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## The social construction of AIDS during a time of evolving access to antiretroviral therapy in rural Malawi

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### Abstract

This paper draws upon a set of conversational journals collected over the past decade in rural Malawi, to understand how perceptions of AIDS are constructed as talk of antiretroviral therapy (ART) filters through social networks. Three distinct treatment eras frame our analysis: the early ART era (2001–2003), the ART expansion era (2004–2006) and the later ART era (2007–2009). We find that the early ART era was characterised by widespread fatalism as people recalled experiences with dying family and friends from what was perceived as an incurable and deadly disease. During the ART expansion era, AIDS fatalism was gradually replaced with a sense of uncertainty as rural Malawians became faced with two opposing realities: death from AIDS and prolonged life after ART. In the later ART era, the journals chart the rise of more optimistic beliefs about AIDS as rural Malawians slowly became convinced of ART's therapeutic payoffs. We conclude with an example of how ART created difficulties for rural Malawians to socially diagnose the disease and determine who was a safe sexual partner.

### Keywords

HIV/AIDS; antiretroviral therapy; treatment optimism; sub-Saharan Africa; Malawi

### Introduction

Over the past decade, access to antiretroviral therapy (ART) has improved dramatically throughout sub-Saharan Africa (UNAIDS 2010). In the generalised HIV epidemics of the region, increased exposure to ART has the potential to change perceptions of the disease and reduce stigma associated with AIDS (Preston-Whyte 2003; WHO 2003; Zuch and Lurie 2012). Most social science research on ART in sub-Saharan Africa, however, focuses on those who are on treatment (e.g., Seeley et al. 2009; Smith and Mbakwem 2010; Zuch and Lurie 2012), rather than the larger body of people navigating the HIV epidemic who may perceive and respond to ART differently. There are a few population-based studies on how beliefs about HIV and AIDS are affected by ART, but these only capture beliefs at a single point in time (Cohen et al. 2009; Yeatman et al. 2012). Such snapshots cannot describe the process of changing beliefs in response to expansive HIV prevention and AIDS treatment interventions.

The way people perceive new health information about AIDS depends upon how this knowledge is situated within local belief systems about the body, illness and disease (Ezekial et al. 2009). Research on HIV interventions designed in the West but implemented in Malawi shows that local interpretations and responses may differ substantially from how

these programmes are intended to function (Tavory and Swidler 2009; Angotti 2010; Angotti, Dionne, and Gaydosh 2010; Kaler and Watkins 2010). Studies from the region demonstrate that ART programmes themselves affect beliefs about AIDS and how people respond to ART at the local level (Kalofonos 2010; Rasmussen and Richey 2012). A broad examination of how ART services are understood and talked about within local discourse is important not only to understand treatment-related behaviour, but to gain a theoretical appreciation for how structural elements of health services are received and interpreted across rural communities.

Social networks provide an important, readily accessible and trusted source of health information and support for people living amongst an AIDS epidemic. Through everyday conversations with each other about what is known, heard or experienced, people collectively formulate their own perceptions of AIDS and its interventions (Watkins 2004; Watkins, Swidler, and Biruk 2011). In this paper, we take advantage of a unique set of conversational journals to study how rural Malawians come to understand AIDS during a decade of evolving access to ART.

### **The social construction of diagnosis and illness**

We adopt Brown's (1995) view of social construction of diagnosis and illness to frame our analysis. In his version of social construction, Brown emphasises the synthesis of both symbolic interactionist and structuralist approaches to examine diagnosis and illness. Brown's perspective goes beyond people's exchange of meanings to include how they relate to professional and institutional structures where this interaction takes place. In our investigation, we focus on the micro-level and follow how rural Malawians' interactions with each other and with larger ART structures influences how treatment is understood and shapes local perceptions about AIDS. We conceptualise ART structures to refer to global, national and local institutions that develop and implement AIDS interventions. While rural Malawians interact directly with these structures, their experiences are often indirectly shaped by AIDS policies developed far from their home villages.

Brown (1995) also argues that the social construction of a phenomenon is a dynamic process and involves a multiplicity of social forces that combine to create and modify the phenomenon. He states, 'Rather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux' (37). In rural Malawi, the emergent phenomenon of ART is constructed not only by factors related to treatment access and availability, but also by the respective roles of healthcare professionals, traditional healers, mass media, government and non-governmental organisations in the AIDS epidemic. Over time, these social forces evolve and combine to influence local understandings and experiences with AIDS and treatment.

