

# Chapter 2

## Anthropological Methods Used in Kuru Research

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### Abstract

This historical account of the methods used by anthropologists studying kuru from 1961 to 2010 illustrates the identity of anthropology as both a humanist and natural science. To understand and analyze complex historical processes anthropologists employ both interpretive and explanatory research methods. This chapter documents the emergence of medical anthropology as a subfield in anthropology, changes that have taken place in the collaborative relations between anthropology and medicine, and importance of the political context in Papua New Guinea, all of which have had an impact on the research methods of anthropologists and medical investigators. Fore forms of health care have also changed as local therapists adopt some aspects of biomedicine while retaining a belief that sorcerers cause illness and death, a theory that supports their own methods of investigation.

**Key words** Anthropology, Humanism, Natural science, Medical anthropology, History, Kuru, Papua New Guinea

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### 1 Introduction

In 1964 the distinguished anthropologist Eric Wolf described anthropology as the most scientific of the humanities, and the most humanist of the sciences, an assessment that holds true for a discipline that has emerged from a century of ethnographic and theoretical work. As a natural science, Wolf noted that anthropology is concerned with the organization and function of matter; as a humanistic discipline it is concerned with the organization and function of mind. Anthropologists thus mediate between human biology and ecology on the one hand, and the study of human understanding on the other. As both observers and participants in the internal dialogues of informants, anthropology is less subject matter than a bond between subject matters, and the anthropologist translates from one realm to the other [1].

Anthropologists who specialize in cultural anthropology, and who form the majority, are likely to have studied physical anthropology, archaeology, and linguistics, the hallmark of the “four-field”

approach in American anthropology. The breadth of training in human biology and social life, and the range of cultures past and present, equips them to make general statements about the human condition, as well as to understand human differences and human possibilities. Wary of Western “objective” research instruments, the anthropological search for meaning places them closer to history, which also explores phenomena as unique, and seeks to interpret them. The charge to generalize and to theorize, however, situates anthropology equally in the social sciences [2].

Anthropologists choose research methods appropriate for the topic and the question. Their methods include recording genealogies and mapping households and gardens. They collect data on particular issues using statistical samples, and provide more descriptive accounts on such matters as rituals, myths, gender, sexuality, health and illness, and use of plants. The most widely recognized form of anthropological research, called fieldwork, involves observing, documenting, and participating in day-to-day community life, to the degree that this is possible. This method of anthropological research applies equally to observing and examining the cultural beliefs and practices of the many actors encountered in the contemporary world. The archives provide a rich source for historical and comparative material.

Current research often requires understanding the worldwide networks of places linked to many field sites, although the anthropologist does not necessarily reside in all of them. Anthropologists record their observations and findings in notebooks and laptops. They use tape recorders, cameras, and video equipment, and keep a daily diary to record the sequence of events, and for personal reflections. With the help of interpreters they record and translate interviews, and ideally become fluent speakers of local languages. Those who work in Papua New Guinea speak Melanesian pidgin, allowing them to communicate across many linguistic boundaries. While living with people in their own communities for long periods of time, initial research usually lasts for at least a year, followed in many cases by one or more return visits lasting for shorter periods. Many anthropologists now communicate by cell phone with village friends and former research assistants, and sometimes by e-mail with those who have access to computers.

In recent years static accounts of social arrangements and cultural beliefs have been displaced by an appreciation of dynamic change. Anthropologists have moved away from an interest in the uniqueness and diversity of local cultures toward the study of regional organizations and historical processes. They look increasingly at the cultural formations of urban areas and nation states, and at transnational and global processes. The tribes and peasants of the world are seen to be responding to the variety of global institutions, ideas, and diseases that shape the experience of per-

sonal and collective life. Anthropologists often become advocates for indigenous people, a commitment that grows organically from an anthropology that gives voice to those whose opinions are rarely heard. As the world changes, analytical frameworks are updated, and most departments now teach a course in the history of anthropological theory. A number of subfields have also emerged. Ecological anthropologists, for example, study relationships among humans, animals, and their biophysical environments. Medical anthropologists study how health and illnesses are shaped, experienced, and understood in the context of global, historical, and political forces. They engage also with issues in biomedicine, once called Western medicine. As a product of the West, biomedicine, like all forms of medical knowledge and practice, takes form in a particular historical, social, and cultural context. Its assumed universalism is thus questioned.

Anthropologists are trained to interrogate their own cultural assumptions and biases. They are also aware that their own presence can influence the processes they seek to observe. The American Anthropological Association ([www.aaanet.org](http://www.aaanet.org)) provides a Code of Ethics for the conduct expected of anthropologists as they undertake their research, as well as information about the range of subfields and associated journals sponsored by the Association.

