

# Carlton Gajdusek & Kuru

## TEACHING NOTES

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### Overview

In the 1950s, a mysterious neurodegenerative disease called kuru appeared among the primitive Fore people of Papua New Guinea. Natives attributed it to sorcery. American D. Carlton Gajdusek conducted epidemiological studies among the remote tribe and later transmission studies in lab animals. He found that kuru was propagated by a “slow virus,” a new disease transmission type, a discovery for which he received a Nobel Prize. Decades later, Gajdusek's “slow virus” was identified as a prion. Gajdusek’s interactions with the Fore people and, later in his life, sexual relations with Fore boys raise many questions at the intersection of science, culture and ethics.

Major NOS elements include:

- posing problems
- research ethics
- science journalism
- interdisciplinary relationships & collective nature of discovery
- public image of scientists [supplemental activity]

## Visuals

- Kuru patient. [Caution: mature content/explicit suffering.]  
<http://www.youtube.com/watch?v=C8tmgpOiWRw>

Other supplemental videos are available online — menu and links to YouTube at <http://www.kuru-doco.com/video.html>:

- First Reports: introduction to Papua New Guinea and a strange disease. (1:07)  
<http://www.youtube.com/watch?v=5aDoAJG6Za0>  
excerpt from “Kuru: The Science and the Sorcery”
- Fore culture. (2:13)  
<http://www.youtube.com/watch?v=4-PgIW2n0Co>  
[archival footage by Gajdusek 1957-1962] daily activities among the Fore: a boy playing with a snake; a boy with bow and arrow; children at play; a man making the centre point to the roof of his house; a woman making a bilim (traditional string bag made from the fibre of bark of a tree); a woman beating the bark of a tree to make tapa cloth; various shots of males from neighbouring groups adorned in head dresses (a boy, a young man, and a man smoking a pipe); and a young boy playing with animals bladder for a toy.
- Sorcery. (2:23)  
[http://www.youtube.com/watch?v=CMmx6\\_fQ9h8](http://www.youtube.com/watch?v=CMmx6_fQ9h8)  
excerpt from “Kuru: The Science and the Sorcery”
- Colonial patrols. (3:17)  
<http://www.youtube.com/watch?v=TSihNlyXK9c>  
[archival footage by Gajdusek 1957-1962] pioneering patrols that helped to define the boundaries of the kuru region. The footage shows locals carrying cargo and medical supplies through the rugged and mountainous terrain, climbing steep descents and crossing dangerous rivers beyond the immediate kuru region.
- Fore Culture, Part 2: Cooking. (1:32)  
<http://www.youtube.com/watch?v=7QELV4mgLf8>  
[archival footage by Gajdusek 1957-1962]

## THINK Exercises

The primary purpose of these questions is for students to develop scientific thinking skills and to reflect explicitly on the nature of science. The questions are open ended, and the notes here are only guides about the possible diversity of responses. In many cases, there is actual history as a benchmark (which can be shared after the students' own work), but by no means does it indicate an exclusively "correct" answer. The teacher should encourage thoughtful responses, well articulated reasoning, and respectful dialogue among students with different ideas or perspectives.

### THINK (1)

The objective, in part, is to show that it is difficult to look for relevant information without some initial clues. The problem-solving strategy exhibited here is a deliberate form of trial and error (or blind variation and selection). Namely, by surveying all the possible causes of diseases, one can generate a list of the corresponding information that would be helpful. One does not know which information will be informative in advance; certain evidence helps "select" a corresponding cause from among the possibilities. (This is the same strategy used by the Centers for Disease Control, for example, whenever a new disease appears [such as AIDS, SARS, H1N1].) Examples:

| <u>Suspect Cause</u> | <u>Information Needed</u>   |
|----------------------|---|
| genetic?             | pedigrees   |
| infectious agent?    | group epidemiology; blood serum (antibodies);<br>inflammation                         |
| —bacterium?          | trial of antibiotics  |
| —virus?              | fever   |
| parasite?            | white blood cell counts (esp. eosinophils)  |
| diet?                | food sources, cooking techniques  |
| sorcery?(!)          | ?   |
| psychosomatic?       | psychological contexts  |
| metal poisoning?     | analysis of food and samples of blood, urine,<br>cerebrospinal fluid or other tissues |
| toxins               | analysis of leaves that are smoked & pigments that are<br>painted on body             |
| plant toxins?*       | plant samples   |
| insects?*            | insect samples  |

\*suggested in 1956 by a consulting medical officer in Melbourne, Australia

If a student suggest prions, one may acknowledge the idea as an appropriate extension to the list, while noting that in 1957, no one yet knew anything about such rare diseases.

