Implications for behavioural change in rural Malawi of popular understandings of the epidemiology of AIDS

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Abstract

For people to change their sexual behaviour in response to the fear of contracting (or transmitting) AIDS they must believe that such change will protect them (or others) from infection. Thus, the effectiveness of interventions against a generalized AIDS epidemic depends at least in part on the accuracy of popular understandings of the epidemiology of AIDS. We draw on spontaneous conversations about aspects of HIV and AIDS that were recorded verbatim as part of a panel study conducted in rural Malawi, which has a severe and longstanding AIDS epidemic, to assess local understandings of the epidemiology of AIDS in light of scientific knowledge. The investigation shows that whereas rural Malawians well understand many salient aspects of AIDS epidemiology they adhere strongly to the erroneous belief that if one member of a couple is HIV-positive then the other spouse must be infected as well. Combating this belief would seem to be a necessary pre-condition to attracting couples to seek voluntary counselling and testing.

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Introduction

The AIDS epidemic in Malawi, which is small, landlocked, predominantly rural, and very poor, is both severe and longstanding, AIDS deaths having begun to elevate mortality rates at least as long ago as 1990 (Timæus and Jasseh 2004). Since 1994, the proportion of adults estimated on the basis of antenatal-clinic data to be HIV positive has hovered around 15 per cent. Life expectancy, which had historically been low even by sub-Saharan African standards, had risen modestly to around 45 years in 1985, but has now fallen back to around 40 years (UN 2003). Verbal autopsies implicated AIDS in three-quarters of the deaths of rural adult Malawians between 1998 and 2001 (Doctor and Weinreb 2003). By the latter year rural Malawians were attending three or four funerals a month (Smith and Watkins 2005).

In this paper we seek to gain an understanding of the local epistemology of HIV and AIDS in rural Malawi. Our aim is to determine where local interpretations and understandings of the natural history of AIDS accord with scientific evidence and where they diverge from it. In the latter case, we ask whether incorrect beliefs might militate against effective behavioural reactions to the epidemic.

After describing our data source we first present material that demonstrates how people use their knowledge and experience of the older sexually transmitted infections to draw parallels and contrasts with aspects of HIV infection. Next, we present examples of how people reach diagnoses of AIDS in the absence of testing, and go on to highlight topics that lead to considerable debate and discussion, and to list some strategies that people have adopted to protect themselves from infection, or that they recommend to others. We conclude with a recommendation for an intervention to promote behavioural change.

Data and Methods

Our data source is a rich set of approximately 700 field journals kept by a total of 22 rural Malawians since 1999 on the instigation of the third author. The keepers of these journals were selected from a pool of fieldworkers on a large and continuing panel survey, the Malawi Diffusion and Ideational Change Project (MDICP). Their task was to be alert to the topics of everyday conversations among friends, family, acquaintances or strangers: fortunately for us, chatting is a major form of entertainment in this poor

country. If a conversation contained some reference to AIDS, family planning or, from 2001, religion, they were to listen carefully, and when they could be alone were to write down, in English, what they recalled, as far as possible describing the participants and the occasion and placing the conversation in context. Some journal-keepers were recruited early; others late. Some have been prolific; others have not. Some worked only briefly on this project; others continue to do so. Completed journals (school exercise books) are word-processed and both the originals and the machine-readable files are delivered to the third author. Some journals are available for public use at www.malawi.pop.upenn.edu, which also has more detail about the production of the journals (see especially Watkins and Swidler 2006).

Our goal is to render audible to a wider audience than were party to the original conversations the voices of people who are living in the midst of an AIDS epidemic. Accordingly, the body of the paper is composed largely of verbatim accounts of these conversations. Since many of the conversations are conducted in public they inform not just the active participants in those conversations but possibly a passive audience as well. The audience may be even wider than the participants themselves: the journals show that some elements of some conversations are then reported to others. Who knows how many further discussions and debates have been stimulated by those original exchanges recorded by our journal keepers by the time we read a completed journal?

Our initial task was to read the texts produced by the journalists. Some journals were picked at random, some were picked because they were early, some were picked because the journalist had not been prolific but may have had a distinct voice, some were picked because we remembered their contents. A file of journal extracts that had been coded using the software package NVivo was additionally useful, but only a little more than one-fifth of the journals had been coded by the time of writing. Given the paper's focus, the extracts we present deal overwhelmingly with sex, disease, and death, but this does not reflect the content of the journals as a whole, some of which are packed with AIDS stories, and others of which say little about AIDS, or nothing at all. Many extracts are generic, meaning that a single extract will make a particular point particularly eloquently, but the message is not unique to that extract. Until all the journals are coded, it is not meaningful to count the number of times a particular subject is mentioned.

The journal-keepers are rural residents, some men, some women; all have high-school education (but no more), and participate in other activities, such as farming, in addition to their occasional work for the panel study and their keeping of journals. It is indisputable that their accounts of conversations are filtered through their own perceptions, their own knowledge, their own histories, and their own fears.

A Practical Note

The journals from which extracts have been taken are identified by the author's name (anonymized) and the date of the first entry, expressed in the form year-month-day. Names of people and small places have also been anonymized.

The extracts have been edited to remove repetition and extraneous material that would add unnecessarily to the paper's length. Most importantly, they have been edited also for clarity. While the linguistic abilities of the journalists are superior to those of native English speakers with comparable education—all speak at least two languages (their mother tongue and English)—English is not a language that they use on a daily basis except when they are working with foreigners on this or related projects. In addition, none of the conversations they record was initially conducted in English. With frequent reading of this material one becomes adept at extracting the meaning of an apparently difficult passage despite errors in spelling, grammar, and syntax, but editing was required in order to achieve our aim of allowing Malawian voices not just to be heard but to be understood by a wider audience.

That being said, even the edited extracts are rarely in standard English. In addition, we have not changed some terms that have entered Malawian English. "To move" connotes sexual activity outside marriage; thus "movious" means "promiscuous'. "To depend", as in "to depend on one's spouse", means "to have no other sexual partner". "To propose" carries a range of meanings, from "to proposition" to "to propose marriage". Sleeping with someone "plain" means without a condom.

