consent. Ethical standards should be applied universally, but it would be difficult to inform

Chinese women from rural areas of the global importance of the research and have them voluntarily participate in the study. Other concerns included Americans' suspicions that China was a totalitarian state coupled with Chinese concerns that the United States was motivated by epidemiological imperialism (pp. 42, 55). They were also unfamiliar with and confused by many aspects of the American way of research and associated protocols, including the use of expensive computers and software packages, discussion-centered teaching, and conversational-style meetings, and the requirement of a strict accounting system for research expenses. Through mutual visits, meetings, discussions, and negotiations, researchers who joined this project proved that this research was feasible and worthwhile, and gained credibility. The US Congress and the Chinese government both approved this project.

Developing a research design posed a serious challenge. Researchers had to work on various technical issues and scientific procedures. Questions researchers had to answer included: How many women and how many pregnancies did researchers need to include in the study? What counties should they select as research sites? How much folic acid should a woman take and how many pills did the study require? How should they communicate with women and provide them with precise guidance? What procedures were required to correctly diagnosis and classify various birth defects? What procedures had to be in place to keep track and record all these cases?

Timing is always crucial for scientific research. While the China-US team was busy elaborating their research plan and conducting pilot studies, scholars from Britain and Hungary achieved significant breakthroughs in the study of NTDs. Each time they learned about new discoveries, the team had to revise their plan. In the end, they decided to conduct a community intervention program. In this program, Chinese public health workers introduced folic acid pills and circulated medical information about pills among local women who had just gotten married. Women could decide whether or not they would take the pills, and public health workers would follow them over the course of their pregnancies. Using these samples from China, the United States would conduct data analysis.

Epidemiological studies require large populations. Preliminary pilot studies and the final community intervention program involved a total of more than thirty counties in northern and southern China. Good coord-

dination with local people was a key to success. Staff from the BMU and the CDC traveled around China, visited counties, and met with local leaders to explain the project. They also organized workshops and compiled manuals to train local health workers for various procedures, such as distributing pills to women and obtaining their informed consent, keeping pill-taking records, monitoring pregnancies, and collecting blood samples. In doing so, local health workers had to follow detailed protocols. These tasks were complicated and demanding, but researchers were able to convince them that in the long run, the study would be beneficial to their communities, their country, and the entire world. The BMU invited county leaders to Beijing every year to have meetings. Likewise county leaders invited people from townships and villages to exchange ideas and share their experience with the project. Increasingly local people gained a feeling that they were participating in something important and contributing to the common good.

This book is informative and engaging. It is a success story and fun to read. Yet it also has some drawbacks and limitations. The entire narrative is written within the conventional framework of "Western impact and Chinese response." While the book is about "China-US partnership" and it includes experiences of various Chinese people, the focus is mostly on what the Chinese learned from American research methods and how they successfully imported these methods to China. I would like to learn more about the Chinese side of the story from local perspectives. The book includes anecdotes about local people's grumblings and discontents. Some leaders complained about the amount of work assigned to them and their people and demanded material rewards, such as cars and computers, and larger monetary compensation in return. Some counties pressed hard and complained that the BMU was "stingy" (p. 139). Since some villages and townships did not have adequate resources to provide prenatal and postnatal services to conduct community interventions, some counties had to find the funding to pay for these services. Such imbalances caused resentment. These are all intriguing episodes that provide rich material for examining interactions between local communities and non-local researchers; however, the author does not elaborate on these topics very much. Participating in this epidemiological study simultaneously brought benefits and troubles; local people were not always passive recipients of the "modern science" delivered to them from Beijing and Atlanta. How did local people, including leaders, doctors, and pregnant women, try to optimize and exploit this opportunity? Who did this project

benefit the most and who did it benefit the least? Did the project change power and human relations among local residents? These are some of the questions the author might have addressed. In this regard, Katherine Mason's *Infectious Change: Reinventing Chinese Public Health after an Epidemic* (2016) discusses the tensions between "common good" to be served and "a sample population" to be examined in the context of China's public health. Mason's work might complement this book well.

One of the recurring themes of the book is "cultural differences." But "culture" here is only narrowly defined. Had the author consulted the large corpus of scholarly literature on China's popular culture, she might have broadened her perspective on such issues.[1] I am particularly interested in educational efforts made by researchers to inform local people about NTDs and to establish the credibility of this project. They decided to organize health campaigns that were similar to those run by the state. They used mass media, such as radio and TV, and visual and oral materials, such as posters, handouts, videos, and songs, to teach people about NTDs. Sometimes the Chinese displayed photographs of babies with severe NTDs and showed videos with highly emotional narrations. While Americans found such images disrespectful, the Chinese believed frank and direct approaches would work best. The author might have studied these educational materials more carefully. A close examination of these materials would help us understand how "scientific knowledge" and China's local cultures and sensibilities interacted with each other. A more detailed ethnographic study based on a bottom-up approach would serve as a counterpart of this book. Such a study would also enhance our understanding of Chinese perceptions of "abnormality" and "deformity."

These suggestions aside, I understand that an in-depth examination of Chinese experiences might be beyond the scope of this study. *The China-US Partnership to Prevent Spina Bifida* is a delightful book. It is a human story of the Chinese and Americans that traces three decades of an international collaborative project. The book reminds us of the many ways that various individuals, through their lives and work, have contributed to scientific achievements.

#### Note

[1]. For example, see Joseph W. Esherick, *The Origins of the Boxer Uprising* (Berkeley: University of California, 1987); Jeffrey N. Wasserstrom, *Student Protests in Twentieth-Century China: The View from Shanghai* (Berkeley: University of California Press, 1991); and Di

Wang, *Street Culture in Chengdu: Public Space, Urban Commons, and Local Politics, 1870-1930* (Stanford: Stanford University Press, 2003).

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