Epistemology and Epidemiology: Local interpretations of the epidemiology of the AIDS epidemic in rural Malawi

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In this paper we use a rich set of ethnographic journals collected in rural Malawi from 1999 to the present in order to examine understandings of the epidemiology of sexually transmitted infections and HIV and to investigate the possibility that local interpretations have changed over the course of Malawi's longstanding and severe AIDS epidemic.

AIDS deaths began to elevate mortality rates in Malawi from at least 1990, and since 1994, the proportion of adults estimated on the basis of antenatal-clinic data to be HIV positive has hovered around 15 percent. The advent of AIDS in rural Malawi challenged ordinary assumptions of bodily security, and destabilized a set of fundamental cultural assumptions about sexually transmitted infections. Malawians have long been familiar with other STIs, which have been endemic in the region at least since colonial times. Various STIs, such as gonorrhea, syphilis and chancroid, are known, named, and distinguished from one another; as are their symptoms and natural course. These illnesses could be painful and embarrassing, but the risk was often considered an acceptable trade-off for the pleasures of unprotected sex. Malawians also recognize a range of traditional illnesses that have AIDS-like symptoms. In contrast to AIDS, however, the well-known STIs and the traditional illnesses could be treated and were observed to be rarely fatal.

By the late 1990s, survey data show that virtually all rural Malawians knew that HIV was sexually transmitted and invariably fatal, and that they attended an average of approximately four funerals per month. Ethnographic data show that the new disease was perceived as terrifying because of its observed inevitable progression from a healthy body to a wasted one, such that the victim became "like a two-year old child" and then to death, a progression accompanied by a bewildering diversity of symptoms. The sight of a neighbor's bodily change stimulated attempts to diagnose the illness by drawing on local networks to pool knowledge about the person's history of symptoms and his or her sexual biography. These were often seen as incompatible and thus puzzling, for example when a wife thought to be innocent died before a husband thought to be promiscuous. As HIV prevention programs were implemented, confusion was heightened as experts in the modern biomedical sector contradicted each other; more importantly, much of what they said contradicted well-established indigenous understandings of disease, prevention and cure.

Our primary data are drawn from a set of approximately 600 ethnographic field journals covering the period from 1999 to the present. Local ethnographers—selected from among fieldworkers on a large and continuing panel survey (see www.malawi.pop.upenn.edu) were asked simply to recall everyday conversations that they overheard or participated in, which made some reference to AIDS (and, later, to religion), and to write their recollections in English in commonplace school notebooks. These were then sent to the senior author (a more detailed description of the production of these journals, including an evaluation of the quality of the data, is provided by Watkins and Swidler, 2006).

The journals vividly show rural Malawians publicly and urgently grappling with epidemiology of the new, confusing and terrifying disease. In their local social networks, people ask each other why some people known to be promiscuous have died, while others known to be equally promiscuous are still alive? Is monogamy more risky than polygamy, or less? Could giving birth to an uninfected baby be a sign of health? Is sex once with an infected person enough to become infected? If an individual with whom one has been sexually intimate—whether this person was a long-term spouse or a one-time sexual partner—develops AIDS symptoms or dies, is it inevitable that one is infected also?

We find that between the first journals in 1999 and the present, some of these questions and contradictions have been resolved to the satisfaction of most people; others remain puzzling. But however comfortable some people are with their understanding of the natural history of this new, distinctive and terrifying disease, is that understanding consonant with what is accepted objectively, on the basis of medical research, to be its natural history? If there are dissonances, might they militate against effective interventions? Or might they merely provide comfort to individuals for whom any intervention, if it actually does come, will come too late?