The journal-keepers occasionally reveal how their vocabularies have been affected by their participation in the project. Words and phrases such as "oedema" and "sexual partner" sit oddly within sentences that are not in standard English, but are the terms the

¹ Significant excisions are identified by "...".

journal-keepers used. We give the English translations of local-language terms for common sexually transmitted infections.

Parallels and Contrasts with Sexually Transmitted Infections

Sexually transmitted infections have been endemic in the region at least since colonial times (Chirwa 1999), and certainly for long enough that Malawian languages have indigenous terms for various internationally recognized infections (for example, gonorrhoea, syphilis) or syndromes (notably buboes, which are a symptom of either lymphogranuloma venereum or chancroid). Understandably, the conversationalists are better at describing symptoms than diagnosing their probable cause. The most obvious confusion is between syphilis and gonorrhoea² but in addition genital herpes is not mentioned by name in any of the journals that we have examined although it is suggested by some descriptions of symptoms.

What is most noteworthy in the following extracts is the linking of symptoms to sexual activity, especially outside marriage.

He went on saying, "Last year in October he contracted syphilis from some sexual partner. He showed me and ... there were some sores; big sores very red and wet, stained with blood. On the front of his penis were many of these sores, like he had burns from a fire, and he said he felt pain whenever he walked. ... He even transferred it to his spouse and both of them were going ... to a private clinic". (Simon 030129)

Then my wife said that when she was at the bore hole her friend came and asked her if she knew anything with regard to the signs and symptoms she was experiencing. ... The friend told my wife ... that in the first day urinating was very painful and also that the urine ... was white and very odorous and producing a bad smell. ... The friend told her that she asked her husband where those symptoms came from. ... Instead of answering her directly he began pleading to her to forgive him. He said that he loved her very much and did not want to be divorced, and ... the big mistake he had done, he will never repeat it.

(Simon 030926)

In demonstration of their acceptance that HIV is also sexually transmitted, rural Malawians draw explicit comparisons between HIV and the older sexually transmitted infections. A common theme of the following extracts, which invoke a past era of greater

² To put this statement into context we note that because the syndromic manifestations of syphilis are so variable it was not distinguished definitively from gonorrhoea until the late nineteenth century (see for example Sparling 1999).

security, is that those other infections were susceptible to traditional treatment whereas AIDS is not just incurable but fatal.

And my mother continued, "In the past we were only concerned we might get buboes, gonorrhoea, or syphilis, but we could look for medicine, herbs and charms, and a patient could get well. But not with AIDS, which has come nowadays and has no medicine, you hear on the radio that even great scientists have no knowledge to combat the disease, hence there is more death among the youth than in our past days. ...

After I had eaten my breakfast I went to the graveyard where most people repeated what my mother had said, that she [the deceased] had been a prostitute and had died, because of her profession, from AIDS. (Simon 000815)

The old man said, "These days are different from our days when we were young. Look, people are just moving anyhow and they don't fear getting diseases. In the past we had herbs to drink in order to protect ourselves from diseases like gonorrhoea and syphilis, but nowadays there is AIDS, which cannot be prevented by drinking any medication or herbs. The only way is to avoid having sex, which is impossible for a man unless he is impotent ["useless"], but for a woman it is impossible. Because even though a woman was born barren she can still have sex." (Alice 010604)

"It was better in the past, when we were afraid of other sexual infections, which were curable, like buboes, so that once you caught them you could look for some herbs and get well. But these days once you have the misfortune to catch that AIDS, you have to know that your passport to the graveyard is ready."

(Diston 030710)

She then began to tell me about her life when she was young. She said that she was very lucky that the time of enjoying her youth was gone and that back then there was not the AIDS disease. She always thanks God because AIDS came when she had already left off enjoying the world, because she would have died. She told me that she had slept with men in her life and she once got infected with gonorrhoea. That was a better time. She did not go to the hospital but she went to a traditional herbalist who helped her to recover. She said that if it was today, she would have got infected with AIDS and she would already be dead.

(Alice 030618)

Some people even say that STIs have become AIDS.

He said that in the old days he could enjoy say eight or ten sexual partners, and he and his friends were only afraid of gonorrhoea, syphilis and buboes because it was simple to get cured with the right traditional medicine but nowadays if one moves with two sexual partners both of them might be infected with AIDS. He went on to say that the diseases he had mentioned like buboes, syphilis and gonorrhoea are nowadays very rare, they have all entered into one disease, AIDS. He said that the badness is that once you are found with it just know that you are certainly dying,

in short you are dead, because there is no medicine even though there are some stupid and foolish traditional healers who claim they can cure AIDS but they are just great liars. (Simon 030813)

People recognize that STI symptoms may appear with great rapidity:

Another friend said that when he was doing tenant farming in Kasungu he had always controlled himself. Then one day when he was completely drunk he met a bar girl there and slept with her ... he regretted in the morning after he woke up and found that he had lost all his money and his male member begun paining a lot and in the first day it was very hard for him to urinate and after a day he ... knew that he had contracted a disease and ... and he showed his best friend who said ... it was gonorrhoea ... (Simon 030905)

In contrast, not days but years elapse between first infection and the appearance of AIDS symptoms. (In the first extract below note the reaction of the main speaker's friends when he mistakenly refers to months rather than years.) The other contrast with STIs is that, as we have already shown, HIV is recognized to be inevitably fatal.

Ndlovi said, "... people take different times to start suffering from that disease, it depends on how strong your blood is. If your blood is weak, it can take only three months for you to start suffering from the day you caught the disease." And Bengo and Lackison laughed and said, "Three months, you're wrong!" And Ndlovi said, "Oh! I am mistaken, I meant to say three years. If your blood is weak, you can die in three years' time and if your blood is strong then you can take up to five years before you start suffering. It is different with other diseases like gonorrhoea, syphilis and buboes because their symptoms appear in seven to twenty-one days from when you catch the disease." (Diston 030219)

The considerable interval between initial infection with HIV and death has been appreciated for some time. Indeed, the first extract below dates from one of the earliest journals, written in 1999.