The story of anthropological research methods that follows draws attention to two “phases” of research associated with kuru. The first describes the topics, questions, and methods that Robert Glasse and I employed from 1961 to 1963, and those I used during a number of short field trips between 1970 and 2008. The second describes the topics, questions, and methods used by the anthropologist Jerome Whitfield from 1996 to 2010.

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## 2 Phase One

Early medical investigations of kuru were hampered by the lack of information about Fore social life, especially kinship. In 1961, Robert Glasse and I were sent to collect this data, supported by a grant from the Department of Genetics, Adelaide University. We chose to live in Wanitabe, a South Fore community in the Eastern Highlands, which had the highest reported incidence of the disease. Our focus on Fore kinship led us to question the genetic hypothesis current at the time. We had been charged to collect “pedigrees,” not “genealogies,” the latter an anthropological term that acknowledges notions of relatedness that are subject to historical and cultural construction. Our genealogies showed that many of the supposedly closely related kuru victims were not closely related biologically, but were kin in what we would call a social sense.

The process of acquiring and assembling genealogical information occupied much of our time during the first months in the field. We began by recording information from what we determined to be the largest locally recognized group of people at Wanitabe to form a distinct political and spatial entity, which we called a parish. This population of 350 people in 1962 was composed of 7 patrilineal lineages, which the Fore called *lounnei*, or lines, and which were considered to be united by notions of patrilineal descent. The Fore lack of concern for strict descent reckoning, however, was manifest in the linguistic distinctions they made about Wanitabe co-residents, who were defined as *magō kina*, ground source people, or original residents (k/gina suffix = people), *tubagina*, people who gather, that is, immigrants, and *aguya gina*, those who have been beaten, or war refugees. Immigrants and refugees were welcomed as long as they demonstrated loyalty and observed their new social obligations. In time, the newcomers were said to possess “one blood” and a common ancestry, conveying the idea that those who reside and act together, and eat food grown on the same land, share bodily substance. Descent was a symbol of unity for a coalition of people with shared social and political interests.

In addition, childless couples could adopt an infant from another lineage family, and kinship could be “created” or “generated” in food-sharing ceremonies with people who had no recognized consanguineal ties. Held in the early afternoon, a time of day called the *kagi-nei* (nei suffix = the), the new kin were referred to as *kagi-sa-kina*, ceremonially created or “fictional” kin. Such flexibility in kinship definition meant that lines of cleavage could undermine unity, finding expression in accusations of sorcery and the emigration of lineage groups settling in distant locations. These two features, fictional kinship and population mobility, had relevance for the distribution of a disease thought to be based on a close breeding unit and a simple genetic factor.

Our genealogies recorded kinship two generations above the adult male being interviewed (the characteristic depth of Fore kinship memory), the informant’s marriages, as well as those of his siblings and all their descendants, including infant deaths. We also interviewed women, but adult women often came from other local groups at the time of marriage, and although they had their own kin networks, they were unable to provide extensive knowledge of the relationships we were investigating. Robert and I first recorded the information in 1961 and 1962, and I brought them up to date in 1993 and 1996. Our genealogies recorded a wide range of data: male and female kuru deaths, male deaths from warfare, other deaths and their causes defined by the Fore, the exodus of women at the time of marriage and of men for employment, as well as religious affiliation (Open Bible, Seventh Day Adventist, Salvation

Army, or no affiliation). Additional information included the form of marriage from the male point of view: matrilineal cross cousins (mother's brother's daughter) the preferred form, more distant maternal cousins, and those said to be unrelated, as well as children's level of education. To make reading easier, the genealogies were color-coded.

The genealogy provided here (Fig. 1) is a simplified version of page 6 of 70 pages for Wanitabe parish. MANOVA, identified in line one as our main informant in this case was about 70 years old in 1961. The genealogy illustrates the gendered and generational impact of the epidemic. In-filled circles represent female kuru deaths, triangles represent men. Cannibalism ended in 1960, and no one born since that time has come down with the disease. The last case of kuru occurred in 2009, but as this genealogy shows, the epidemic was waning in 1996, and the population was increasing. Fewer men were dying during warfare, a significant cause of death still present in Manova's generation, with brothers inheriting the wives. A government clinic was now providing health care that included vaccinations for infants. All the children in the third generation were attending primary school, grades two to six, and only one child had died, one of Manova's great grand-daughters. The note in the right margin indicates that further information about this particular genealogy could be found on page 7.