### **The local context**

Approximately 11% of adults in Malawi are infected with HIV (National Statistical Office & ORC Macro 2011). Antiretroviral therapy first became available for pay in urban public hospitals in 2000, although at the time only a small group of patients could afford the drugs (Van Oosterhout et al. 2007). During early rollout, clinical shortcomings, drug supply interruptions and difficulties determining eligibility imposed limitations on quality of care and access to ART. With the assistance of donor funding, ART was scaled up between 2004 and 2006 at large hospitals and offered free of charge. Adults were eligible if they were HIV-positive and in WHO clinical stage 3 or 4, or had a CD4 count less than 200 cells/L (Ministry of Health [Malawi] 2003). Over this period, the number of patients on ART within the public sector increased from approximately 4000 to 60,000 (Lowrance et al. 2007). In

2009, almost 200,000 people were taking ART (Ministry of Health [Malawi] 2009). However, recent WHO estimates show that only 48% of adults in immediate need of ART currently receive treatment in Malawi (WHO 2010). Challenges remain for ART programmes to overcome clinical problems with ART staging and eligibility, continuity of care and staff shortages (Makwiza et al. 2009; MacPherson et al. 2012). Nonetheless, the ART programme in Malawi is widely heralded as a success in the region (Harries et al. 2011).

## Methods

### Data collection

The data for the present study come from the Malawi Diffusion and Ideational Change Project (MDICP), a longitudinal study exploring the role of social networks in shaping AIDS and fertility-related attitudes in Malawi (Watkins, Zulu, Kohler, and Behrman 2003). Data collection has been ongoing since 1998 in three rural research sites across Malawi: Mchinji in the central region, Rumphu in the north and Balaka in the south. This study does not use MDICP survey data but, rather, takes advantage of a wealth of qualitative data consisting of approximately 900 journals written by local Malawians around the MDICP study sites. The journals span the period from 2001 to 2009, when ART was gradually expanded throughout Malawi.

The MDICP journal project asked local interviewers to listen to everyday conversations about AIDS, recall what was discussed as close to word-for-word as possible and to write down the details as soon as possible after the conversation occurred. Since the researchers never defined what was meant by ‘conversations about AIDS’, the journals reflect the writers’ own judgements about what was appropriate to document. While conversations took place in the local languages, all the journals were written in English.

The journalists were in their 20s or early-30s, English-speaking and relatively educated (with the equivalent of a high-school degree). They were paid approximately \$30 USD for each 80-page notebook they filled, with the average notebook consisting of 7500 words. The project hired 22 journalists (9 women, 13 men) to document conversations around AIDS, with 3 journalists (2 males, 1 female) contributing very frequently, 13 frequently and 6 only occasionally. See Watkins and Swidler (2009) for more details on the journal methodology. Since journalists often wrote about personal conversations with friends and family, we changed all names – including those of the journalists – prior to data analysis. All journal excerpts are cited using the pseudonym of the journalist and the date of the journal entry.

### Analysis

The data were coded in two stages. In the first stage, graduate students associated with the MDICP project coded the entire set of journals using the NVivo 7 software by allowing topics and themes to emerge from the data. We focused the present study on entries that received the broad code of ‘VCT/ART’, which was assigned to passages on voluntary HIV counselling and testing (VCT), AIDS drugs and treatments (including traditional medicine) and treatment issues such as access, side-effects and expense. All relevant passages were output from NVivo 7 to a text editor, where we examined the reduced set of journal entries line-by-line, eliminating passages relating only to VCT and retaining passages that mentioned the following words: medicine, medication, cure, incurable, drug, heal, healed, healing, herbs, traditional medicine, treatment, treat, vaccine, vaccination, tablets, capsules,

ARVs, antiretrovirals, antiretroviral therapy, AZT<sup>1</sup> and *Chambe*.<sup>2</sup> This process resulted in approximately 835 passages from 575 journals.

In the second stage of analysis, we employed a more detailed coding strategy and inductively looked for recurring themes in the discussion of AIDS treatment (Boyatzis 1998). One of the advantages of using a set of journals that span a decade is the ability to capture changing perceptions of AIDS as ART became more available. We focused our analysis around three ART time periods: the early ART era (2001–2003), the ART expansion era (2004–2006) and the later ART era (2007–2009) by comparing and contrasting the major themes within and across each era. Each author analysed the data independently, compared codes and resolved any differences until final themes were agreed upon.