The young man said, "And it is a better death than dying with AIDS". Some people murmured in agreement.

But someone else said, "It is not a better death, for it's so sudden there is no time to repent one's ways and wickedness. But if one happens to die with AIDS it can take five to eight years." (Simon 990819)

And I said, "So, after the disease AIDS has stayed for three years in the body of the victim, then if the victim catches TB she or he can't last for a whole year, but dies the same year?" "Yes," he said.

And I asked, "This means one can last four years then die of HIV/AIDS?"

"Indeed," Sankho said, "and very few stay up to ten years ... it depends on the strength of their blood ..." (Simon 020615)

The notion that symptoms take years to appear may be well accepted in general, but people still puzzle over the relative survival times of individuals. The simplest view is that they are constant: the person who dies first must have been infected first.

I asked, "Who brought that infection into these families?"

The man replied, "The husbands, ... because the husbands were first to die of that AIDS. In the case of my elder sister, her husband died in 1991 and she followed in 1995, while her daughter's husband died in 1997 and the daughter followed in 1998."

(Diston 020308)

Yet with knowledge of a particular series of AIDS deaths and suspicions of how individuals were infected, many people are dissatisfied with such a simple view. Thus, some puzzle about the relative survival times of women and men, and of adults and children.

And I asked, "Who will be the first to die?"

Sankho said, "It depends on the power of one's blood, if the husband has less powerful blood then he dies faster than his spouse, and vice-versa".

And I said, "What about the children?".

He said, "Children die the fastest because they have less and weaker blood than their parents". (Simon 020615)

If it is possible to conceive of any positive aspect of contracting a sexually transmitted infection it is that it may serve as a warning and prompt a change in behaviour.

The man in the white shirt answered that he got infected with buboes when he was 20 years old ... fortunately he had no wife then. ... He was afraid to tell his parents that he was ill, especially the disease that he had. He told them that he was suffering just from malaria but the disease came to the boiling point so that he started crying with it and he showed his friend the wounds. His friend told him that he was infected with buboes. He escorted him to the herbalist but he was not helped and they began visiting the hospital for help. He was helped very well, and he recovered. Since that time he never had sex with any woman without the use of condoms until he got married. His friends asked him if he is still using condoms with his wife but he ... said that it is not possible to use condoms with your spouse because it means that you suspect her and you don't love her. That case can reach the marriage counselors and they can shout at you.

(Alice 030618)

He then told me that during the abstinence period after his third daughter's birth, he went and slept with a woman ... it was a matter of hit-and-run and he did not even think of using a condom. A week later, he realized that his sperms were coming out, soiling his underwear. I joked to him that since they have a new baby, he will be renewing that affair ... He answered, "Do you think I'd repeat that mistake? I was just lucky that I realized that quickly, ... otherwise I could have infected my wife as well". (Michael 030803)

A sexually transmitted infection may also serve as a warning that the individual may be exposed to the risk of contracting HIV. In that case, there is no second chance.

We had finished eating supper and were sitting at the table chatting. My wife told me that she'd heard that the first marriage of our neighbour Mr. Chandidya is now ending. ... yesterday at the bore hole she heard that Mr. Chandidya had given his wife gonorrhea for the third time. Mrs. Chandidya knows that she is not movious and is certain that her husband gave it to her. And my wife said that everyone at the bore hole agreed that indeed Mrs. Chandidya is a very faithful wife. She doesn't even go to peoples' houses to chat. She goes only to the bore hole and to the market (but not often since Mr. Chandidya usually brings everything from the market for her) and to funerals and to the maize mill. Unlike other women in the village, she doesn't go to initiation ceremonies that do not involve her own relatives. She goes to the mosque every Friday.

My wife said that she is sure the case has already been presented to the marriage counsellors [family elders appointed at the time of marriage]. Mrs. Chandidya's parents are tired of their son-in-law's behavior. ... They say that three times is enough for their daughter to be contaminated by the same sexually transmitted disease and if they do not rescue her from that bad man ... finally he will give her AIDS. (Simon 030918)

Diagnosing AIDS without a Blood Test

Only in early 2006 was voluntary counselling and testing (VCT) introduced into district hospitals in Malawi. Previously, it was available only in the three large cities and to the participants in a few special projects, which effectively excluded most rural Malawians from these services. The near absence of formal testing, however, does not mean that diagnoses—whether correct or not—are not reached through other means.

News of an adult illness or death often creates a suspicion of AIDS. The participants in a conversation typically establish a "social diagnosis" or, in the case of a death, conduct a "social inquest", "social" because the diagnosis is accomplished through a social rather than a clinical process.

A social inquest sometimes rules on the basis of symptoms alone that an individual died of AIDS.

"How do you know that these people died of AIDS?"

[He said] "We know ... because they became thin, developed oedema, had pneumonia, and lastly they had diarrhoea and vomiting." (Diston 020308)

A woman, a neighbour, joined the conversation and said that she had seen the dead woman, that she had lost a great deal of weight and that one could not believe she used to be a plump and giant lady. Even her hair showed that she was suffering from TB accentuated with AIDS. Another woman, also a neighbor, agreed ... Then the friend of my mother said that indeed ... the woman had died of AIDS.

(Simon 031218)

[He said] "According to what I know myself, a person suffering from AIDS always has a weak body and his or her body is always thin and looks pale, especially the face. Their hair is scraggly and they have frequent and persistent malaria". (Simon 020615)

These extracts show that pneumonia, TB, and malaria can be viewed, like weight loss, as "symptoms" of AIDS. But there is also a sense in which such diseases are felt, like the older STIs, to have merged with AIDS.

