



***The Search for A Cause: An Anthropological
Perspective on a Neurological Disease in Guam,
Western Pacific***

Review by JOHN MOSS

The Search for A Cause: An Anthropological Perspective on a Neurological Disease in Guam, Western Pacific by Verena Keck. Guam: Richard Taitano Micronesia Area Resource Center, University of Guam, 2011. 268 pp. \$40.00.

Verena Keck's fascinating anthropological research explores two inter-related neurological diseases that have been present on the island of Guam since the early nineteenth century. Locals who live on the island know these diseases as Lytico and Bodig, or Lytico-Bodig. Neurologists and medical researchers know them as amyotrophic lateral sclerosis (ALS), or Parkinson-dementia complex (PDC), respectively. Both conditions are associated with a build up in the brain of a harmful protein called "tau" which causes nerve cells to thicken and develop unusual "neuro-fibrillary tangles" (Keck 2011, 7), which is why they are called "tau-pathologies." Both diseases have a decades-long latency period between exposure and the onset of symptoms and are extraordinarily debilitating conditions requiring 24-hour care for sufferers. The age of onset of these illnesses is typically between 30 and 40, with symptoms that can linger for at least 3 years (usually longer), resulting in death. Lytico symptoms include muscle loss, followed by a progressive inability to walk, speak, and swallow as the sufferer becomes "increasingly paralyzed" (Keck 2011, 7). Bodig symptoms, on the other hand, resemble Parkinson's disease which includes "slowness of movements, difficulty with walking and balance, stiff limbs, often tremor, and an expressionless face" (Keck 2011, 7), symptoms which may or may not be accompanied by dementia. Despite over 100 years of medical research concerning Lytico-Bodig on Guam and elsewhere, the causes of the build-up of tau remains a mystery. What is known is that ALS and PDC are more common in Chamorro families than other ethnic groups on Guam, and that the disease is much more common on Rota and Guam's Southern villages than it is elsewhere in the world. It is also common in Papua New Guinea. Apparently, the disease reached its apex on the Guam between the 1940s and the 1970s before declining in the 1990s. However, these changes in prevalence rates could be a result of the fact that the diseases during this time were more likely to be noticed because of the intensive public health programs that tracked the disease during this time period.

One ongoing causal hypothesis is that some unknown historical event is to blame for the unusual prevalence of these neurological diseases on Guam and Rota. Following this etiological framework, Keck provides a concise overview of 300 years of Guam history in the second chapter, focusing on the health of the Chamorro people and other historical evidence related to ALS and PDC. Keck's historical synthesis overviews 300 years of Guam history, blending colonizers' primary source accounts of the health and lifestyle of the Chamorro and Filipino

people along with numerous secondary scholarly sources, twentieth century newspaper articles, and oral histories of the Japanese occupation of Guam and its aftermath. Rota's history is only discussed briefly from the period of 1899 to the 1990s, because this island's past is not as well documented. Keck does an admirable job weaving these numerous pieces of evidence into a well-written narrative. Supplementing this history are several original drawings by early colonizers and photographs from the early part of the twentieth century.

Researchers with interests in the medical perspectives of the disease will appreciate Keck's review of the voluminous biomedical literature of ALS-PDC in the third chapter. Readers unfamiliar with medical terminology will need to have their medical dictionaries handy to fully understand this section of the text. Here we come to understand how scientists attempted to untangle the medical complexities of ALS and PDC on Guam. We learn that the unusually high prevalence rates of the disease has likely endured since at least 1900, when the high rates of the disease were first discovered by United States Naval doctors. Keck summarizes this research in a matter-of-fact tone that, surprisingly, avoids a critique of medical researcher's assumptions. Nevertheless, her cataloguing of the available evidence is a very useful addition to the conversation. Particularly helpful is her debunking of two popular etiological narratives of the disease that still linger to this day. The first theory Keck debunks was popularized by Oliver Sacks in his book *The Island of the Colorblind*, where Sacks reports that Lytico-Bodig may be caused from eating flour made from the inadequately detoxified fadang nut of the cycad plant. A related theory was that the source of the disease was caused from eating fruit bats who fed on these toxic fadang nuts which become concentrated in the bats. Other rejected etiological theories include the aluminum toxicity hypothesis, which argued that the "low calcium and magnesium concentrations in the soil and water cause an excessive absorption of aluminum" (Keck 2011, 107), which led to ALS and PDC. Keck also rejects the theory that the disease was caused by incest, which created genetic pathologies. Today, the medical causes of Lytico-Bodig remain unknown, caused by some combination of an unknown genetic predisposition and some unknown environmental factor.