## Results

### The early ART era and AIDS fatalism

We found that the early ART era was characterised by an overwhelming sense of fatalism as people witnessed others in their communities dying from ‘an incurable disease’ known as AIDS. Fatalistic beliefs about AIDS were juxtaposed against more favourable attitudes towards other curable diseases, particularly sexually transmitted infections (STIs). Rural Malawians drew upon their knowledge and past experiences with STIs in order to situate AIDS within the broader discourse on health and illness. Even though AIDS was contracted through the same sexual routes as STIs, it was distinguished from other infections by its lethality and incurability. People talked about how their ancestors sought care for common STIs through traditional healers, but found that these same herbs did not work for AIDS. People commented that it was better to contract a curable STI, because with AIDS, ‘once you get it, you end up in the grave’ (Diston, 13/8/2002). In one account, a journalist named Alice wrote about her conversations with a man named Mr. Phiri. While talking on the veranda, they overheard a conversation among a group of men passing by. One of the men bragged to his friends about his sexual partners. In response, Mr. Phiri told Alice how these men were stupid because ‘these days are different from the past days when our grandparents were young’. He continued:

That was the time [before AIDS] when sexually transmitted diseases were common in the world. People were suffering from *bubos*,<sup>3</sup> syphilis, and gonorrhoea. If one was not moving well [sleeping around], he/she was getting infected with those diseases but they were lucky because the diseases had some medicine for people to recover. Some people who were shy to go to the hospital were just going to the traditional healers who were also able to heal that disease. But these days of ours are very different from those days. We are in more danger than our parents and our grandparents. These days we have the disease, which has no cure. It is only one disease but it is killing many people because it has no medicine from the hospital or even at the traditional healer. Nobody can manage to heal someone who is suffering from AIDS and therefore we must take care.

(Alice, 14/8/2003)

As exemplified above, many of the conversations around incurability and death concluded with warnings to others about the perceived dangerousness of AIDS and the need to ‘take

<sup>1</sup>Malawians used the acronym ‘AZT’ to refer to a commonly prescribed antiretroviral drug called *Zidovudine*.

<sup>2</sup>*Chambe* is the local term given to traditional herbs used to treat HIV and AIDS.

<sup>3</sup>The Chichewa word *bubos* literally translates to Chlamydia, but is often used colloquially among rural Malawians to refer to any type of sexually transmitted infection.

care', a local euphemism for practicing safer sex. Without ART to fall back on if one got sick, the journals showed that people provided their own form of HIV prevention counselling by encouraging neighbours and friends to be cautious so as not to get AIDS from an unfaithful partner or through other non-sexual routes.

Antiretroviral therapy did not reach the rural areas until 2005 and so rural Malawians –even if they had heard of the new medicine – still lacked access to it. Therefore, many people understood the disease as synonymous with death. The journals showed that once a person was diagnosed with AIDS (either locally or through official routes), the individual was considered 'already dead' or in a liminal state of 'waiting for their death' (see Kaler and Watkins 2010 for more discussion). These beliefs grew out of negative experiences with hospitals and traditional healers who could not cure AIDS and could do little to treat opportunistic infections. In the following passage, a female journalist named Alice recalled her conversation with a friend about how a dying woman's family sought multiple forms of care for her, but she was unable to recover:

I asked her to tell me what she heard about the reason why Miss Banda was chased away from the hospital and she told me that the doctors knew that the patient was suffering from AIDS therefore there was no need to keep her at the hospital since they knew that she was waiting for her death. He told them [the family] that the hospital had no medicine for that disease which the patient was suffering from. When they went back home, they were trying to look for the traditional healers and tablets, which they were buying from the groceries. Still nothing was showing any progress [helping] with the sickness so they went back to the hospital again. The nurse told them that she wouldn't have given their patient any treatment since she had already seen that the person was dead. The relatives were told to carry their patient back home on the same day and they stayed home for another year while she was still suffering from many different diseases at the same time. Her relatives reached the point of leaving her like that. Everyone stopped buying tablets for her.

(Alice, 23/5/2003)

Around this time there were whispers of new life-prolonging drugs that were locally referred to as 'ARVs'. The news about these drugs was usually followed by doubt as to whether poor villagers would ever be able to access them. Even for those who had access, ART was considered to only delay an inevitable death and people expressed concern that they had to be taken every day for the rest of life – unlike any other drugs they had seen before. A journalist named Simon documented one of the first references to ART in the journals. In his account, a woman talked about how she heard on the radio about new drugs for AIDS but perceived them to be largely inaccessible to the rural poor. She said:

AIDS has no medicine, even the radio announces. And one time I heard that the medicine was found, not to cure, but just to prolong the life of the patient a little bit longer. But the drugs are very expensive that a poor person like me or us born from a poor family cannot afford them but rather be dying like chickens.