He also said he didn't mean that people don't die of malaria but the malaria of nowadays is mixed with the virus which causes AIDS, and that's why when one has malaria and dies of it, it's AIDS, but in the past it was different when there were no people with AIDS. Nowadays a lot of people have the virus, and what's worse is when one suffers from TB, the major sub-branch of AIDS. Nowadays it's very rare ... for a person to be cured completely of TB, instead, the person suffers until he or she dies. (Simon 040314)

He laughed and said that it's true because AIDS came a long time ago and its signs and symptoms are widely known to everyone now because each and every day the radio or newspapers or even people when they meet talk about AIDS, and its signs and symptoms, such as when a person who was normally black in complexion, when he or she has been suffering for months, their hair becomes soft like Tinala's, and [their face] pale like his, and they become thinner and thinner like him, nowadays that AIDS is everywhere, one can likely conclude that it's nothing apart from AIDS.

I said, "Maybe it's not AIDS but TB".

He said, "Of course, but the TB of nowadays is three-quarters AIDS, and among the 100 people suffering from TB and admitted to the hospital for treatment, two or five people can be cured because it's real TB which they are suffering but the rest cannot be cured because their TB is a mixture of TB and AIDS.

(Simon 050126)

Some diagnoses draw not only on symptoms, including TB and malaria, but on an individual's sexual behaviour and sexually transmitted infections.

Then Francis said, "That one died in 2001 and his wife died later in 2002. ... That man was a problem, as you know he was operating a bar and he was also a salesman there at Vingula [in the south] and he did not stay with his wife at that time as she was at home at Lumbe [in the north]. Because he was away from his wife for a long time, he was going with bar girls who were coming into his bar so that he caught three sexual infections at different times. First in 1998 he got buboes and he was treated at a traditional healer there at Vingula and got well. He did not change his behaviour towards bar girls so that early in 1999 he got syphilis, he went to a private clinic there at Vingula and it seemed like he was OK, but two weeks later he realized that he was not fully OK as the disease started up again, so then he went to Nsukwa clinic where he was told that he had syphilis and was given some medicine. But he said that he was not feeling any change with that medicine so he went to Banja La Mtsogolo Clinic there at Nsukwa where he was also examined and told that he had two infections at a time, syphilis and gonorrhoea, and he was treated there and he was also given some medicine to use at home and after three weeks, he got well. ... After a year, he had some health problems, he was always down with malaria so that his relatives decided to send him home so that he could seek treatment there. ... His bar was closed and he went home but still things did not go well with his health so that he became worse than before until he died in 2001. Meanwhile, when he died, his wife was not in good health, she was also sick, she did not live a long time but died the following year." (Diston 030614)

But diagnoses can also be made on the basis of symptoms and assumed sexual history alone, without knowledge of an individual's medical or STI history.

Then one of the men told his friend who sat with him, "That lady is found everywhere. I used to see her at Mzuzu, Salima, Mchinji, Kasungu, Zomba, Mangochi, Blantyre, everywhere she was going to these places with different men. Those days she was fat. She had to fight off the men. But now she is becoming sick, and I am sure that she has taken this HIV because her body talks." ...

But his friend said, "... I say that the lady has got AIDS because of how she moved, I have seen her. If someone wishes to sleep with her he should know that he is making his grave."

(Anna 050330)

On the 13th June 2003, I went to attend a funeral at the village of my friend Qualida. The man who died, Mr. Tingo, was the older brother of her aunt, her mother's older sister. ... He worked in South Africa but his sister Qualida did not know the type of job that he'd had.

Mr. Tingo stayed there for about five years without coming home to see his parents and his wife. ... When his friends came back from South Africa to see their parents, they told his parents and relatives that he had got married in South Africa and also had other partners apart from his wife and that what he was doing was very bad.

Now this fifth year, Mr. Tingo came back from South Africa because he was very ill. ... he was very thin, he could not walk or sit down by himself. At that time he

was opening his bowels and he was also coughing very much. He was sometimes vomiting if he started to cough. ... he died in the third week after he arrived.

My friend Qualida sent me a message that her uncle had died and I went to the funeral. Many people knew that Mr. Tingo died of AIDS because they had heard that he was very movious with women in South Africa and his friends had advised him to stop but he refused to listen to them. Some people were gossiping that he had died of AIDS.

(Alice 030618)

Diagnoses are sometimes informed not just by an individual's own symptoms but also by the symptoms and even deaths of newborn babies. The following case is a rare example of an individual confiding to a journalist that she fears she is HIV positive.

I was ... walking with my son ... on a small path which was a short cut to my maize garden and I passed near a certain house where I found a woman with her child in her arms.

She greeted me and my son and I asked her about her child, she had told me some time back that the child was coughing and had sores all over her body ... She said that she doesn't think that her child will recover, it was because ... of her husband's behaviour. Her husband is not faithful and he likes to marry a new woman every year. She complained that her husband sometimes get diseases from other women which he gives to his wife. She also complained that her body has changed since five years ago. She said she had a child two years ago but the child passed away within a few months of her birth, the child had sores on her whole body and after some time, she began coughing ... then she had diarrhoea and died. Still her husband did not stop having many sexual partners. During that time her husband gave someone a pregnancy and the woman had just given birth to a boy child. But both women have the same problem. Mrs. Iweni complained that when she was seven months pregnant she was feeling itching in the whole of her body and when she reached the ninth month she saw that her private parts had sores and the sores were itching ...

Mrs. Iweni is very worried. She said that she thinks that her husband was infected with the AIDS disease from other women and she is worried that her children will be passing away because of that reason. ... (Alice 021108)

Sometimes, conversationalists are ready to infer that an individual is HIV positive solely on the basis of what they believe to be that individual's sexual behaviour. Although such observers claim no knowledge of subjects' symptoms or past ailments, they may draw on what they believe to be the disease status of their sexual partner or the cause of death of a partner's partner: they are moving into the terrain of sexual networks and infection networks.

Adam said, "Look at that young girl." I sensed that he was mocking her and turned to look.

"But she is so beautiful!", I exclaimed.

