

The Search for Healing: the AIDS Epidemic in Gwembe Valley¹

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How people respond to their own and others' illnesses due to AIDS depends in part at least on timing: timing with reference to occurrence within the time span that AIDS related illnesses have been known and to other occurrences within the same support group, and a personal history of being ill or providing support to others. Responses also reflect national and family resources and the resources and social status of an individual patient. In Zambia, cabinet ministers are flown to South Africa for treatment at government expense even when death is imminent while most citizens have no access to ARVs and government health centres lack other medications. This paper uses data from the Gwembe Tonga longitudinal study to examine how the search for healing and the ability to mobilise support systems have varied over a twenty year period as Gwembe Tonga first became aware of the threat caused by the spread of HIV and then tried to deal with it. Their responses built on a recognition of increased morbidity and mortality among kin and neighbours, information campaigns about the nature of HIV, an increasing ability to diagnose symptoms as indicative of AIDS, and continuing reappraisals of both western explanations (biomedical and religious) of how HIV is transmitted and the efficacy of western and traditional medicine to treat and cure. But how people have responded has also reflected perceived obligations to support kin and the variability over time of familial and national resources, for these limit what can be done whatever one thinks should be done in a search for a cure or the sustaining of those who are ill.

¹ Material for this paper derive from a long-term study of Gwembe Valley initiated in 1956 by myself and Thayer Scudder. Information on the study are to be found in Thayer Scudder and Elizabeth Colson, "Long-term Research in Gwembe Valley", in George Foster et al., eds, *Long-term Field Research in Social Anthropology* (New York, Academic Press, 1979), 227-254; "Long-term Research in Gwembe Valley, Zambia", in Robert V. Kemper and Anya Royce, eds, *Chronicling Cultures: Long-term Field Research in Anthropology* (Walnut Creek, Altamira Press, 2002), 197-238; Lisa Cliggett, "Multigenerations and Multidisciplines: Inheriting Fifty Years of Gwembe Research", in Kemper and Royce, eds, *Chronicling Culture*, 239-51. Initially field work was supported by the Rhodes-Livingstone Institute (later the Institute for African Studies and now the Institute for Economic and Social Research in the University of Zambia), and thereafter by various agencies including the Social Science Research Council, the National Science Foundation, and for Scudder, the John Guggenheim Foundation. Over the almost fifty years of the study we have been indebted to many people both in Zambia and elsewhere, and especially to village research assistants and the people of Miyaka, Mpwe, Chezia, and Siamēja neighbourhoods in what are now Siavonga, Chipopo, and Sinazongwe Districts. Dr Thea Savory has been most helpful in alerting me to recent developments in the ARV programmes and responses to these. Lastly, I am indebted to Thayer Scudder, Lisa Cliggett, and Brendan Carmody for comments on an earlier draft, and to the members of the Berlin seminar on "AIDS and the Moral Order in Africa", most especially Christine Obbo and Ute Luig, for their comments on the draft presented at the conference on 3-6 March 2005.

The context

Much that is said here will resonate with what has happened and is happening elsewhere in Africa, but I am dealing with the impact of AIDS at a particular place and time: the Gwembe Valley of Zambia's Southern Province¹ in the decades after 1980. For data, I draw upon the Gwembe Long-Term Study of Social Change initiated in 1956 long before AIDS was known. My last visit to the Valley was in 2006.

In the slightly over twenty years since the mid-1980s, when Zambians, including the people of Gwembe Valley, first became aware of the existence of a new threat to their existence identified under the rubric AIDS, they have gone through a series of responses, including denial – denial that AIDS existed in their country, and then, denial that it could be involved in one's own illness or the illness of one's kin. Denial in itself was a sign that they refused to give up hope of a cure, and this justified the continued search for a cure. As long as it was possible to cling to denial, any illness due to HIV/AIDS was likely to be assimilated to previously known illnesses. Indeed, many were previously known illnesses taking advantage of impaired immune systems. So long as illnesses were not identified as AIDS related illnesses, they raised no particular new moral issues, even though illness episodes were recognised as costly in that they involved medical fees and the loss of wages or other forms of productivity by patients and caretakers. This was nothing new. Illness was a fact that had to be faced like other difficulties that required decisions about what people could do under given circumstances. Very often this meant a balancing of various obligations, not all of which could be met at the same time.

From the beginning, people's responses to AIDS were affected by the fact that it was but one of many difficulties with which they had to contend in the last decades of the 20th century and the early years of the 21st. The epidemic emerged when Zambia was already in trouble, due first to the decline of the national economy dependent on copper exports when copper prices fell on world markets in 1973 while prices of imports rose rapidly, and then beginning in the 1980s to structural adjustment programmes urged upon a now indebted country by the World Bank and the International Monetary Fund. The public health system was one victim of the economic decline. Retrenchment here coincided with emergent drug resistance of various diseases, including malaria. Climatic change also became apparent with more frequent drought years beginning in the early 1980s: this meant more years when survival depended on access to imported food and people still went hungry.

