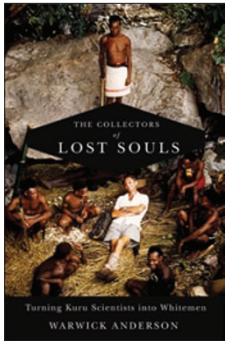


Kuru, moral peril and the creation of value in science



The Collectors of Lost Souls: Turning Kuru Scientists into Whitemen

by Warwick Anderson

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Reviewed by Adriano Aguzzi

When the term 'prion' was coined in 1982 by Stanley Prusiner, the enigmas surrounding prion diseases had already captured the interest of scientists, physicians and veterinarians for more than a century. Scrapie, the prototypic prion disease of sheep and goat, was extensively investigated in the nineteenth century and the rare human Creutzfeldt-Jakob disease was reported in 1929. But it was the discovery of kuru, ravaging the Fore tribes of Papua New Guinea, that spurred the burst of scientific and public interest in prion diseases.

Warwick Anderson, an Australian medical historian, has recently written a new account of kuru research. His book is distinguished by captivating storytelling and a historiographically rigorous account of the events. *Lost Souls* is not only enjoyable for any interested layman, but it also provides a thoroughly researched account of a remarkable scientific adventure that spans four decades. The towering hero of this tale is the recently deceased American scientist D. Carleton Gajdusek. Anderson paints sympathetic, yet realistic, portrait of Gajdusek's complex personality. The book highlights Gajdusek's scientific talent, but it also explores his destructive traits, including the irresponsible enactment of sexual obsessions that led to his infamous destitution, imprisonment and exile for the last decade of his life.

I have spent the past 20 years in prion research and I am personally acquainted with many of the book's characters. Nevertheless, Anderson's book has taught me numerous surprising anecdotes and has changed my perception of the early days of this research field. I had not been aware that the anthropologists roaming Papua in the 1930s and 1940s had already seen many cases of kuru (the most prevalent cause of death among the Fore people at that time), yet had completely failed to recognize it as an organic disease. Anderson leads the reader to admire Gajdusek's intuition as he gradually recognizes kuru as being a bona fide medical problem and forcefully dismisses the prevailing misconception of kuru as a 'hysterical' reaction of Papua natives suddenly being confronted with Western civilization.

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Although Gajdusek was doubtlessly a very sharp mind, his genius alone would not have sufficed to disentangle the enigma of kuru. He was neither gifted nor interested in the actual experimental benchwork. But he was a charismatic motivator who mesmerized and, to a considerable extent, manipulated his affiliates into executing his research program. He was also an outstanding manager who efficaciously supervised the complex logistics of acquiring fresh-frozen brain autopsy samples in the Papuan jungle, shipping them to Bethesda and assessing the effects of their inoculation into the brains of chimps. Mind you, all of this was done long before e-mail, satellite phones and overnight couriers! Anderson's narrative is refreshingly devoid of romanticizing undertones and instead highlights the importance of teambuilding and organizational skills to successful biomedical science. What a great lesson for any PhD student!

The book's dramaturgy pits Gajdusek's scientific élan against a parochial colonial bureaucracy whose pecking order antagonized all progress. This is entertaining, particularly for those of us who endured the stupidity and arrogance of public health officials amid the mad cow disease crisis not too long ago. At times, however, I can't help but wonder whether Anderson skews historical realities for the sake of his narrative. The portrait of F. Macfarlane Burnet, for example, Nobel laureate and ideator of the antibody clonal selection theory, appears more uncharitable than is strictly necessary.

Anderson's book is not perfect. His prose is frequently cumbersome, with long, tortuous sentences that defy understanding even after multiple readings. The first half of the book, recounting Gajdusek's first years among the Fore, is poorly organized, contains unnecessary repetitions and sports a confusing chronology full of undeclared flashbacks. The book's sections dealing with the developments after Gajdusek received the Nobel Prize are more linear and much more readable.

The book satisfactorily accomplishes its 'edutainment' goal, but it is somewhat lacking as a reference work. Although each quote is laudably corroborated by a bibliographic footnote, all of those footnotes are relegated to the end of the book and their numbering is reset for each chapter, which makes them irritatingly cumbersome to find.

My largest problem with the book, however, stems from Anderson's singular and pervasive bioethical convictions. Anderson believes that Gajdusek committed a kind of original sin by appropriating and 'alienating' body fluids and autopsy materials from the Fore, then using the specimens to create a scientific network and to enhance his own scientific stature. Although Anderson takes care to refrain from stating this explicitly, the reader is unavoidably led to conclude that Gajdusek's alleged alienation of body parts represents a kind of sociopathy akin to his irresponsible sexual conduct.

Any author is certainly entitled to airing his views, but I couldn't disagree more with this alienation theory! I am not disputing the moral necessity of informed consent for research with donated organs and body fluids, but Anderson appears oblivious to society's legitimate expectation that medical progress be pursued. What he condemns as alienation is indeed standard operating procedure in any clinical pathology laboratory. Gajdusek set the stage for his own unraveling by indulging in his troubled sexuality and he paid dearly for his actions. To my eyes, however, Gajdusek's scientific accomplishments have no relation to those inexcusable acts: his identification of the cause of kuru represents a scientific monument that will greatly outlast him. ■