Fore genealogical knowledge, like that of most Eastern Highlanders, is shallow. Hearing about my genealogical enquiries in 1996, some men from outside Wanitabe asked for their grandfather's names to bestow on their children. One interesting feature of our focus on where wives came from meant that we could provide a statistical estimate of the degree to which marriages were endogamous (marriage within Wanitabe) or exogamous (outside Wanitabe). Arrows in Fig. 1 show the exodus of women at marriage. The genealogy reveals the high frequency of endogamous marriage on the one hand, and the wide dispersion of exogamous marriage on the other, evidence of a high rate of gene flow within and between Wanitabe and other local groups, as well as a multitude of channels for interacting with many other groups [3].

The process of taking genealogies often attracted a small group of interested male participants (the women were busy working in the gardens). The men helped to document, and sometimes correct, the detailed data we were recording, which was enriched by spontaneous accounts of local politics and military victories over aggressive neighbors, as well as insight into local values, such as the way the hunting abilities of certain men made them attractive to women, or the psychodynamics of gender formation, when as youths they overcame the pain, terrors, and hardships of male initiation. These long genealogy-recording sessions proved to be a rich source of unsolicited ethnographic and historical information

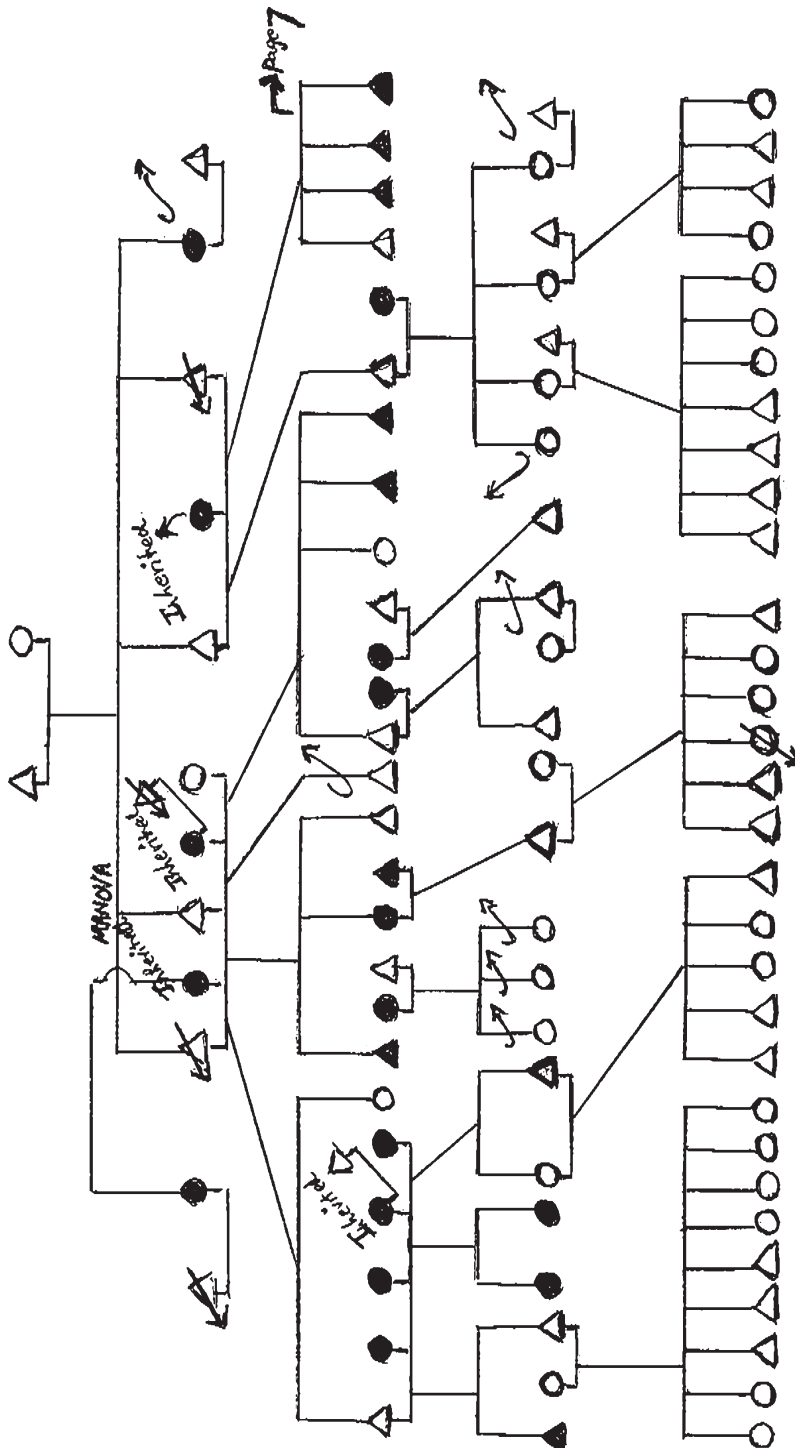


Fig. 1 Genealogy of a Wantabe lineage in 1996 showing the gendered and generational impact of the epidemic

on many seemingly unrelated topics, and illustrate the often indirect anthropological method of collecting and interpreting data.