Moral dilemmas

My understanding of how Gwembe Tonga have responded to the epidemic, as to other difficulties, is influenced by what I have learned over fifty years of their premises about the human condition. First, they stress the importance of personal autonomy. They do not like to be told what to do. People should make their own decisions. But in doing so they should take into account what can be summed up as a moral order. This means that they expect to give consideration to how their obligations to others restrict their freedom of action. In practice, this usually means obligations to kin. But the ramifications of kinship mean that everyone is faced with many competing claims. One of the arts of Gwembe life involves creating claims on others that they can be shamed into acknowledging while at the same time avoiding claims upon oneself.

Life had always been difficult in the Valley whose people were accustomed to drought years and food shortages as well as the epidemics characteristic of the first half of the 20th

¹ Gwembe Valley is the local term for the Middle Zambezi Valley, the river formerly providing the boundary between what are now Zambia and Zimbabwe. Much of the valley floor is now occupied by Kariba Lake formed when the Zambezi River was dammed at Kariba Gorge in 1958.

century. Certainly, food shortages and epidemics can create moral dilemmas, but on the whole Gwembe people, are realistic pragmatists who try to meet obligations when they can but know that on occasion they will fail and then must live with the knowledge of failure. Village memories include much that is grim. Most families have secrets that should not be mentioned, for village society depends upon a willingness to recognise that even if people behave badly on occasion, they remain members of the local community. In hunger years, people may be forced to triage and decide who should be fed and who go hungry.¹ In the 1940s, while working on the nearby Plateau, I met women who had been sold as children by their Gwembe kin for the grain that fed their elders. Even in the 1980s and 1990s people whispered of elderly men and women, or someone badly disabled, left to starve during bad hunger years and of people who survived through theft of the scanty food resources of kin and neighbours. People thought this shameful, but understandable.²

Decisions about whom and when to help were based on premises other than the western one that life must be preserved at all costs.³ People would probably agree that one is obligated to assist kin who are ill and to participate in mourning both kin and neighbours. The obligation to contribute funds to pay for a cure is recognised, though not always met, if cure seems probable. On the other hand, it is difficult to refuse help when you see no hope, for that means you open yourself to a charge of witchcraft since only a witch could speak this confidently. The obligation to feed and care for the ill continues to exist even though the case is hopeless, but people must still decide whom to help and how much to give. They have rarely had the luxury of being able to afford infinite compassion. The sense of obligation is tempered both by the nearness of ties of kinship and by an appreciation of help received in the past or expected in the future. Even though many are now Christians aware of the teaching of their churches on the sacredness of all human life, this does not relieve them of the need to allocate scarce resources among the many with claims.

In the past, people made decisions about who should live. Children born with obvious disabilities, along with those regarded as anomalies, were either killed at birth or allowed to die, and I have known elderly Gwembe Tonga deplore the use of drastic measures to keep premature babies alive. Better, they said for the weakling to die and the parents try again to produce viable children. People might also leave the very ill untreated on the premise that death was inevitable, and those who were very ill might decide to hasten death by refusing food and water and have their decision respected. Against this was the fear that those who died neglected by their kin would become *ibandwa*, vengeful spirits of those dying aggrieved at bad treatment or failure to provide proper mourning who return to punish descendants or lineage members for neglect.

Only matrilineal kin, however, had an obligation to care for the ill and dying until health centres and hospitals were established: even then kin were expected to accompany and nurse those admitted. It was generally agreed that only lineage kin, or perhaps a man's children, would nurse someone no longer able to take care of bodily functions, though sometimes wives cared for incontinent husbands. People did care for ill and dying kin, for various reasons: empathy, fear of how spirits would reciprocate after death, or a thought to reputation since while their neighbours might not hold to account, they judge them. Support for those ill and in need, therefore, was and is based on complex considerations, that give rise

¹ Elizabeth Colson, "In Good Years and In Bad: Food Strategies of Self-Reliant Societies", *Journal of Anthropological Research*, 35/1 (1979), 18-29.

² See also Lisa Cliggett, *My Mother's Keeper: Changing Family Support Systems for the Elderly in the Gwembe Valley, Zambia* (Ann Arbor, UMI Dissertation Services, 1997), 111-112.

³ Gilian Paterson, "AIDS and the African churches: exploring the challenges", paper read at the conference "Consolidating a Christian Response: HIV/AIDS in Africa", PACANet, Nairobi, 19-20 September 2003, 2.

to many possibilities for anxiety, discontent, and a sense of exploitation on the part of both those who give and those who receive.

When one can not adequately fulfil obligations either to the living or the dead, it is appropriate to make a gesture indicating a desire to do one's duty. Debtors acknowledge their debts even if they do not pay them, just as people may provide only a token acknowledgment of their obligations to the spirits of the dead when they can do no more. In a hunger year, when there is no grain for brewing when a divination finds that a spirit is demanding beer, the solution is to offer using water in which a few grains have been put to soak, informing the spirit that beer will be offered when it is possible to brew. Or someone living in an urban area, where it is held offerings cannot be made, pours water beside a tree at the edge of town, while assuring the spirit that beer will be provided on return to the village. So also with the ill, care may be minimal, a token of what one might do in other circumstances.