"Indeed, but she is HIV positive" said Adam.

I asked, "How do you know?".

Adam said, "She is in love with Mr. Kaunda, the shopkeeper at the trading centre, the one who is just getting thinner and thinner...". (Simon 990819)

Then my friend said, "I think that Samuel has AIDS because he married Mrs. Mekison who was a teacher at the primary school. ... Mr. Mekison definitely died of AIDS, and Mr. Samuel has been going with several sexual partners besides his two wives." (Simon 030206)

Not only do people recognize the existence of sexual networks in theory, and the effect that they can have on the spread of HIV, but many evidently believe that they can identify actual sexual networks.

That one is sharing HIV with this village. Many people will die because of her," Baina said.

"Is that true?" Winece asked.

"Yes, she has made a partnership with Mr. Nkhonde, your priest", I said. ...

"You should know that Luwaza has given the virus to Nkhonde and Levison. Then Levison has given the virus to Mrs. Thaimu. And Mrs. Thaimu to her husband, I didn't know if she's got other partners. And Mr. Nkhonde has given it to his wife."

Baina said, "No, Mrs. Nkhonde is a prostitute, they have given it to each other. Did you know that Mrs. Nkhonde has made partnerships with Jonasi and Tijesi?."

"And there's a rumour that Mrs. Jonasi died of AIDS. Jonasi got that AIDS from Naliyera Ndlovi who died last year", Winece said.

"Does the wife of a priest behave like that?", I asked. (Anna 061108)

Such is the strength of the belief in a link between HIV transmission and sexual activity that, as the following extract shows, some people refuse to accept a diagnosis of AIDS made on the basis of a blood test if they believe that the affected individual was not sexually active.

"What happened is that there was a funeral at that village for a certain guy. He had been sick for a long time and was taken to Queen Elizabeth Central Hospital where ... the doctors told his parents he had AIDS. But his parents and other relatives did not believe this so that they took him to MACRO-Blantyre where after a blood test they also told them that he had AIDS. But his parents and other angry relatives did not believe those results saying that he did not use ["was not used to"] girls and asking how it could happen that a guy who did not use girls

could be said to have AIDS. So they took him to a witchdoctor for traditional medicine ... But still the guy died one week later."

Then Mr. Kassim said, "... how could they not believe that he had AIDS when told so by the medical doctors? Did they follow him everywhere he went so that they knew he was not using girls, and so couldn't have AIDS?". (Diston 030614)

Correspondingly, some have difficulty accepting a negative HIV test result if the individual was known to have many sexual partners.

In the evening ... we went to a certain beer drinking place ... and we were chatting there while drinking some beer and as we were chatting, there came a certain man and Mr. Nasitanzia said to him, "Your friend was here yesterday, our sister is admitted at the hospital and she was found that she is lacking some blood. So we her relatives went there to offer her some blood. There were some six people who went there to offer her some blood and among the six, it's I and your friend who have been given an OK to offer her some blood. The other four have been rejected ["condemned"]. But I am wondering about why ... he is fit to give someone blood because he is the only person I thought was going to be rejected because of the way he behaves with women. But he has been allowed ["recommended"] to give her some blood and the people whom I was trusting to be OK are the ones who have been rejected. But he now has to change his behaviour after he has been tested to have infection-free blood. When he has gone for beers, he doesn't just go for beers only, he is always going for women, he doesn't allow a nice looking woman ... to just go by without going for her." (Diston 030116)

Debates and Disagreements

That HIV is sexually transmitted appears from these conversations to be beyond dispute: the same behaviour that might once have led to a sexually transmitted infection now may lead also to AIDS; and people who have too many sexual partners or whose partners, or whose partners' partners, are sick with AIDS or dead, are often believed to be infected themselves. Moreover, whereas the older STIs could be cured, the new one—HIV—cannot.

The unanimity of beliefs concerning these aspects of HIV infection, however, does not extend to all aspects of the virus's epidemiology.

Non-sexual Modes of HIV transmission [but never in a social autopsy]

Despite their conviction that HIV is transmitted through sexual intercourse, rural Malawians also discuss other modes of transmission that they have heard about.

The old man said, "Those men cannot get AIDS because they ... don't have sex". But the second woman disagreed. "Those men can also get AIDS. I heard that there are other ways of transmitting AIDS, like using the same razor blade as your

friend, being injected using a needle which someone else has used, taking care of an AIDS patient and eating together with an AIDS patient. The dangerous way that you cannot prevent is through an injection, because you cannot know whether someone else has used the same needle, and maybe that one is HIV positive, especially our injections in the villages."

(Alice 010604)

The man who was being shaved had sores all over his body and even on his head. He was very thin, he looked as though he had escaped from the TB ward at the hospital...

And an acquaintance said that if another person comes immediately after and wants to have his hair shaved, then definitely he could contract AIDS. ... because the machine razor was cutting the man's sores and definitely it has blood and contains AIDS virus so that if the another person immediately comes, as we hear on the radio that when say a razor blade, a pin, a needle or a knife has cut someone who has AIDS viruses and the same object is used by someone else within ten minutes, the result is the next user contracts the disease.

(Simon 030206)

The women laughed, and one woman said, "Indeed you people who drink beer are at high risk ... some of you when drunk you spit inside the carton and then give it to your friend ... who then catches the virus from your saliva". ...

Another woman said that if indeed saliva also transmits AIDS then no one will be spared because in our homes ... we have patients suffering from AIDS and we eat together with them using the same plate and ... share water from the same cup ... (Simon 041218)

Yet some people are sceptical that HIV can be spread in these non-sexual ways.

Then my in-law said that if it is true what the government is saying on the radio that barber shops can facilitate the spread of the virus which causes AIDS then a lot of people have contracted it and almost every man starting from a young boy and men and some of the women and girls. (Simon 040217)

One Infected, Both Infected

The belief that if a husband is infected then so must be his wife, and vice versa, is expressed with great conviction.