In addition to gaining an understanding of local concepts of kinship and marriage, our early investigations focused on kuru. We were surprised when people at Wanitabe said that kuru was a new disease, and that they could remember the first cases of the disease in their own and in neighboring communities. With several Fore research assistants we spent several weeks visiting Fore hamlets from the south to the north, and into the borderlands of the neighboring Keiagana, a different linguistic and cultural group, gathering accounts of “first sightings.” We conducted interviews in Melanesian pidgin, our research assistants providing translations of Fore and other local languages. These oral histories showed that the Fore understood kuru to be of recent origin. Their stories depicted an epidemic that had spread within recent memory, emerging on the North Fore border around the turn of the century, and then spreading south along a traceable route until it reached Wanitabe and further south in the early 1930s [4]. This finding was a second challenge to the Mendelian model of genetics, which assumed that the disease was of remote evolutionary origin, and that it ought to have been in epidemiological equilibrium. However, as John Mathews, a medical investigator studying kuru, observed, the disease was too common and too fatal to be a purely genetic disorder, unless the hypothetical kuru gene was maintained at high frequency by a mechanism of balanced polymorphism. There was no evidence to support this latter suggestion [5]. Mathew’s speculation would be shown to be relevant in the later identification of a human prion protein gene imposing strong balancing selection on the Fore population during the kuru epidemic.

The people we interviewed also said that those who died of kuru had been consumed. Before we began fieldwork we had read anthropological accounts of cannibalism in the Eastern Highlands, particularly among the Fore [6]. We collected more detailed information about the Fore practice and learned that all body parts were eaten, except the gallbladder, which was considered too bitter. Significantly, not all Fore were cannibals. Some elderly men rarely ate human flesh, but small children residing with their mothers ate what their mothers gave them. Youths who were initiated around the age of 9 or 10 moved to the men’s house, where they began to observe the cultural practices and dietary regimes that defined masculinity. Consuming the dead was considered appropriate for adult women and small children, but not adult men, who feared the pollution and physical depletion associated with eating a corpse, especially that of a woman. Body parts were not distributed randomly, but were consumed by particular kin. We compiled tables to illustrate the different customary rights, defined by kinship, to consume a male or a female corpse [3].

In 1957, Carleton Gajdusek and Vincent Zigas had published two articles in which they referred to kuru as a disease new to Western medicine [7, 8]. The articles noted the high incidence of kuru in certain families and hamlets, its localization to the Fore and adjacent peoples with whom they intermarried, and the predilection for children and adult women. This epidemiological data seemed to match Fore rules for human consumption. Robert wrote about this in our 1962 and 1963 fieldwork reports to John Gunther, the Director of Public Health, the institute that had funded our second year of research [9, 10]. In 1967 Robert then presented the case for cannibalism to the Division of Anthropology at the New York Academy of Sciences [11].

Our reports were initially viewed with skepticism by many medical investigators and some anthropologists. John Mathews, however, embraced and further investigated our findings. His mathematical analysis of our genealogies [12] confirmed that kuru was of limited time depth, and that the genetic theory proposed by the geneticists was probably wrong. In 1968 Robert and I joined Mathews in a publication that would reach a wider medical audience [13]. This paper showed that the cannibalism hypothesis was supported by a wealth of epidemiological and ethnographic data consistent with Fore stories about named individuals who had taken part in mortuary feasts, and who had themselves died of kuru, and predicted what was likely to happen if the cannibalism theory was true.

A key focus of medical anthropology concerns the ways in which local populations experience, understand, and respond to illness and death, and the historical context in which this occurs. The late 1950s and early 1960s were crisis years for the Fore. The marital histories of Wanitabe men that we recorded in 1962 showed that they had contracted 76 marriages, or one-and-a-half per man. Two marriages had ended in divorce, and 45 with the death of the wife, 40 of them from kuru [4]. At that time, the motherless nuclear family was a common domestic unit.

When we first arrived in the South Fore in 1961, however, we were surprised by the absence of kuru victims. We learned that between April and August 1961, over 70 kuru victims had recently walked or were carried to Uvai, a community of Gimi-speaking peoples on the other side of the Yani river, where a Gimi therapist was said to be providing a cure for kuru. With our interpreters and a small team of Fore men carrying our equipment and food supplies, we followed the path of the pilgrims to Uvai. For over a week we observed and interviewed the patients and their relatives, as well as the Gimi therapist and his assistants, and then returned to Wanitabe traveling slowly through Fore villages where we interviewed returned patients who were still alive. In the following months, the Gimi therapist and his assistants visited the South Fore



to provide follow-up treatments, which we witnessed and photographed. Forest medicines and bloodletting sessions were used again, but the therapist now alluded to the identity of the sorcerer, ambiguously suggesting his place of residence.