For most Gwembe people, life involves frequent compromises, between the ought and the possible. Responses to the AIDS epidemic involve such compromises. The help people give varies from case to case reflecting knowledge of HIV/AIDS, appraisal of resources available for underwriting treatment or to cushion a patient who is ill and dying, an evaluation of the likely outcome of treatment, fear of becoming infected, fear of being stigmatised by the community if the illness is identified as AIDS, and fear of future vengeance if a spirit departs life angered by neglect. With the massive flocking to churches in the 1990s, the teaching especially of charismatic churches that HIV/AIDS is God's punishment for sin or due to Satan, also affects how people view those ill with AIDS and their right to support.

For a decade or more after AIDS was first known, many considerations discouraged people from being willing to label an illness, whether their own or that of a kinsperson, as AIDS related. Whatever else they knew about HIV/AIDS in those first years, people heard early on that a diagnosis of AIDS was tantamount to a death sentence. In Zambia, in fact, death usually occurred within about two years after the first appearance of full-blown AIDS.¹ People were also told that HIV/AIDS was spread through sexual intercourse, assumed to be illicit, with the implication that the one afflicted was responsible for the illness and the problems this caused others. When the ill denied that they had AIDS, they denied both that responsibility and their own imminent death. Refusing the label and looking to other diagnoses with a better outcome justified requests for help and the use of family resources for a member seen as temporarily in need of support.

By the end of the 20th century, denial began to break down in the face of the massive epidemic and the diagnostic skills acquired through watching what happened to kin and other associates. People began to live with the knowledge that they could do nothing to bring about a cure. Then, in the early 21st century, the arrival of ARV therapy confronted those who knew of it with new dilemmas, for the cost was prohibitive for all save the rich or the powerful. The remainder of this article looks at these developments more carefully within the time frame through which the epidemic has been known.

The onset

On returning to Zambia in 1982, I was puzzled at the number of men, known to me as boys in the 1940s when I worked on the Plateau, who had died since my last visit to Zambia in 1978. Usually, it was said, from pneumonia. The late 1970s and early 1980s were hard times for Zambia, but that hardly accounted for the death of so many men in their forties or early fifties, a time of life when few deaths were expected. Neither I nor probably anyone else in Zambia in 1982 knew anything about AIDS: it was only late in 1982 that I read reports in American newspapers and journals of unusual physical symptoms and an unusual number of deaths

¹ Douglas Webb, *HIV and AIDS in Africa* (London, Pluto Press, 1997), 4

among younger men in the United States. Shortly thereafter, the term AIDS was invented to designate the phenomenon, but biomedicine was still uncertain about how it had originated, how it spread, and who might be at risk. The HIV retrovirus was not identified until the following year.¹ Since the reports cited a form of pneumonia as one of the AIDS associated illnesses, I then wondered if here lay an explanation for what had seemed to me to be an abnormal number of deaths among Tonga-speaking men I had known as youngsters and perhaps also for more frequent references to cases of tuberculosis 1982 when tuberculosis had seemed largely under control by 1972.

I now suspect that by 1982 many in Southern Province harboured HIV and that those deaths in the late 1970s or early 1980s represented the beginning of mortality due to HIV/AIDS and also signalled increasing morbidity as various diseases attacked already compromised immune systems. The timing is not unlikely. Lwanda, extrapolating from later rates, believes that HIV reached Malawi about 1977 and was implicated in the observed increase in unexplained deaths of urban youths in the early 1980s although the first hospital diagnoses in Malawi came in 1985.² But in 1982, neither on the Plateau nor in Gwembe Valley, did people suggest that they thought themselves confronted with something new. This was very unlike their response to the influenza epidemic of 1972 when they mobilised as communities to drive out the illness. Nobody dwelt on symptoms later regarded as indicative of AIDS, such as swollen legs, emaciation, and diarrhoeas. Emaciation and diarrhoeas were present, but emaciation was associated with a shortage of food due to poor harvests, low wages, or unemployment, and diarrhoeas with dysenteries long common to the region, just as pneumonia had long been present. These were old problems. They were known to respond to treatment, and were dealt with either by old African remedies or by a resort to biomedical treatment at hospitals and rural health centres even though the decline in the Zambian economy was already beginning to affect the quality of care and availability of medicine at the centres. If people were perturbed by a larger number of deaths or a greater number of illnesses, they did not say so. Therefore, in Gwembe Valley, as in the West, the first impact of HIV/AIDS went largely unnoticed at the conscious level, though it may have heightened the general unease of the early 1980s and helped to trigger the spate of witchcraft accusations and summoning of witchfinders³ that occurred throughout Southern Province in 1981 and 1982 as neighbourhood after neighbourhood tried to identify and nullify the witches who caused illness and death.⁴ It is more likely that people were responding to the general economic and political malaise that affected Zambia, including Southern Province, from the mid 1970s, made the more bitter because it followed on the economic buoyancy and ebullient expectations of a better life associated with the coming of independence in 1964. In 1982 people seemed more deeply depressed about their circumstances than they had been even after their forced resettlement when Kariba Hydroelectric Dam on the Zambezi River flooded much of their former territory in 1958. They were bitter that their hopes were being frustrated. They talked of the scarcity of jobs and commodities, the decline in government services, and the bleakness of the foreseeable future. It was to these that Scudder attributed “the community unravelling” he perceived at that time.⁵ The early 1980s was also a time of drought, which meant hunger and dependence on imported grain. The AIDS epidemic was too insidious to

¹ *Ibid.*, xi.