She said, "Yes, indeed, people say that lying together is dying together. If he has HIV/AIDS, I have HIV/AIDS, but I know that we don't have it."

And I asked, "How do you know? Did you go for a blood test?"

She said, "I know my own behaviour ["I know myself"], and he told me one day that he doesn't have HIV/AIDS. He went for a blood test and found that he doesn't have it." (Simon 020319)

Whether the marriage should end if one partner is infected, implying that both are infected, is a topic for discussion and some disagreement.

Paul answered, "If my wife has the disease then it means I have it as well. And ... the marriage can end because I will know that one among us has brought the disease into the family and I will be suspecting her always even though maybe she is not the one but myself."

The others said that for them, the marriage could continue because they would know that they had AIDS, because of the movements we men do we would know that it's the man who brought the disease into the family. (Simon 020506)

The belief that if one spouse is infected it is inevitable that the other is as well leads to considerable puzzlement when one dies, supposedly of AIDS, but the other survives for some years, apparently in good health.

Miss Kananji said that she does not believe that her husband died of AIDS. During the time that he was ill, many people said that he had AIDS since he had several sexual partners. Women did not refuse Mr Masikini because he had money and when people said he was suffering from AIDS, she believed them. When his illness became serious, she took him to the hospital where VCT was done on him and the results were that he was HIV positive.

... It is now almost seven years since Mr Masikini died but Miss Kananji does not show any signs that she has HIV. She said that if her husband was HIV positive she should be HIV positive as well because they slept together, having sex without ever using a condom. (Alice 041124)

My friend said that his brother did not suffer as long as other AIDS patients, say, for a whole year. But what really amazes him is that if his brother did indeed die from AIDS the wife he left behind should have started showing signs of AIDS. ... Four years and some months have passed but still she is very healthy. Indeed, now she is married to another man. (Simon 031112)

Avoiding AIDS

Rural Malawians' understandings and beliefs about HIV and AIDS can affect the AIDS epidemic there only if they act on them. The final set of journal extracts therefore deals with strategies for avoiding AIDS that people either recommend or say they have adopted. All strategies derive implicitly or explicitly from the conviction that HIV is sexually transmitted, rather than from non-sexual means, although not all people are willing to declare that it is possible to modify one's sexual behaviour.

He said that people are now aware that AIDS is mainly spread though sex. People are avoiding sharing razor blades, needles, toothbrushes because the message is well known to them and understood, but even though they understand ... that it's

good to abstain from sex, people are failing to control their nature ... Other means of preventing themselves from contracting AIDS they are able to follow, but not abstinence. (Simon 030711)

References to condom use have already appeared in the context of preventing becoming infected by an extramarital partner with an STI. One conversationalist explained, however, that he did not continue to use condoms after he married because "it is not possible to use condoms with your spouse". The efficacy of condoms in preventing HIV transmission also appears in the journals, but again in the context of non-marital sex; the headmaster below clearly has a fondness for paradox.

The headmaster said that nowadays, those who sleep with movious girls are the ones who are safe from the virus which causes AIDS.

He said this is because any man sleeping with a movious girl or woman, a prostitute or one working in a bar, makes sure to use a condom and hence is protected, while a man who doesn't sleep with bar girls ... and trusts his sexual partner ... that she doesn't move around ... how many sexual partners she had he never knows, and whether the partners were safe from the virus or not, and because of trusting her he ends up sleeping with her plain and hence catches AIDS. (Simon 040308)

The notion of "trusting" one's sexual partner appears in various guises. One way is to take care in selecting a spouse or a partner.

"And because I knew about her behaviour from the beginning, even when she was at school, and then when she was married, I know she will indeed be a good wife. She has good manners, and other people commend her. Mr. Mkumba commended her right there when we were drinking. I waited for almost three months ... trying to find out more about her." (Simon 990819)

Care in partner selection, however, clearly means different things to different people.

We chatted and then one man said that it's better nowadays to go after these young girls because they are not really sexually active, if anything ... they've just started and not had more than five sexual partners ... and the chance they have the virus is lower than for an adult woman who has slept with many partners...

(Simon 041002)

Some people—perhaps many—view AIDS widows and widowers as particularly dangerous.

My friend said that it would be good that if a husband died of AIDS then anyone proposing the wife should stop proposing her, and the one who is proposed to should not accept the man's proposal, and the same if a wife died of AIDS. If

people did this, AIDS could not have spread as it has nowadays.

(Simon 040314)

A strategy mentioned in various conversations is to marry, and to be faithful within marriage.

He said that when AIDS came to Malawi, people say in 1981, he was not aware of it and he was not married then and had many sexual partners, ... until 1996 when he began hearing more about AIDS. ... By that time he was older and he noticed that some people who were movious and not married but instead went with sexual partners were losing weight and dying. So he decided to marry, taking into consideration his late grandfather's advice that he should marry rather than just move around ... From the time he married he began living a faithful life, and to say the truth, his wife is a faithful one ... he knows that he will never meet another wife as faithful as her. (Simon 031223)

She said she is very lucky because AIDS came after she changed her behaviour and got married. I asked her if she is faithful to her husband and she told me that she had stopped those things that she was doing and now depends only on her husband. She fears getting infected with AIDS and dying. We did not continue talking about that because I reached home and I left her proceeding on her journey to her house.

(Alice 030618)

And his friend said that this is not the time to play with life, there is AIDS. He said that he had stopped having sexual partners and now two years had passed and when he wanted to have sex he asks only his wife and not any other partner. We were still drinking and the young man continued by saying that he had observed that women are the same and we differentiate them by their faces and their clothes but the fact is that all women were created the same, we men tend to feel ... that such and such a woman is sweeter than my wife, but this is a foolish idea in these days of AIDS. (Simon 031016)

These individuals changed their sexual behaviour when they married, or after marriage, because they feared AIDS; indeed, the first individual married precisely because he feared AIDS. Other people, however, did not change their behaviour unaided but sought outside assistance.