Many of these causes and types of information become relevant as the narrative unfolds — occasions to recall and validate individual student's contributions.

**THINK (2)**

Student answers will vary. Reflecting on the problem helps prime appreciation of the challenges that Gajdusek faced, described in the narrative to follow.

**THINK (3)**

This question assumes the current principle of informed consent, which may be explained as needed. That principle itself might be open to discussion. This case also illustrates some of the practical limits of informed consent. Discussion should consider alternatives and possible creative solutions, and not be limited merely to voicing positions or the reasons for them.

**THINK (4)**

A primary principle relevant here is respect for persons (versus “instrumental” use of others): namely, treating others as ends in themselves, not merely as a means to an end. Gajdusek’s motives and perspectives are profiled in the text that follows.

**THINK (5)**

As an imaginative exercise, a wide spectrum of responses is possible, although each should be “plausible.”

**THINK (6)**

Some of the differences include:

| <u>Time</u>         | <u>Historical Comment</u>  |
|---------------------|--|
| “laughing death”    | sensationalizes disease by focusing on only one peripheral symptom, exaggerates for drama, tends to trivialize suffering in another culture    |
| “maniacal laughter” |  |
| “roaring laughter”  |  |
| “one body, one ax”  | hides difficult ethical issues, oversimplifies, reduces inter-cultural exchange to economics, trivializes research by comparing it to shopping |
| “haggle”            |  |
| “bargain price”     |  |
| “he”                | typical patients (over half) are women   |
| tukavu stories      | irrelevant to the disease, sensationalizes foreign culture   |

**THINK (7)**

Discussion should highlight, first, that research involves resources. Costs, especially in animal research, may limit idealized investigations. Second, ethical considerations, by themselves, and scientific or intellectual values, by themselves,

may each indicate different actions. Creative solutions that accommodate both sets of values (rather than strike a “compromise”) should be encouraged.

The role of replicates, or sample size, may be introduced, as needed.

An important principle — developed well after these studies were done — is that animal research is acceptable only when other animals (conspecifics, not merely humans) may benefit from the research.

In recollections, Michael Alpers speaks very fondly of the chimpanzees in the experiments:

We spent a lot of time together in the company of Georgette and Daisey—and Joanna . . . and, indeed, all the other inoculated chimpanzees in the unit. (Alpers 2008)

He notes that the chimps were named and that, accordingly, each of their names, as well as the names of the Fore who donated tissue, are respectfully acknowledged in the published papers (Alpers 2008). Also see image of researcher David Asher with chimps: <http://rstb.royalsocietypublishing.org/content/363/1510/3618.2/F3.expansion.html>

**THINK (8).**

Answers will vary widely. Encourage students to think concretely and invite elaboration of specifics or details where appropriate. It may be fruitful to remind students that Westerners have not gotten kuru.

**THINK (9).**

As profiled in the case study here, one may include:

| <u>Individual</u>          | <u>Field/Expertise</u>    | <u>Contribution</u>                         |
|----------------------------|---------------------------|---|
| Jack Baker and others      | patrol officers           | originally noticed kuru                     |
| Carleton Gajdusek          | virology, outdoorsman     | epidemiology, leadership                    |
| Lucy Hamilton Reid         | nutrition                 | ruling out diet                             |
| [unnamed]                  | genetics                  | pedigree analysis                           |
| Fore assistants            | local Fore knowledge      | surveyed territory, collected samples, etc. |
| Joe Gibbs & Michael Alpers | laboratory virology       | transmission expts.                         |
| William Hadlow             | veterinary medicine       | vital clue about transmission               |
| Bob & Shirley Glasse       | anthropologists           | data on cannibalism                         |
| Stanley Prusiner           | biochemistry/molec. biol. | “slow virus” as prion                       |

Lucy Hamilton Reid, who had done the nutrition studies, acknowledged that she had not discovered any cause for kuru, but her testimony is valuable: “Overall, in my work, I indispensable disproved some of the negative ‘causes’ of kuru, thus enabling Dr. Carleton Gajdusek to score his deserved Nobel Prize!” (Reid 2008, p. 3659)

Shilrey Lindenbaum (formerly Shirley Glasse) was likewise explicit about the role of anthropology:

“To understand kuru and solve problem of its cause and transmission required the integration of knowledge from both anthropological and medical research” (Lindenbaum 2008, p. 3715).