² John Lloyd Lwanda, “Politics, Culture, and Medicine: An Unholy Trinity? Historical Continuities and Ruptures in the HIV/AIDS Story in Malawi”, in Ezekiel Kalipeni et al., eds., *HIV and AIDS in Africa: Beyond Epidemiology* (Oxford, Blackwell, 2004), 35.

³ A witchfinder is a diviner who specializes in the diagnosis of witchcraft and the identification of witches.

⁴ Elizabeth Colson, “The Father as Witch”, *Africa* 70/3 (2000), 333-358.

⁵ Thayer Scudder, “Economic Downturn and Community Unravelling”, *Culture and Agriculture*, 18 (1983), p. 16-19; “Economic Downturn and Community Unravelling Revisited”, *Culture and Agriculture*, 23 (1984), 6-10.

compete with all the rest that frustrated hope and raised anxiety to be a major cause of concern.

The Growth of Knowledge

In the twenty years following 1982, the people of Gwembe Valley, like their contemporaries elsewhere in the world, went through various phases of denial and acceptance, as knowledge of HIV, its transmission, and effects upon the human body became available and spread. As Schoepf¹ noted, most countries in Africa went through a stage of denial early in their experience of the epidemic. The warnings that began to circulate in the late 1980s, largely stemming from the United States and Europe, gave people little information on how to act, due to the early uncertainty among biomedical workers as to whether they were dealing with one or a number of diseases, what the modes of transmission might be, and the prognosis. Schoepf also points out that the lengthy incubation period between infection and first physical symptoms encouraged uncertainty and made it difficult for people to accept that someone who looked healthy already carried a fatal infection that could be transmitted to others and would end in death within a few years.

Zambians may have been inclined to give more credence to the epidemic when President Kenneth Kaunda spoke on Radio Lusaka late in 1988 to announce the death of his son from AIDS and warn of the need to take precautions against infection. Most Gwembe people still thought that even if the threat was real it was unlikely to affect them: AIDS was something that happened in other countries.

In 1987 I recorded the first known deaths from AIDS in our longitudinal sample population, which includes all resident in four Gwembe villages in 1956-57 and subsequent census years, whether they remained resident or moved elsewhere, and their descendants.² These first deaths were of two men in their early thirties who had gone to secondary school and then worked in Lusaka where they were treated and diagnosed at the University Teaching Hospital. I learned of the diagnoses from friends who saw the hospital records. At that time, Zambians still had access to free medical care, and for many, especially in urban areas, the first choice of treatment was biomedicine, dispensed at government hospitals or health centres, even though they might also use home remedies, visit an African practitioner, and consult diviners to discover the underlying cause of the illness in witchcraft, the anger of the spirits of the dead over neglect, or spirit possession.

In the village from which the men came, no one openly associated their deaths with AIDS even though by 1987 people had begun to talk of illnesses and deaths, especially among young educated town-based elite, from what some called “slim disease” although AIDS had already entered the national vocabulary. In Gwembe villages, the mode of transmission was beginning to be known. Some at least knew that there was no known cure for the condition even if particular manifestations might be temporarily overcome. They found it difficult to accept that transmission was through sexual intercourse. For one thing, they had long been familiar with sexually transmitted diseases introduced through labour migration, and knew these could be cured with antibiotics. There was also the fact that some remained healthy who were known to have had numerous sexual partners.

By 1990, 99% of the women interviewed for the *Zambian Demographic and Health Study* reported that they had heard of HIV/AIDS, and 90% knew that AIDS was transmitted through sexual intercourse. This was true of both rural and urban women, and did not differ

¹ Brooke Grundfest Schoepf, “AIDS, History, and Struggles over Meaning”, in Ezekiel Kalipeni et al., eds., *HIV and AIDS in Africa: Beyond Epidemiology* (Oxford: Blackwell, 2004), 20, 22.

² Sam Clark et al., “Ten thousand Tonga: a longitudinal anthropological study from southern Zambia”. *Population Studies* 49 (1995), 91-109.

by province. Fewer women knew that AIDS could be transmitted through shared needles or razor blades or blood transfusions, or that it could be transmitted from mother to child.¹ Gwembe women can be assumed to have been as well informed as those interviewed for the Study, for they attended health centres and the majority of them had experienced town life either as residents or as visitors to kin or in search of medical treatment or for education. Some were traders who sold rural produce on urban markets. By the 1990s, one could think of Zambia as essentially forming a single disease and knowledge pool.