As kuru victims continued to die, however, the Fore were aware that they faced a demographic emergency, the dimensions of which they grasped clearly. From November 1962 to the end of March 1963, they held public meetings in different parishes to demand the outlawing of kuru sorcery, and to repair the sexual imbalance that was affecting daily life. Speakers declared that sorcerers had exceeded all moral boundaries, ignoring the limits they placed on their own behaviors during warfare. The ritualized meetings, a Fore method for investigating and stamping out the disease, provided a forum for reviewing mutual suspicions and hostilities, and a public arena for confession, expressions of self-denigration, and a concern that the colonial administration would consider them to be the guilty actors. To the often-expressed fear of extinction from the loss of women's reproductive powers, they now added the fear of internal disruption so great that the bonds that had long held them together were themselves endangered. Robert and I attended and recorded the meetings, and discussed them later with several speakers who came to our field house to register their own views [4].

In the 1960s anthropologists renewed an interest in the analysis of myths, rituals, and symbolism. Victor Turner's accounts of the ritual response to severe misfortune among the Ndembu in Africa provided comparative material for analyzing these Fore rituals in which common values were similarly stressed, as were the confessions of guilt by those who felt they had broken some norm governing the intercourse of the living with the dead, allowing individuals to purge themselves of rebellious wishes and emotions [14].

In short field trips between 1970 and 2008, I continued to document economic, political, and social changes taking place in the South Fore, particularly after Independence in 1975, showing how the changes had affected the way Fore now spoke about the epidemic and its causation. A particular challenge was how to explain the decline and apparent disappearance of the disease that had once endangered their survival. By the 1990s most people said that kuru had decreased with the arrival of Christianity, the school, and the market, a set of coherences that seemed causal, and that kuru would disappear when the last of the generation of elders had died, taking with them knowledge of the sorcery that had caused the epidemic. The Fore did not assume, as many scholars have supposed, that all belief in sorcery and witchcraft would end with "modernization" and modern science. This has not been the case in Papua New Guinea or elsewhere in the world [15]. The Fore

still thought that kuru sorcerers caused kuru, but had turned to more profitable ventures, and they described a new form of sorcery coming to them from their Gimi neighbors. They were correct, however, in their historical observation that “modernity” had a place in ridding them of kuru. As a result of their encounters with the messengers of modernity, the missionaries and colonial administrators, who spoke out against cannibalism, which they viewed as a perversion and legal offense, the Fore gradually gave up the practice. At that time, the Fore, the missionaries, and government officers saw no relationship between kuru and the consumption of deceased relatives, but all three had unwittingly halted the transmission of the disease. New therapists had also begun to displace the local practitioners who had once provided cures for kuru. This new generation treated gonorrhea, syphilis, chlamydia, cancer, and AIDS, and they continued to use medicines from forest plants and trees, their identity no longer revealed in dreams, but in visions sent by God. Some of them took their medicines to be tested in biomedical institutes. In their view, the efficacy of their treatments did not depend on biomedical assessment, but on the foundations of Fore knowledge: visible proof, the power of spirits beings, and the authority of a Christian God.

As we see, the Fore now have access to two forms of medicine, which are not seen as incompatible, one based on their own understandings of the natural world, the anatomical self, and the world of social and spiritual relations, and the other on biomedical treatments provided by the local government clinic. Ethnographic accounts of health care elsewhere in the world provide similar reports of the integration of these two therapeutic modes.

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### 3 Phase Two

The second phase of anthropological research takes place in a historical context in which the relationship between medicine and anthropology had changed. Kuru research in Phase Two is also carried out in a new political environment, following Papua New Guinea Independence in 1975.

Anthropological research in Phase One had begun during the 1960s, before medical anthropology was a recognized field of anthropological study. The Society for Medical Anthropology was formed in 1972, and its impact was not apparent until the 1980s, when the AIDS epidemic began to draw many anthropologists to study health and illness. In 1988, the Wenner Gren Foundation sponsored a conference to examine the historical development of medical anthropology, and to consider the directions in which it was headed [16]. By 2001, the Society for Medical Anthropology had become second largest Section (of 40 Sections) in the American

Anthropological Association. Medical anthropology is now taught in many departments of anthropology. Anthropologists also teach in medical schools, and some are members of multidisciplinary research teams, as kuru research Phase Two illustrates.