(Simon, 19/6/2002)

At that time, ART was offered as a fee-for-service in the large cities and thus it was not surprising that villagers expressed disbelief that the ordinary person would ever be able to access treatment. In the next section, we show how AIDS fatalism was gradually replaced by uncertainty and confusion as rural Malawians became faced with two opposing realities: death from AIDS and prolonged life with ART.

## The ART expansion era and uncertainty around ART

As access to ART improved, conversations slowly shifted from an emphasis on fatalism to a more active debate about the perceived benefits of and barriers to ART. Compared to the past, rural Malawians now talked about their direct personal experiences with people on ART or others they had heard about through their social networks. Some of these individuals were reportedly revived from the dead, while others showed no signs of improvement and later died. At this time in Malawi, patients initiated ART only once they developed AIDS-defining symptoms (WHO Stage 3 or 4) and many were unable to recover with such compromised immune systems. As a consequence, the effects of ART on health and prolonged life appeared almost stochastic: that is, some people on ART remained sick and later died, while others appeared to fully recover. A journalist named Alice recalled a discussion from a village meeting about HIV/AIDS. One man in the group started the conversation with an example of a married couple on ART where the wife improved, but the husband did not. He stated:

Mr. Phiri and his wife started buying the tablets [ARVs] and they were drinking them. The woman is now better off [healthier] but her husband is still not feeling well. Though he is taking the tablets, they are not helping him. If one is infected with HIV, he will stay with it for life.

All the attendees agreed. Then the group chair said:

He had been hearing from people that HIV/AIDS is a disease which has no medicine. People have been trying by taking their patients who have AIDS to the hospital to be admitted there, but the result is that they go home with a funeral. Even if the patient is at home or at the hospital, the result in both areas is death. This means that it is a disease which does not allow any type of medicine.

(Alice, 10/9/2004)

In this group of people, uncertainty regarding who recovers from the disease and who does not led to a more fatalistic conclusion that AIDS was still incurable and deadly. More credit was given to ART's failure to help the husband over its demonstrated success with the wife. The uncertainty of ART resonated in another conversation between an optimistic man and a sceptical woman about the benefits of ART. Alice wrote:

The man was saying that the ARVs are helping some of the people in the villages so that their bodies are changing and becoming strong. The woman answered that those who are lucky are feeling well, but some of them are found ill because of the ARVs and they are causing many other diseases.

(Alice, 29/10/2004)

For people who seemed to tolerate the drug, the woman equated the success of ART to pure luck as opposed to the triumphs of modern medicine or to a discernable characteristic of the ART patient.

While discussions often led to negative conclusions about ART, some journal entries offered a more nuanced perspective of ART characterised by lively arguments around ART's effectiveness and its positive impact on the AIDS epidemic. In one such debate, a journalist named Daniel overheard a conversation in a restaurant among a group of people who just attended a community event on HIV/AIDS at the local trading centre. One of the women started talking about the event and said:

That last speaker bored [irritated] me. He cannot say that one should go for VCT. The moment one can know that he/she is positive, like myself, I can commit

suicide. I can kill myself because for one to be told that he or she is HIV-positive, it is a problem!

People in the restaurant laughed and she continued to say:

Ah! You think AIDS is a simple pandemic. But there is death after being found positive to it. I tell you *kachilombo* [literally a small animal, used locally to refer to the HIV virus] is dangerous. To my side [in my opinion], if I can be found positive I will think of dying immediately.

In response to her pessimism around AIDS, another event attendee, named Mr. Kamphilu, spoke up and said:

Eee! Sister, why do you make that decision? Please, people are surviving for some years, there is a bit of life after being found positive to the *kachilombo*. These are drugs called ARVs. There are a lot of people who are currently taking these drugs, maybe a million people, but they are still alive. Do not think that it is bad.

(Daniel, 30/4/2006)

The above passage highlights the contrast in opinions about ART and its implications for AIDS during this period. The woman said she would commit suicide since AIDS would take her life regardless, while the man presented an overly optimistic example with ‘a million people’ on ART who are surviving. Perceptions of ART, such as those of Mr. Kamphilu, became more ordinary during the later ART era as fatalism and scepticism were gradually replaced with more optimistic beliefs about ART.