By 1992, the effect of AIDS on the longitudinal sample was evident in reports of illnesses and deaths. But whatever people admitted to knowing, by then HIV/AIDS was a stigmatised condition. This meant that whatever knowledge people displayed with respect to HIV/AIDS in the abstract, they were not prepared to admit that they themselves or any of their kin might have AIDS, nor did they speak of fellow villagers or other close associates as ill from AIDS. At most people were willing to say “he has swollen legs (or is very thin)”, or “some might say it looks like AIDS”. By 1996, people admitted that fellow villagers as well as those in other villages were ill or had died from AIDS, but they gave other diagnoses when kin showed the same symptoms. Only in 1998, did I hear men and women attribute AIDS to kin, and then it was usually only if they were living in different homesteads.

Those affected and their supporting kin clung to other diagnoses. Recognising symptoms associated with tuberculosis, malaria, or dysentery, or some other condition long familiar to them, they identified each manifestation as a specific disease, as indeed it was, treatable by biomedicine, for antibiotics had brought cures for tuberculosis, dysentery, and pneumonias. When this failed them, it was common to claim that biomedicine was mistaken about the condition and lacked knowledge of how to treat it. What biomedicine called AIDS, many said, was an illness previously known to Tonga-speakers as *kahungo* or *chihungo*, acquired through contact with a woman who had not been purified after miscarriage or stillbirth, and its treatment was known to some practitioners of African medicine.² In a search for better biomedical treatment people might move from rural health centres with their limited resources to nearby hospitals or to the University Teaching Hospital in Lusaka or consult some of the private clinics beginning to appear in larger urban centres where biomedical treatment could be obtained by those with enough money. They also moved around the countryside in search of an African practitioner who had effective medicine for the condition, sometimes on the advice of workers at the Health Centre who told them this was a matter for African rather than European medicine. Treatment by an African practitioner might cost them substantially more than the fees paid to health centres and government hospitals, but so long as they had funds and some confidence in the treatment they were prepared to pay. Some used every resource available, using biomedicine to treat the specific manifestation and African medicine to rid themselves of the disease itself. In the early 1990s, questions about people in the village censuses frequently brought the answer that they were staying elsewhere in Gwembe Valley or on the Plateau being treated by an African practitioner though the nature of the illness was left vague.

In appraising early reactions, it is important to remember that many of the first Gwembe AIDS patients known to me were members of the educated elite who were likely to look to biomedicine for cure. Unlike those maturing in the early 21st century, they had grown up in a Zambia where immunisation of children, beginning in the 1960s, controlled many childhood diseases, malaria had been practically eliminated in the 1960s and early 1970s through the use of DDT, antibiotics rapidly cured many previously intractable ailments including tuberculosis, even leprosy was being successfully treated, mortality rates had fallen

¹ *Demographic and Health Survey 1992* (Lusaka, Central Statistical Office, 1992).

² H. Mogensen, *Aids is a Kind of Kahungo that Kills* (Oslo, Copenhagen, Stockholm and Boston, Scandinavian Universities Press, 1995).

drastically, and life expectancy was steadily rising. By the mid 1980s, however, the antibiotics and anti-malarial drugs which had given biomedicine its high status in the 1960s and 1970s were less effective as drug-resistant strains began to appear. Then when biomedicine could diagnose AIDS as implicated in an illness and provide information on one's HIV status, but had no cure, people preferred to trust in African resources, which they knew had provided effective treatment for some conditions in the past. The diagnosis and prognosis provided by biomedicine which gave no hope of cure, were repudiated, and they sought support elsewhere, among practitioners of African medicine including those who claimed to heal through the use of new forms of spirit possession.¹ It was only in 1996 and later that I heard people, whose children had already died after a search for treatment, comment that a practitioner of African medicine who said he or she had a cure was lying and only wanted your money. They might still clutch at hope by claiming that an illness involved witchcraft and a cure was possible if the witch could be identified and forced to counteract his attack. At this stage, it was common to hear people say that if witchcraft were involved, then it could not be AIDS, whereas if AIDS was involved it could not be witchcraft. In 1996, most funerals still involved a consultation with a diviner as to the cause of death, and now for the first time I heard divinations announced attributing the death to AIDS rather than to witchcraft or the ancestors. Mothers especially might refuse to accept the divination and continue to insist that it was witchcraft.

