We see what we are trained to see, or must we? Some personal lessons from a brush with kuru research

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It began in 1957 when I received via a colleague a batch of sera from kuru patients and some controls from Carleton Gajdusek. I was immensely excited, as was Carleton, when I found a quite remarkable elevation of some $\alpha$ and $\beta$ globulin components in the kuru sera that seemed to be absent from the controls. However, our excitement cooled in the face of more data that indicated that the sera in question had come from very sick, malnourished people suffering from major intercurrent infections, decubitus ulcers and the like. That is, we were observing a reactive hyperglobulinaemia, an epiphenomenon rather than a finding central to kuru. My overreaction to the initial finding was almost certainly due to the fact that at the time I was very interested in the paraproteinaemias of myeloma and other malignancies of the immune system and was ready to put down our kuru findings to some unique dysproteinaemia. So, the first great lesson that dipping into kuru research taught me was that we see what we are trained to see.

In 1953, the anthropologists Ronald and Catherine Berndt thought that the disease reflected a hysterical reaction of the Fore people to existential threats to their lifestyle by the advent of Europeans in the Eastern Highlands. So, this was another example of scholars seeing what they were trained to see.

However, the kuru genetic hypothesis was the prime illustration of the dangers posed by a firmly held scientific viewpoint when held by an influential group. The first genealogies collected in the field showed that the disease had a strong family association and, in their scientific viewpoint when held by an influential group. The first genealogies collected in the field showed that the disease had a strong family association and, in their...
their impact on public opinion and the practicality of enforcement. About the same time, opposition to Carleton’s early return to the field was dropped. Again, the decision was based on pragmatism rather than principle. Carleton had the full support of the National Institutes of Health of Australia’s ‘great and powerful friend’ and it was becoming clear, even to the sceptics, that his energetically pursued multi-pronged approach offered the best chance of understanding this baffling disease. From then on, the Papua New Guinea Department of Public Health gave him every assistance, making a major local contribution to solving the problem in its own right.

The final lessons that I learnt from those early kuru years were that tightly held hypotheses and public policy were a dangerous mix and that bureaucratic decision makers and their advisers frequently favour expediency over principle. Although in the case of kuru the issues were simple enough for those of goodwill to negotiate a positive solution, in more complex situations such an approach has frequently ended in disaster. These lessons have stayed with me over a varied career that included some studies, independent of kuru, in Papua New Guinea and periods as a research programme manager in various settings in CSIRO.

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The expanded Laboratory of Collaborative and Field Research

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Along with David Asher and Richard Benfante, who also attended the End of Kuru conference, I spoke there as a member of the wandering and far-flung community of Carleton Gajdusek’s Bethesda Laboratory at the National Institutes of Health (NIH). I worked there, originally talking my way into a clerical job, despite having no particular qualifications, as a ‘social science analyst’ from 1967 to the mid-1970s; I tend to think of my job description throughout, however, as ‘handmaiden’. For years I worked on whatever came to hand, or whatever was thrust into my hands by Carleton. After I left the laboratory to go to graduate school in anthropology, I edited with Carleton the volume called Kuru: Correspondence and Field Notes from the Collection of D. Carleton Gajdusek. Since then I have been working on health and medicine in China as a social anthropologist, teaching and doing research in Chicago, North Carolina and Beijing.

Like many nostalgic historians and travellers who can claim many homes, like Carleton, even, I have a very partial, very personally motivated version of that place and time. Still, because Carleton, kuru, its scientists and the laboratory had such an important role in my own formation as a person, it interests me to ask: ‘What was kuru from the point of view of the laboratory? What kind of a place was the laboratory?’ My answers to these questions have become broader and vaguer over the years but my interest in understanding this past is no less intense than it ever was.

1. THE LABORATORY

We used to answer the phone, ‘Dr Gajdusek’s Office’, though the formal name was the Laboratory of Collaborative and Field Research. This moniker, which both over- and understated the mission of the research unit, signalled both the ambitions Carleton had for his own laboratory and the character it increasingly took on in the course of the 1960s, 1970s and 1980s. This laboratory was both a small set of physical sites, including (at times) two suites of rooms at NIH, a building at Fort Detrick and various animal facilities, and a node in a network of research activities. It would not be amiss to see the network itself, vast as it was, as both ‘Dr Gajdusek’s Office’ and the ‘Laboratory of Collaborative and Field Research’. The global coordination of kuru research, at least in the early years, could not be confined to the laboratory benches, file cabinets, photo archives and specimen collections of just a few sites in the USA. It could not even be limited to the community of scientists whose relations with each other—ranging from romances to resentments (and sometimes including both)—were so dependent on the work of the laboratory. I seem to recall periods of time in which Carleton had to fiercely defend to the NIH administration his conception of the work of our unit as collaborative and field based. The good scientific reasons why it was imperative to fund international travel for scientists (and, in the case of the Alpha Helix expedition, even handmaidens), as well as to support and transport, sometimes halfway around the world, field collections ranging from blood specimens to cinema films, had to be spelled out again and again.

As long as this vision of the scientific project succeeded, it had interesting results for those of us who mostly stayed in Bethesda. The Laboratory of Collaborative and Field Research accumulated an ever-thicker global network, instantiated in Carleton’s ‘Family and Friends’ list that for a time I helped to