He said, "... In 1996 we heard about Chisupe³, the traditional AIDS healer ... I went with my spouse and children to drink the medicine there, as others were going. After I had drunk the traditional medicine, together with my spouse, we agreed that it was time to trust one another and that each should be faithful to the other. Since 1996 up until now, I have never slept with anyone besides my spouse. In this time of AIDS, I can't do that. (Simon 020319)

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³ Billy Goodson Chisupe gained considerable fame in Malawi in 1995-6, and hundreds of thousands of "patients", by offering a herbal cure (*mchape*) for AIDS: see for example Voysey and Gray (1995).

Implications for AIDS Prevention in Rural Malawi

The dominant theme of many of these overheard conversations is that HIV is transmitted through heterosexual intercourse. Indeed, the link with sexual activity is so firmly established that people may disbelieve a clinical diagnosis of AIDS if they believe that the sufferer was not sexually active, and may disbelieve a negative diagnosis if the individual is believed to be highly sexually active.

AIDS diagnoses among these rural people are commonly made without the benefit of a blood test. Sometimes, as in two of the cases mentioned above, the social diagnosis (which conflicts with the clinical one) was reached solely on the basis of what was known or believed about an individual's sexual history. More generally, the evidence that informs a social diagnosis or a social inquest comprises some combination of an individual's symptoms, his or her sexual history, and the symptoms (or survival) and sexual history of the individual's sexual partners or partners' partners.

Whether or not such individual diagnoses are correct, the processes by which they are formed reveal that people possess a great deal of accurate knowledge. They know the physical symptoms of AIDS, and they know that a symptomless individual may yet be HIV-positive. They understand that opportunistic infections such as TB and malaria may be involved—not that people use such language, rather they say that TB and malaria have "become" AIDS. They appreciate the protective benefit of sexual fidelity, and the danger of dense sexual networks—not, once again, that they use such terminology.

Many conversationalists draw on their understanding of the older sexually transmitted infections as a template for understanding the newer HIV and AIDS. Most obviously, the same activity that in the past led merely to a sexually transmitted infection may now lead to HIV. Yet people also contrast STIs with HIV. They claim, albeit incorrectly, that STIs were curable by traditional means, curability being claimed perhaps because these infections are episodic, with symptoms receding after some time, with or without treatment. People contrast such curability with HIV, which they judge, correctly, to be fatal. They are also correct in contrasting the short incubation periods of STIs with the long one of HIV.

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⁴ Deaths from tertiary syphilis do not seem to have registered on the popular consciousness: background mortality is high; such deaths are not inevitable; they could have occurred decades after initial infection; and their symptoms are highly variable.

The debates and disagreements recorded by our journal-keepers are revealing. One such debate concerns non-sexual modes of HIV transmission although most of the routes mentioned do not in fact pose a danger of transmission since HIV is a fragile organism, highly susceptible to exposure to air. However, such conversations tend to have an air of high abstraction, and it is difficult not to suspect that there is sometimes an element of one-upmanship, as in "I know more ways than you do, I remember them from the radio!". In being able to list numerous non-sexual ways in which HIV can be transmitted people demonstrate not that they believe these ways to be significant: no social diagnosis or inquest concludes that the virus was transmitted by sharing a razor blade, a cup, or a plate; nor is avoiding sharing such items ever seriously recommended as a prevention strategy. Rather, people demonstrate that they are receptive to information disseminated over the radio or by other means. Given such evident receptivity it is regrettable that at least in the past such public-health messages were not invariably accurate.

Some topics of debate or disagreement are more salient to AIDS prevention than others. People puzzle over relative survival times—Is the first infected the first to die? Do women survive longer than men?—but such questions are more informative about people's desire to understand this new disease and the difficulties they face in appreciating its long incubation period than they are suggestive of possible interventions. In contrast, there is considerable talk but no disagreement concerning the inevitability of mutual infection. So strongly is it believed that if one spouse is infected then so must be the other that people are puzzled when one spouse dies of AIDS but the other remains alive and apparently healthy, so puzzled, indeed, that they may doubt that the death was AIDS-related in the first place. Correspondingly, some view AIDS widows and widowers with deep suspicion, believing that AIDS could not have spread as it has if such people had abstained after the death of their spouse.

Other information collected in the course of the Malawi Diffusion and Ideational Change project is consistent with the belief in the inevitability of mutual infection. For example, when respondents to the 2001 MDICP survey were asked how likely it was that

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⁵ Injections, which were named in some conversations, pose a danger if syringes are re-used. Blood transfusions were not mentioned although transmission via infected blood is inevitable, but transfusions are rare in rural Malawi.

a single act of sexual intercourse with an HIV-infected person would infect the other partner, over 90 per cent answered that the probability of transmission was either certain or highly likely (Anglewicz and Kohler 2005). A comparison in the 2004 round of the MDICP of individuals' self-assessed HIV status with their actual status revealed a tendency to pessimism: seven out of eight incorrect self-assessments were false positives (Bignami-Van Assche, Chao, Anglewicz *et al.* 2007).

The belief in the inevitability of mutual infection is probably reinforced not just by knowledge of cases where both spouses have died of AIDS but also by an analogy drawn with the older STIs. In this case, however, the analogy is ill-founded because whereas STIs are highly contagious, HIV is not. The per-coitus male-to-female probability of transmission of gonorrhoea, for example, which is the most infectious STI, is as high as 0.50, but that of HIV may be as low as 0.003 or even lower (Anderson 1999). Indeed, the only estimate derived from an African study places the per-coitus transmission probability at 0.001 (Gray, Wawer, Brookmeyer *et al.* 2001). Even allowing for a considerably higher transmission probability in the very early (and asymptomatic) stage of infection, and in the presence of an STI, HIV is still orders of magnitude less likely to be transmitted than an STI. As a result, the inevitability of mutual HIV infection can be rejected on the basis of probabilistic considerations alone.