As AIDS became more common, frustrated anxieties had become manifest in frequent resort to witchfinders throughout the 1990s. The young, especially those in rural areas, believed that they were being exploited by senior kin who worked them hard without sufficient reward and were intent on enriching themselves through medicines that drained the life force of others. They retaliated by calling in a witchfinder to detect and destroy the charms of an individual suspect or cleanse an entire village or neighbourhood of its witches. Such treatment too came at a cost, usually of four cattle or their equivalent for each witch identified and cleansed, but hope justified it.²

When witchfinding had been tried, and people continued to fall ill and die, other possibilities also began to be canvassed. At the end of the 1990s, people began to speculate that HIV/AIDS was a punishment for their neglect of old rituals and taboos which had kept them in harmony with the spirits of the dead and the spirits associated with the land and that it might be wise to reinstitute them. Meantime, in Gwembe Valley, as elsewhere in Zambia, beginning in the 1980s but escalating in the late 1990s, there was extensive experimentation with newly arrived charismatic churches, especially those associated with the Faith Gospel movement or Universal Church stemming from the United States. While these may preach that AIDS is punishment for sinful sexual activity, or something sent by Satan, they also preach that a strong enough belief in Jesus, frequently assessed by a willingness to contribute to the finances of the church can heal any illness as well bring prosperity in this world. Some of them claim to heal through the laying on of hands.³ In a search for healing, people move from church to church much as they have tried to exploit the possibilities of medicine.

Despite disillusionment with various possible means to cure and widespread knowledge about the outcome of AIDS, people have clung to hope and continued to pay what they could for anything that promised a cure even though this drained resources that

¹ Ute Luig, "Constructing Local Worlds: Spirit Possession in the Gwembe Valley, Zambia". in Heike Behrend & Ute Luig, eds, *Spirit Possession, Modernity and Power in Africa* (Madison, University of Wisconsin Press, 1999), 136.

² Colson, "The Father as Witch".

³ Hugo Hinfelaar, *History of the Catholic Church in Zambia* (Lusaka, Bookworld, 2004), 309, 332; Thomas Kirsch, "What is Belief? Restaging the Will to Believe: Religious Pluralism, Anti-Syncretism, and the Problem of Belief", *American Anthropologist*, 106/4 (2004), 699-709.

otherwise might have been spent on food, clothing, or school fees for children. Unfortunately by the first years of the 21st century, when ARVs began to be available, many families had little left to pay for further treatment given all they had spent on the many who have been ill, sought a cure, and died.

In the years before ARVs became available, when the biomedical establishment and its allies, the international charitable agencies, were unable to offer hope to those infected, they expended their resources in fostering educational programmes on HIV/AIDS and its mode of transmission, the need to adopt safe sex through limiting the number of partners and the use of condoms made available through health centres, and more recently combating stigmatisation of those with HIV/AIDS and their close associates. Information was transmitted via radio and newspapers or through public meetings, often associated with the performance of dramatic skits featuring the need to avoid infection. Such programmes aimed at containing the epidemic by changing behaviour to prevent infection, disregarding evidence that by the late 1990s they were preaching to those who had already heard and did not want to listen to further messages assuring them that if they were already infected, as many suspected they might be, they were doomed to early death. In the circumstances, the informational programmes were more effective in adding to the anxieties of those who heard them than they were in altering behaviour with respect to sexual activity.

Gwembe people regarded sexual activity as a pleasure. Most men, whether single or married, thought it enjoyable to engage in affairs, and even married women might have lovers. With the emergence of townships around administrative centres, mines, fishing camps, and transit points from the 1960s on, some women had been drawn into prostitution serving both transients and village men. Condoms, if available, were unpopular, in part because they were said to lessen sexual satisfaction, but also because some churches preached that their use was both sinful and dangerous to health. Such preaching may have had greater impact than preaching about the sinfulness of sexual relations outside marriage.

The incidence of HIV infection began to fall nationally in the early 21st century, and this probably applies also within Gwembe Valley although we cannot demonstrate this and can only speculate about why it might be so. Some aspects of sexual behaviour did begin to change in Gwembe by the mid to late 1990s. It is doubtful how much the national campaigns were implicated in this and how much was due to the intimate knowledge Gwembe people had acquired through watching their fellows fall ill, become dependent, and die. In the late 1990s, the ritual purification of survivors from death pollution, which involved sexual intercourse, began to be altered or eliminated under pressure from surviving kin intent on protecting themselves from infection. This happened even before Gwembe chiefs were induced to ban the purification in the early 21st century. Increasingly, if AIDS was implicated in a death, surviving spouses were suspect of being infected even though they might appear to be healthy, and the inheritance of widows by matrikinsmen of the dead husband began to be avoided. In other circumstances, however, risks continued to be taken, even though by now people said openly that they did not want the burden of care for those who knowingly placed themselves at risk.¹

HIV/AIDS has carried stigma since the late 1980s, and stigmatisation may have increased as fear of infection has increased. While people know that AIDS is sexually transmitted, they also think it can be transmitted through contact with items used by one infected or through contact with the blood or other body fluids of those infected. Research teams in Southern Province have found people trying to distance themselves from those thought to be infected with HIV even before AIDS symptoms appear, and from those closely

¹ Elizabeth Colson, "AIDS und Verhaltensänderung am Beispiel des Gwembe-Tals in Sambia", *Peripherie*, 93/94 (2004), 42-63.

associated with them.¹ This means that those infected and their kin, even when they recognise an illness as AIDS related, usually persist in public denial. Few, so far, have wished to know their HIV status. This adds to the burden of anxiety attached to AIDS; for people live with the knowledge that they do not know all those among their associates who may be a danger to them.