We read about Keck's research into indigenous Chamorro perspectives of the disease in chapter four, which is where Keck makes her most significant contribution to medical anthropology. She begins by emphasizing how etiological theories of ALS-PDC denigrated Chamorro culture as they were filtered through newspaper accounts containing misinformation. Keck finds that Chamorro maintain many competing theories of causation. These causal narratives weave elements from neurological research studies gleaned from popular newspapers, along with other causal theories focusing on Guam's colonization and jungle spirits. Some Chamorro think the unusual prevalence of the disease is a result of military conflicts and military disposal practices, both of which left toxic pollution in the land and water. Alongside this is the idea that early immigrants to the island during the Spanish colonization period brought Lytico-Bodig with them. Another theory views the cause of the diseases as being due to unhealthy food, or eating habits, though all the people that Keck speak to rejected the fadang hypothesis. Stories are also told about an eighteenth century Catholic priest, Father Cristobal Ibanez de San Onofre, who cursed a family with Lytico-Bodig after a dispute over mangoes. Others involve the idea that Bodig is caused by a lack of exercise and physical activity, or that the valleys near the southern villages keep in bad air that comes off the Pacific, which cause the disease. One more explanation is that Lytico-Bodig is a "curse from God" (Keck 2011, 141).

Traditional healers, known as Suruhãnu or Suruhãna, have other explanations. These healers think healthy people have a balance between hot and cold, a theory that resembles

humoral theory of ancient Greek medicine, but which Keck argues is likely unique and traceable back to the ancient Chamorro. This theory posits that illness is caused when a person experiences a rapid temperature change or sits outside on cold nights, creating an imbalance in the body, resulting in either “hot” illnesses or “cold” illnesses, each of which is treated with herbal medicine meant to bring the body back into balance. Traditional healers also think that ghostly spirits who roam the island’s jungles are responsible for disease. These include three kinds of spirits known as the taotaomo’na, the duhendi, and espiritu malingu. According to Keck’s informants, Taotaomo’na are the spirits of ancient superhuman Chamorro chiefs who protect the island jungles and environment from harm. If a person disrespects the taotaomo’na by neglecting to ask permission when entering the jungle, or from accidentally stepping on or running into one, the taotaomo’na will cause inexplicable illnesses like Lytico-Bodig to occur. Yet another class of spirits is the duhendi, mischievous trickster spirits of children who died before they were baptized and are left to roam the earth. Malevolent spirits known as espiritu malingu also wander the jungles and are viewed as more dangerous than the previous two types of spirits. While each kind of spirit is different, sometimes all are categorized as taotaomo’na.

We learn that the Suruhãna and Suruhãnu must overcome enormous difficulties getting plants for their remedies because many of the best places for gathering are in areas of the island held by the military and are inaccessible without the permission of United States forces. The other problem is that most traditional healers are elderly and have difficulties gathering herbs without help and there are very few younger people willing to learn the profession at the time of Keck’s writing. The herbal medicines are either massaged into the body or turned into small packets and then inserted into the body. Keck writes that most Suruhãnu and Suruhãna admit they cannot treat Bodig, thinking this form of the disease is a result of “bad blood” through intermarrying families. But she describes three second-hand reports of several people who were cured of Lytico through the treatments of traditional healers.

We discover that many family members notice the dementia-related forms of disease when a loved one’s memory begins to falter, or when activities that caused them enjoyment no longer interest them. The other forms with no dementia are noticed when movement becomes inexplicably slow. Full-time care-giving of patients with dementia begin when sufferers endanger themselves by wandering into dangerous places, or when paralysis of limbs occurs, which makes it impossible for sufferers to care for themselves. Suruhãna or Suruhãnu provided spiritual support and massage treatment to every sufferer interviewed. These encounters were perceived as helpful, but were unsuccessful in curing the disease, though all Chamorro that Keck interviewed apparently stopped the recommended treatment before completion. The sufferers she spoke to were eventually cared for around the clock by adult family members, partly because of a long-standing custom of chenchule, or family reciprocity. Keck’s informants tell her that chenchule is an important Chamorro practice in which generosity to one person or group is later reciprocated. In the family, chenchule is often practiced inter-generationally as the younger generation cares for elderly members of the family. In this way, they reciprocate the care the older generation bestowed on them as children. We learn that many ALS and PDC sufferers also attempted to practice chenchule with local medical researchers when they signed consent forms and agreed to be studied in exchange for expectations of research results that will eventually cure the disease. Family members that Keck interviewed were later disturbed when they learned that the signed consent forms enabled medical researchers to harvest the brains and other neurological organs of sufferers for further study, making traditional funeral practices for their family member impossible. Keck includes lengthy excerpts from two interviews with people