Members of the Fore who helped to survey the territory, collect and deliver samples, conduct autopsies, etc., are also proud of their contributions (Collinge & Alpers, 2008).

Take Gomea recalls:

When we patrolled with Carleton it was under difficult conditions; we had to climb mountains and cross fast-flowing rivers. When we approached some villages they tried to chase us away, threatening us with their bows and arrows. We would placate them by giving them salt and other small presents.

... I really wanted kuru to stop and that is why I was happy to work so hard. (pp. 3643-44)

Inamba Kivita recalls:

I worked with Shirley Lindenbaum when she came to live in our village, and I helped Michael Alpers with his research. I was asked to work as a translator, also to assist with the fieldwork and carry personal things like camera, books and film. The older men carried the heavy boxes from one village to another on kuru surveillance patrols.

There were other medical scientific officers who came later with whom I worked as well, such as Dr Hornabrook and John Mathews. I was trained by them to perform autopsies on kuru dead bodies. Though my position with the project was as a translator, sometimes it was my duty to take human samples collected from the field to Goroka by plane from Tarabo airstrip and return back to the field by the same route. (p. 3646)

Tiu Pekiyeva recalls:

I was approximately 12 years old living in Agakamatasa village when Dr Carleton Gajdusek came and stayed with us in the village. I was selected by Carleton among other boys to help him take photographs of the village and the people. We toured other provinces and visited Lae, Madang, Rabaul, Hoskins, Chimbu and Mt Hagen in search of kuru disease but we found nothing. We settled down in South Fore and worked. When a field reporter informed us of a new kuru patient, I used to go out and collect samples and take them to Okapa to be sent to the United States. (p. 3653)

Koiye Tasa recalls:

I was less than 10 years old when Dr Carleton Gajdusek came into the Purosa Valley to carry out his research on kuru disease. Michael Alpers came after him and I worked alongside them to patrol out into the villages that were affected by kuru. My job was mainly to accompany Carleton and assist in collecting kuru patients' samples and diagnosing their disease. I also worked

as a kuru surveillance officer and went on my own into the villages to locate kuru patients. Sometimes, I was given the task by Carleton of transporting brain tissue and other selected internal organs to Kainantu station by tractor or Landrover. (p. 3671)

Wandagi H Pako described some of his responsibilities as an assistant:

1. Arrange field patrols for kuru surveillance of villages in remote parts of the kuru-affected region every quarter and prepare a report.
2. Assist Jerome Whitfield in conducting interviews on the cultural and mortuary practices of the Atigina and Pamusagina people.
3. Diagnose and film suspected kuru patients and compile reports for Jerome and Michael Alpers.
4. Check and regularly report on the sickness status of suspected kuru patients.
5. Transcribe recorded tapes from the Fore language into English. (p. 3652)

## THINK (9)

One may help students recall relevant information:

- posing problems
  - mounting investigation of any disease; facilitating role of hypotheses (even if later incorrect)
  - [supplemental: hypotheses for gender and age distribution]
  - in transmission study, determining type of animal, type of tissue, number of samples
  - response to failure in initial transmission experiments
  - further studies, based on knowledge of “slow virus” transmission
- research ethics
  - cross-cultural challenges; paternalism
  - compensation for samples; informed consent
  - Gajusek’s adoption practice
  - use of animals in transmission studies (mice, monkeys, sheep)
- science journalism
  - *Time* magazine article
  - possibly TV documentaries
  - modern accounts on the Internet may be explored
- interdisciplinary relationships and collective nature of discovery
  - see notes for THINK (8).

## Review

One aim is to keep the discussion focused on the concrete details of the case, even if general ethical principles are invoked. Many of the appropriate questions for highlighting relevant information are provided in the text.