Stigmatisation originally may have been influenced by knowledge that AIDS was stigmatised in Europe and the United States, standard-setters for many Zambians, especially the young educated elite,² but the association of AIDS with illicit sexuality and death also resonated with existing concerns about contact with pollution. Among Tonga-speakers, illicit sexuality and death were seen as polluting. Those who came into contact with either could pass on the pollution if they were not properly cleansed. While carrying pollution, they were expected to observe various taboos to avoid transmitting the condition to others. With education and experience with antibiotics and other resources of biomedicine, fear of the old forms of pollution may have diminished or lapsed in the 1970s and early 1980s, only to be reinvigorated with the advance of AIDS.

The arrival of ARV therapy created new dilemmas and new ambivalences about learning of the HIV status of oneself and others. In the first place, the cost of treatment was prohibitive for most individuals and their families. Even at the subsidised price available at one Gwembe hospital by 2003, the cost of treatment for one person outran what most Zambian families could pay, and they might have a number of members with HIV. Drought years and crop failures continued in the early 21st century, and most families were unable to buy food and depended on international aid. They had little or no surplus to spend on other things. And they were not alone in Zambia in being in this condition. By 2004, 73% of the Zambian population was estimated to live below the poverty line, up from 68% in 2000, while malnutrition was said to affect 53% of the population.

Even in 2004, when international donors underwrote free ARV treatment for 100,000 Zambians infected with HIV, in a population with an estimated HIV incidence of 15.6% among those in the 15 to 49 year age range,³ there was no rush to discover HIV status or apply to be enrolled. Those who knew about the availability of free treatment also knew that it was limited to a period of five years after which the cost would have to be met by individuals or by government. The treatment could have serious side effects. Enrolment for treatment was a public acknowledgment of HIV infection. And ARV treatment was a lifetime sentence rather than a cure.

Most people in Gwembe Valley in late 2004 probably knew little about the availability of free treatment. Those who did, including health workers, were not necessarily eager to take advantage of it even though they might know or suspect that they themselves had HIV. They knew it unlikely that government would or could pick up the tab after five years, or that they themselves could afford to do so, especially since salaries have not kept up with inflation and government is frequently in arrears in paying salaries of health workers, teachers, and other government employees. Some said cynically that only those in powerful positions or their kin would receive treatment.

¹ Virginia Bond et al., "HIV/AIDS and Prevention of Mother-to-Child Transmission in Zambia". *Evaluation and Program Planning* 25/4 (2002), 347-356; Laura Nyblade et al., *Disentangling HIV and AIDS: Stigma in Ethiopia, Tanzania and Zambia* (Washington, DC, International Center for Research on Women, 2003).

² N. Ngulube, *Some Aspects of Growing Up in Zambia* (Lusaka, Kenneth Kaunda Foundation, 1989).

³ *HIV/AIDS in Zambia: Background, Projections, Impacts, Interventions* (Lusaka: Central Board of Health, 1999).

Living with AIDS and no ARVs

In 2004, Gwembe people continued to deal with HIV/AIDS much as they had done since knowledge of the condition first emerged: by denial if possible, by the use of biomedicine to cure opportunistic illnesses associated with AIDS when this is available, and/or by consulting African healers for a cure. The majority were likely also to search for underlying reasons why they themselves should be afflicted and find explanation in witchcraft, the anger of ancestors at the abandonment of old ways or failure to honour them, the invasion of new forms of spirits associated with the threatening international order, or, among Christians, God's punishment for sin or the machinations of Satan. But given their current knowledge of diagnostic traits associated with AIDS and their knowledge of what these imply, it is difficult for people to deceive themselves about the nature of a case whatever they may say publicly.

In the 1990s, it became accepted knowledge among Gwembe people that AIDS related illnesses signalled certain death, and people became generally knowledgeable about typical symptoms and modes of transmission. They were then able to diagnose their fellows' illnesses even though sufferers and their kin claimed a different origin. Denial was a refusal to accept a death sentence, as well as a continued claim to the use of resources in a search for a cure. At the same time, denial encouraged the stigmatisation associated with AIDS, for the nature of an illness became hidden knowledge not to be revealed to outsiders and therefore suspect. Since the early 1990s, as the incidence of HIV infection has risen and the number of those unable to work productively and in need of care has grown, the stigma has increased along with fear of AIDS.

Although there is widespread knowledge that HIV is spread through sexual intercourse, and also through the sharing of needles and razors, people also know that you cannot predict who will become infected among the many who have multiple sexual partners or have been exposed to injections (once a favourite form of treatment), and that there may be a long time elapse between infection and the appearance of the first symptoms. Few know their HIV status and many live with the knowledge that they may already be infected, and they do not know who among their fellows is infected. All this leads to a general sense of malaise, made no easier because of the difficult economic conditions under which people have lived since the late 1970s. Angry frightened people, whether they be patients, caregivers, or only worried about their own status, have turned to blaming others as the witches who direct the infection and by combating the witch think to rid the community of the disease. During the 1980s and 1990s, witch finding became endemic to Gwembe Valley as elsewhere in Zambia and throughout southern Africa. Payment to witchfinders was a further drain on scarce resources but was acceptable as a means to at least temporary reassurance.