With the appearance of bovine spongiform encephalopathy (BSE) in the United Kingdom in 1986, and the identification of variant Creutzfeldt-Jakob disease, the kuru epidemic had acquired a new global relevance. The (MRC) Prion Institute in London established a research outpost at Waisa, a South Fore community, about an hour's walk from Wanitabe, where the Papua New Guinea Institute of Medical Research, under the direction of Michael Alpers, had a research base. The Institute's old research house at Waisa was refurbished and made liveable, equipped with solar power for lighting and recharging batteries. A small laboratory for the fractionation and freezing of blood samples was built and fully equipped with lighting, water supplies, a hand-powered centrifuge, and a  $-40^{\circ}\text{C}$  freezer. A specially adapted Land Rover to support the project was shipped from the United Kingdom, and a helicopter landing pad area was cleared for the use of charter helicopters when road conditions were hazardous or impractical. The Institute of Medicine in Goroka (IMR) provided the project with office space and administrative support. John Collinge, the Director of the London Prion Unit, made annual visits, and other members of the Unit occasionally visited the field site.

The Unit's scientific objectives were "to identify and study all the remaining kuru patients, and document the maximum inoculation periods; to provide further data for accurate epidemiological modeling of the kuru epidemic to estimate key epidemic parameters and traditional beliefs of the aetiology of kuru by interviewing surviving participants and other members of the Fore community; to study the clinical features of the current kuru patients and to compare clinical and other diagnostic features with other human prion diseases, notably iatrogenic and variant CJD; to investigate any evidence of maternal or other routes of kuru transmission; to identify genetic susceptibility factors to kuru by study of recent patients and archived samples, long-term survivors of multiple feast exposures and the normal Fore and adjacent (exposed and unexposed) populations; to study the peripheral pathogenesis of kuru and tissue distribution of infectivity; and investigate the possibility of sub-clinical prion infection by analysis of autopsy tissues from patients and elderly exposed, but clinically unaffected individuals" [17]. Jerome Whitfield, an anthropologist with a Diploma in Nursing and a background in emergency and tropical medicine, was recruited to assist in carrying out many of the program's social and scientific objectives.

Whitfield arrived in Papua New Guinea in 1996 to begin research on the anthropological and medical dimensions of this

multidisciplinary project. With a local field staff of 14 young men, he lived and worked in the South Fore for 7 years, and then visited for a further seven. To update and keep track of the epidemic, ten “kuru reporters” in the field team were responsible for identifying kuru cases in their home locations. Whitfield and several team members then visited the family, and with the family’s consent, Whitfield examined the patient, took a case history, and made a neurological examination, which was filmed and sent to Alpers and Collinge for verification. If they were available, Alpers or Collinge would visit the patient. This method of surveillance documented all cases of kuru from 1996 to 2010; one local reporter continued to provide information until 2012, when the project ended.

Six months into fieldwork, Whitfield began to collect blood samples. Sometimes assisted by IMR nursing staff, Jerome and the team collected blood samples from 3322 individuals in the kuru-affected region, and another 984 from surrounding linguistic groups (Gimi, Keiagana, Kanite, Yagaria, Yate, Kamano, Auyana, Awa, and Usurufa). Where blood sampling was of little benefit to the health of participants, they introduced malaria and anemia screening, and with the results in hand, Whitfield and the team returned to the village to treat those with malaria and anemia. Genealogical information associated with each blood sample, such as language group, place of birth, and ancestral group names, was recorded. In some cases the genealogies resulted only in the names of parents and children; in others, the information included the names of grandparents or occasionally great-grandparents and their children. Adoptions were recorded when this was common knowledge, as well as the names of second and third wives, or husbands. Fore age estimates were calculated based on a chronology of local events; non-Fore age estimates for other populations in the Eastern Highlands, taken from government census data, were less complete. Genealogical data associated with blood samples in populations not affected by kuru consisted mostly of father’s name, mother’s name, village, and language group. Initially logged in field books, the data are now digitalized, allowing the information to be linked readily to the blood donor. The field books were also copied and entered into the Prion Unit database [18].