More direct information, on the sero-statuses of husbands and wives, further confirms that mutual infection is far from inevitable. According to a recent study of couples in five AIDS-affected African countries, at least two-thirds of infected couples were sero-discordant (that is, only one of the two was HIV positive); accordingly, no more than one-third of infected couples were sero-concordant (both people infected) (de Walque 2007). These are the proportions for Kenya, where 11.0 per cent of couples overall were found to be affected by HIV. In Tanzania, with 10.5 per cent of couples affected, only one-quarter of infected couples were sero-concordant.

As de Walque (2007: 505) concludes, this finding suggests an additional target population for HIV prevention—not just the "women and girls, youth, men who have sex with men, injecting and other drug users, sex workers, people living in poverty, prisoners, migrant laborers" and so on—namely, the HIV-negative cohabiting partners of people who are HIV-positive. An important step in implementing such an intervention, unlike

ones directed at those "key populations", would be to encourage and enable couples to undergo voluntary counselling and testing. A major obstacle to such an exercise, however, would be the popular belief that mutual infection is inevitable. Either both are sero-negative, or both are sero-positive, people might argue, so what would be the point of being tested? A critical first step in this intervention, therefore, should be to attempt to dispel the belief in the inevitability of mutual infection.

Probabilities are abstract constructs, and rural Malawians are not alone in exaggerating their magnitude. For example, women of reproductive age who were interviewed at five American shopping malls grossly overestimated the risk of pregnancy while using contraception. Forty per cent of participants thought that the annual risk of pregnancy using a "very effective" method (sterilization, implants, injectables and IUDs) was 15 per cent or greater although the actual risk is no more than one per cent (Steiner, Dalebout, Condon et al. 2003). Nevertheless, the proportions of women who were able to answer correctly greatly increased after they were provided with information. Similar results were obtained in intervention studies of reproductive-age women in India and Jamaica: initially they exaggerated the risk of pregnancy while using contraception; after they were given information their knowledge improved (Steiner, Trussell, Mehta et al. 2006). Given rural Malawians' susceptibility to information broadcast on the radio or by other means, as evidenced by their "knowledge" of non-sexual modes of HIV transmission, we do not believe that it is over-optimistic to predict that a well-designed, pre-tested public-information campaign to counter the belief in the inevitability of mutual infection could be successful. BEANSpaper

Fears have been expressed that the provision of antiretrovirals in sub-Saharan Africa, or the knowledge that antiretrovirals are available, may lead to behavioural disinhibition (for example, Wawer, Gray, Serwadda *et al.* 2005). (Even so, such pessimists do not advocate that antiretrovirals not be used.)

Likewise, fears that behavioural disinhibition might create objections to a public-health campaign that broadcast the information that the transmission probability of HIV is so low that mutual infection is not inevitable. Nevertheless, failure to counter the popular belief that mutual infection is inevitable would seriously hamper a programme to encourage couples to be tested, thereby jeopardizing the identification of sero-negative

spouses of sero-positive individuals. Moreover, failure to take active steps to counter this mistaken popular belief might be seen as tantamount to supporting the position that AIDS in sub-Saharan Africa can be combated only through fear.

The conversations on which we have been eavesdropping reveal that rural Malawians are struggling not just to understand AIDS—and that they understand a great deal—but that they are struggling to understand AIDS in order to combat it. People do talk about behavioural change. For example, some individuals say to their friends that after contracting a sexually transmitted infection they either started to use condoms with extramarital partners or refrained from illicit sex altogether. An acquaintance of the "movious" man unexpectedly found to be HIV-negative says that he must now change his behaviour. Some people have taken marrying to signify that they will now limit their sexual attentions to one partner; others have come to the decision to have only one sexual partner only some time into their marriage. External assistance has been of benefit to some, notably the couple who, after having together sought out and drunk Chisupe's "cure" for AIDS, swore to be faithful to one another thereafter. That intervention will have been effective independent of their sero-statuses. If they were both sero-negative, they will have remained that way. Although it is a little early to pronounce the marriage infection-free—they vowed mutual fidelity in 1996 and the journal extract dates from 2002—at the very least, if either of them were sero-positive in 1996, infection will not have spread beyond that family.

Voluntary counselling and testing of couples can be viewed as providing a similar watershed opportunity as the drinking of that herbal "cure". Some reviews of the literature are enthusiastic about its potential (e.g. Obermeyer and Osborn 2007), others more skeptical (e.g. Yeatman 2007). Even those who are sceptical of the general effectiveness of VCT on the grounds that the implications of a negative result are identical to those of a positive one—the ABC of Abstain, Be faithful, use a Condom to protect oneself if one is sero-negative, to protect others if one is sero-positive—do not dispute the value of couple testing, because the detection of sero-discordance might lead to the adoption of measures to protect the uninfected partner from the infected one (for example, Yeatman 2007). In that event, the effect of VCT would have been superior to that of drinking the herbal cure since the probability of transmission within the marriage

will have been reduced.

Rural Malawians demonstrate considerable ingenuity in forming social diagnoses of AIDS and in performing social autopsies, and in aggregate terms their assessments may compare rather well with the results of blood tests. Nevertheless, what matters to individuals is surely not the aggregate picture but their own HIV status, and that of their spouses and lovers, but it takes a blood test for that to be determined unequivocally. Indeed, that 71 per cent of self assessments in the 2004 round of the Malawi Diffusion and Ideational Change Project, whether negative or positive, were validated by HIV testing is impressive, but should not be allowed to obscure the fact that 29 per cent of self-assessments were incorrect, primarily because so many thought they were positive when they were not (Bignami-Van Assche, Chao, Anglewicz *et al.* 2007).

The HIV-negative spouses of HIV-positive individuals have been identified as an important target population for AIDS prevention efforts, but the widespread belief in rural Malawi—and possibly elsewhere—that mutual infection is inevitable militates against effective interventions to encourage couples to seek voluntary counselling and testing. To counter the belief in the inevitability of mutual infection and thereby encourage the testing of couples would give the numerous HIV-negative individuals who would be identified not just hope but the opportunity to take steps to remain that way.

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