Meantime, international agencies and local NGOs, equally helpless to cure the condition, stressed the need to change behaviour to prevent further spread of HIV, urged people not to stigmatise those with AIDS, and began to provide some support for the large number of orphans whose plight became a subject of international discussion. Some of the church based NGOs also provided a limited amount of support for the chronically ill. After 2000 they made available a limited supply of ARV drugs, at low cost or as from 2004 at no cost for a fraction of the infected population. What they could not do was make tolerable the circumstances under which those with AIDS are usually cared for or provide the kinds of resources in food and other comforts known to prolong the working life and delay the onslaught of AIDS among those already infected with HIV.¹

HIV has spread at a time when economic conditions have undercut the resources needed to ease the impact of the epidemic upon those infected and those who must care for them. Government support for the health system was radically cut in the 1990s, partly due to

¹ Emma Guest, *Children of AIDS: Africa's Orphan Crisis* (London, Pluto Press, 2003).

the demands of structural adjustment programmes which ignore basic needs. Since then, people have been expected to pay fees for previously free services at a time when medical supplies are frequently lacking and medical personnel is disappearing as doctors and nurses take jobs outside the country. Sanitation, including water supplies, is probably poorer than in 1980, leading among other things to outbreaks of cholera. Two of these struck Gwembe Valley in the 1990s. Unemployment and more frequent droughts mean that people have less money to buy food or to pay for health services. Many can't obtain the nourishing food that delays the onslaught of AIDS infections and speeds recovery from them. Care takers may lack such basic nursing supplies as soap, or clean clothing and bedding. They may be badly nourished, hungry, exhausted, and feel cut-off from others by the stigma that now attaches to those in close contact with AIDS patients. They know they are at risk, for hard-working hands frequently have abrasions and without protective covering come in contact with body fluids. Few outside agencies do anything to help the care-takers, who are mostly women who are also expected to produce much of the family food. They work knowing that they serve those who will inevitably die.

Even the phenomenal growth in membership of charismatic fundamentalist churches has provided little material relief, given the prevalence of stigmatisation and fear of stigmatisation if one is known to have HIV or be in close association with an AIDS patient. On the other hand, assurances that religious belief in itself can both cure and provide one with material success may ease the burden for some.

It says much for the moral fibre of Gwembe people, their fellow Zambians and others in infected regions of Africa that they have continued to provide care for the sick, have come together to bury the dead, and have tried to care for the children left behind. There has not been a total debacle. Somehow they have maintained a respect for their own moral integrity. Many have shown abundant compassion, not just for the moment but over the long months of illness of those for whom they have accepted responsibility. Once, one could have argued that they did this as part of a system of general reciprocity: as they cared for others, so they could expect to be cared for in their turn. But given the death of so many of the intermediate generation, leaving the old without caretakers in their turn, something other than reciprocity is at stake. I would argue that they conceive of themselves as responsible human beings, meeting their obligations as best they can, and so maintain their own self respect.

ARVs and hope

What is described above reflects the situation when I left Zambia in October 2004, when ARVs were just becoming available to the general public. Between then and my return in June 2006, a transformation had occurred as people observed the rapid recovery of those with advanced AIDS who had gone on ARVs. They saw and were convinced. For the first time many were willing to be tested for their HIV status, knowing that now a positive test was not the end of hope. Many who had AIDS, though certainly not the majority, were willing to announce publicly their status as they could point to restored health. AIDS counselling for those on ARVs spread, and so did the provision of special feeding arrangements for those who needed nutritional support. People reported unpleasant side effects as a result of taking ARVs, but found them endurable given their new ability to cope, and weight gains were approved rather than deprecated. Caregivers found their burden lightened as those who had needed care regained health and returned to work. Stigma attached to AIDS continued to exist, but lessened as people no longer lived in such fear of contamination. All this had a general effect as people saw the future

through less pessimistic eyes. People seemed to have new energy and new pleasure in life, though deaths continued and people continued to fall ill. The heroes of the hour were the Europeans who had found a remedy and the donors who supplied the drugs.

During the following year, optimism was maintained and people continued to ask that their HIV status be tested and to go on ARVs if this was appropriate. But those who work in HIV programmes and serve AIDS patients are concerned about what will happen when those now under treatment need new levels of medication, for which so far there are, as of mid-2006, no financial provision.

Responses to the AIDS epidemic over the years have reflected a multitude of factors including knowledge of outcomes, sources of infection, and possibilities of treatment. Responses can be expected to continue to shift as conditions change and so will the moral implications of HIV for those infected, those associated with them, and the wider society which must sustain them.