This body of data contributed to a number of important medical findings. In 2003, some elderly women known to have consumed deceased kin were shown to have a distinct genetic type of prion protein gene (heterozygous at position 129), which provided protection against kuru as a result of exposure to the prion infectious agent, in keeping with balancing selection. Global patterns of diversity in the same gene suggest that European populations show similar, but older, evidence of selection and survival advantage as a result of presumed endocannibalism and prion-related epidemics in the past [19]. In 2009, with data from a larger sample of the

Eastern Highlands' material, the medical investigators located a novel variant of the prion protein gene (at position 127), again in elderly women survivors of the epidemic, which was also a powerful acquired prion-disease resistance factor [20]. And in June 2015, the Unit reported that the amino acid change that occurs at codon 127 (127 V), replacing a glycine with a valine, had a different and more powerful effect than the substitution at codon 129 (129 M). Transgenic mice with the codon 127 mutation were completely resistant to kuru and Creutzfeldt-Jakob disease (CJD). The selection of a single genetic change which occurred during the kuru epidemic is said to provide a striking example of Darwinian evolution in humans. While the collapse of the Fore population was prevented by the cessation of endocannibalism in the late 1950s, this new data suggested that if transmission had continued, the epicenter of the affected region in the South Fore might have been repopulated with kuru-resistant individuals in a population genetic response to the epidemic [21].

With the earlier anthropological hypothesis that kuru was transmitted by cannibalism now accepted, Whitfield was charged with providing further information about Fore mortuary practices that might have relevance for the changing epidemiological patterns of the disease. This ethnographic research had one novel methodological addition: two Fore members of the research team initially interviewed their own family members about the beliefs and practices of mortuary cannibalism in order to test the feasibility of the study. With this established, unstructured interviews were followed by larger group discussions with many of the team members' elders. The members of the team had not undergone initiation, where this information would have been transmitted, and thus had no knowledge of beliefs and practices that had ended in the 1960s, and like their elders, they now considered themselves to be Christians. As the elders confirmed, information about mortuary cannibalism had been kept secret from the younger generation and from most outsiders. Conducted in the Fore language, the interviews were translated into pidgin and back again into Fore, to ensure the accuracy of translation.

Spreading out from Waisa, Whitfield and several team members interviewed 65 men and 11 women in 20 different villages, the gender imbalance reflecting the death of women as a result of kuru. Although adult males did not participate in eating the dead, the elders had participated in, or had witnessed, mortuary feasts as children. The interviews focused on concepts and behaviors associated with body, the soul, and the mourners, the three dimensions identified in Robert Hertz' legendary contribution to the sociological study of death, first published in 1907 [22]. This provided a template for Whitfield's analysis of traditional mortuary ceremonies

among the Fore and in nearby Eastern Highland populations where cannibalism had once been practiced [23].

Postcolonial Papua New Guinea in the late 1990s, with its heightened sense of nationalism, presented a difficult political environment for the Prion Unit's investigations. Sensitive to these conditions, Whitfield had been charged with establishing and maintaining contact with local communities, continuing a legacy of the reciprocal interactions and obligations established earlier by anthropologists and medical investigators, which had consisted mainly of gifts and support to individuals and families. (My fieldwork obligations during the 1990s also expanded to include contributions to an education fund to pay school fees for South Fore children, and toward construction of a new elementary school at Wanitabe.)

With his medical qualifications Whitfield could assist in providing health care to communities in the project. This support, of necessity, differed from the "community medicine" adopted elsewhere in the Eastern Highlands, in which epidemiological studies could identify the causative factors in illness and death, such as the consumption of contaminated pork during local festivals that resulted in a form of food poisoning called *enteritis necroticans* (pig-bel in pidgin). The epidemiologist could then work to alter dietary behaviors to prevent occurrence of the disease, and to introduce economic development (such as smoke houses) to sustain the change [24]. The behaviors causing kuru, however, had already changed, the epidemic was ending, and the Prion Unit wished to undertake research that could promise no apparent future benefit. Instead, responding to local requests for assistance, the Unit provided the local health center with medicines when clinic supplies ran out, evacuated patients by car or helicopter to the hospital in Goroka, and, in collaboration with Save the Children Fund, initiated a village birth attendant program. The field team, led by Whitfield, also held medical clinics in remote areas, and provided malaria and anemia screening and treatment in low-lying villages affected by malaria, assisted at times by nursing staff from the Institute of Medicine. Outside funding was gained to provide water supplies for the local marketplace, and in a number of villages, for the construction of primary schools. When the last kuru autopsy took place in 2003 (carried out by an Eastern Highlander), and with the agreement and cooperation of the extended family, a compensation payment was made for the future education of the family's children. The "End of Kuru" conference, held in London in 2007, was attended by 15 Papua New Guineans, 12 of them Fore. Several of them provided testimonies of their own memories and experience [25].

## 4 Discussion

This historical account of anthropological research methods associated with kuru can be read in several ways. It demonstrates the similarity and variety of the research methods anthropologists deployed in Phases One and Two: recording customary rules associated with kinship, marriage and the consumption of the dead; a focus on ritual behaviors, observed or recalled; maintaining a field base at a specific location and gathering data from a wide area; and working with research assistants to interpret Fore and other languages to enhance an understanding of local histories, concepts, and social events. In both phases, anthropologists compared Fore data with examples in the anthropological record.