who suffered from Lytico-Bodig, one with dementia and one without dementia. She also includes data from two long-term caregivers of people who suffered from the disease, but never tells us how many people she sampled for this chapter, nor how many hours of observations she conducted. Keck presents her interviews verbatim, leaving much of the analysis up to her readers. At the end of this chapter, Keck laments that the long period of Guam's colonization means that the Chamorro do not have a purely indigenous world-view of ALS-PDC, uncontaminated by western knowledge producers. She argues much of Chamorro culture was lost to the long period of colonization.

In the final chapter of her book, Keck summarizes her findings and briefly criticizes the researchers who studied Lytico-Bodig. She rightly argues that these scientific investigations stigmatized individuals, the Chamorro culture, entire island villages, and even the islands of Guam and Rota themselves. Part of the stigma involved is a result of the local term "Lytico-Bodig," which suggests that Guam is the site of some frightening and deathly illness that is unknown elsewhere in the world, when in fact, the disease is present everywhere, but called a different name. The research ethics of expert scientists is also criticized. Local Chamorro who experienced the disease first-hand had no idea that the consent forms they signed during the research process required them to surrender their relatives bodies for dismemberment, research, and long term preservation. The scientific language researchers used was inscrutable to the Chamorro community, allowing these researchers to intimidate and take advantage of the goodwill of the Chamorro people. The research into ALS-PDC led only to dead-ends and the Chamorro received nothing in return. Many Chamorro are hotly resentful of the research that was undertaken on Guam; others feel shame about the disease and hide it when it occurs, while trying to downplay the hardship it causes to avoid unwanted attention. But the book ends just as this critique gets started, and we are left with no suggested reforms that would address these injustices. Readers interested in these critiques can refer to the introduction by Dr. Vincent P. Diego, a Chamorro from southern Guam who takes up this issue.

There are other criticisms that can be made about the text as well. As I mentioned earlier, Keck spends very little time discussing her methods in her chapter about Chamorro perspectives, leaving her readers to guess her methodological assumptions, the length of her interviews, some of questions she used with the Suruhānu/Suruhāna, her sample size, and how much many hours she spent in the field. Because of this, we are left with difficulties in evaluating how sound her conclusions are. There is also no rationale provided for why she presents long passages of interviews verbatim with very little analysis of the interview transcripts. While this strategy preserves her participant's voices, it is highly unusual in qualitative interview studies. The author could also contextualize her findings more thoroughly by reviewing essential works in medical anthropology that are essential for her analysis, such as Arthur Kleinman's *Illness Narratives*. Her chart of ALS and PDC in the Santiago family in the first chapter could use additional explanation for lay readers who have not encountered family genograms before. And while she promises readers definitions of medical jargon in her chapter on perspectives of medicine towards ALS and PDC, she never fulfils this, leaving readers to fend for themselves. These relatively minor problems with the presentation of her data could be easily corrected with a little more care. Like Dr. Vincent P. Diego, who wrote the introduction, I also think Keck could spend more time connecting the scientific practices in her text to the ongoing exploitation of the Chamorro and how we can prevent scientists from taking advantage of similar research participants. It would be good, for example, if Keck connected her criticisms of medical researchers to other similar criticisms of medicine on Guam, such as Anne Hattori's *Colonial*

Dis-ease, a book that is mentioned only briefly. This is one section of the text that deserves a more developed and extended criticism of the practices of Western medicine. But perhaps this was beyond the scope of what Dr. Keck intended to do.

Despite these criticisms, this text is absolutely essential reading for anyone interested in medicine, colonization, and scientific practices in Micronesia. It has a very comprehensive bibliography of studies into ALS-PDC, a well-written historical chapter with impressive pictures and drawings and extremely useful information about Suruhåna healing practices and Chamorro perspectives and experiences of ALS-PDC. It addresses a topic—neurological disorders—that is rarely researched in anthropology, and she writes about a region that very few anthropologists have studied. To Verena Keck's credit, there is simply no better social science resource concerning ALS-PDC on Guam. Keck's interdisciplinary work is path-breaking and a valuable contribution to medical anthropology in the region. It deserves your attention.

References

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