In Phase Two, however, the relationship between anthropology and medicine had changed, as medical anthropology became institutionalized in academia. As the story of kuru research illustrates, anthropologists may maintain a collaborative relationship with medical investigators, and some may become part of a multidisciplinary research team. Changes in the political environment also had an impact on the relationships among anthropologists, medical investigators, and the Fore, reflecting a general shift in sensibilities. Anthropologists and medical investigators began to focus more on the community services that the Fore expected. Medical investigators would no longer carry out autopsies. Not to be overlooked, Fore methods for investigating and preventing kuru also changed. The ritual events, seen as a solution in the 1960s, were no longer held. With the decline in kuru cases, their long collaboration with a variety of investigators, and some familiarity with biomedical clinics and hospitals, the Fore began to fold biomedical practices into their own forms of inquiry and health care. To study the complexity of this interacting community, anthropologists selected from a range of procedures, both interpretive and explanatory, for a discipline that, as Wolf observed [1], is part history, part literature, part natural science, and part social science.

### References

1. Wolf ER (1974/1964) *Anthropology*. W.W. Norton, New York
2. Keesing RM (1981) *Cultural anthropology*. Holt, Rinehart and Winston, New York
3. Glasse R, Lindenbaum S (1976) Kuru at Wanitabe. In: Hornabrook RW (ed) *Essays on kuru*. E.W. Classey, Faringdon, Berks
4. Lindenbaum S (2013) *Kuru sorcery. Disease and danger in the New Guinea Highlands*, 2nd edn. Paradigm Publishers, Boulder
5. Mathews JD (1971) *Kuru. A puzzle in culture and environmental medicine*. Dissertation, University of Melbourne
6. Berndt RM (1952) A cargo movement in the Central Eastern Highlands of New Guinea. *Oceania* 23:40–65
7. Gajdusek DC, Zigas V (1957) Degenerative diseases of the central nervous system in New Guinea. *N Engl J Med* 257(20): 974–978

8. Zigas V, Gajdusek DC (1957) Kuru: clinical study of a new syndrome resembling paralysis agitans in natives of the Eastern Highlands of Australian New Guinea. *Med J Aust* 44(21):745-754
9. Glasse R (1962) South fore cannibalism and kuru. Territory Papua New Guinea, Department of Public Health
10. Glasse R (1963) Report of fieldwork by R.M. Glasse and S. Lindenbaum. Territory Papua New Guinea, Department of Public Health
11. Glasse R (1967) Cannibalism in the kuru region of New Guinea. *Trans N Y Acad Sci* 29(6):748-754
12. Mathews JD (1965) The changing face of kuru: an analysis of pedigrees collected by R.M. Glasse and Shirley Glasse and of recent census data. *Lancet* 1(7396):1139-1142
13. Mathews JD, Glasse R, Lindenbaum S (1968) Kuru and cannibalism. *Lancet* 2(7565):449-452
14. Turner V (1957) Schism and continuity in an African Society: a study of Ndembu village life. Manchester University Press, Manchester
15. Geschiere P (1997) The modernity of witchcraft. University of Virginia, Charlottesville
16. Lindenbaum S, Lock M (eds) (1993) Knowledge, power & practice. The anthropology of medicine and daily life. University of California Press, Berkeley
17. Collinge J (2008) Lessons of kuru research: background to recent studies with some personal reflections. *Philos Trans R Soc Lond Ser B Biol Sci* 363(1510):3689-3696
18. Whitfield J (2015) Personal Communication
19. Mead S, Stumpf MP, Whitfield J et al (2003) Balancing selection at the prion protein gene consistent with prehistoric kurulike epidemics. *Science* 300(5619):640-643
20. Mead S, Whitfield J, Poulter M et al (2009) A novel protective prion protein variant that colocalizes with kuru exposure. *N Engl J Med* 361(21):2056-2065
21. Asante EA, Smidak M, Grimshaw A et al (2015) A naturally occurring variant of the human prion protein completely prevents prion disease. *Nature* 522(7557):478-481
22. Hertz R (1960/1907) A contribution to the study of collective representation of death. Free Press, Glencoe
23. Whitfield J, Pako WH, Alpers M (2015) Metaphysical personhood and traditional South Fore mortuary rites. *J Soc Ocean* 141:303-321
24. Brener M (2015) Infectious personalities: the public health legacy of three Australian Doctors in Papua New Guinea. *Health Hist* 17(1):73-24
25. Tarr PI (2008) The late 1970s: a lull in the action on kuru. *Philos Trans R Soc Lond Ser B Biol Sci* 363(1510):3668-3670





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