### The later ART era and the rise of optimism

During the later ART era, beliefs about AIDS continued to evolve as people who were presumed to be HIV-positive were reportedly brought back to life through ART. Not only did ART have a transformative effect on physical appearance, but some people became so healthy that they could once again lead normal lives fulfilled by sex, marriage and childbearing (see Smith and Mbakwem 2007 for similar findings in Nigeria). In the following passage, a journalist named Trueman wrote about a conversation he overheard about an upcoming wedding in the village. The groom was rumoured to have AIDS and be on ART, and people recalled when he almost died from the disease:

That’s true, he is on ARV treatment. I remember the way he was a year ago, he was almost dead. I think that this medicine has assisted him a lot. [interrupted John].

As long as you follow the instructions you get from the hospital, you get fully recovered and you can do all your work as you normally do. You know that people who don’t know him cannot think that he has got AIDS, he is almost the same as everybody else. [Chanzo interrupted].

And this is the goodness of getting tested, you are able to know about your blood status and if you are found with the small animal [HIV virus] you are able to start treatment. [explained Andrew].

But what I know is that people with AIDS are told to refrain from sex and not to marry. Then why has this one married? [asked Charles].

Listen, the truth is that its not that people with AIDS should not marry, no! But he/she should follow all the instruction given at the hospital and one of them following safe-sex practice and the like. But with these two people it’s a different issue. The two met at the people living with AIDS club. [added Andrew].

Does that means that the woman has also got AIDS? [asked John].

Yes, they are all HIV-positive and they take the medicine together. That's why they are getting married because they know one another and they belong to the same club, you see. [explained Moses].

But are they able to do the family job [have sex]? Are they not afraid of one another? [asked John].

Yes, they are able to do it as a family but they are advised to use a condom all the time to avoid increasing the number of the small animals [HIV virus] and they are also advised on other issues. That's why you can see that they are able to work. They are able to garden their field because they are following these advices. [explained Andrew].

(Trueman, 31/1/2007)

The conversation illustrates how one man with AIDS appeared normal and 'almost the same as everybody else' because he took ART and diligently followed the advice given to him by health professionals. Antiretroviral therapy allowed this man to get married, have an active sex life with his wife and even perform laborious work in his vegetable garden. It is noteworthy that none of the five men in this conversation expressed any fatalism towards AIDS as they attempted to make sense of the groom's lived experience with ART. In another conversation documented by Alice, two women talked about a girl who was expected to die from AIDS but initiated ART and survived. She eventually appeared so healthy that it was hard to recognise her from before:

The first woman said, "She just used the ARVs for two years then we saw her body changing. She was not able to walk, but when she began using the ARVs, she was now becoming fat little by little. She is now looking like a healthy young woman. I can see that she looks pregnant. Am I wrong?" Mrs. Kalenga answered, "you are not wrong. That one is pregnant. We heard that she is married to her fellow AIDS patient." The other woman asked, "Are you sure?" And Ms. Kalenga replied, "Yes. She is married to her fellow AIDS patient and now she is pregnant."

(Alice, 1/9/2008)

A few journal conversations suggest that ART might normalise HIV infection by allowing people to live longer, productive lives thereby reducing the perceived dangerousness of the virus. In the following excerpt, a journalist named Alice and her friend talked about how the epidemic of today is different from the past when some people were so fatalistic they would kill themselves upon a positive diagnosis:

The friend said, "Now the situation [the AIDS epidemic] is changing. It seems that HIV is now powerless. It is not taking place [affecting people] as it was the past few years ago. People will enjoy the world very soon because this disease will end for sure." Alice asked, "Are you sure?" The friend responded, "Yes, can't you see that in these days people are not talking much about HIV. People were afraid going to the hospital for the blood test but not in these days. Many people are going there voluntarily in order to know their status and even if they have heard that they are HIV infected, they are asking the doctor to be giving them the ARVs. While in the past, people were committing suicide after hearing that they are HIV-positive."

(Alice, 6/11/2007)

The friend dismissed the dangers of HIV with her comment, 'people are not talking much about HIV', as if it is no longer new and important health issue but rather something that is ordinary and manageable. In another passage, two women concluded that ART is not only changing lives, but also the trajectory of the HIV epidemic. The first woman said:



“But those who decided to make the ARVs will be blessed. They are saving people’s lives. Many people would have already died because of this disease but they have tried their best making the tablets, which are helping people in their lives.” The journalist responded: “That is true. As far as we heard about that HIV, it is a dangerous disease with no medicine. That was a long time ago, many years have gone by since then. It had been killing people until now and had it been that there was no protection [referring to ART] given to people, something would have happened I tell you. This world would have ended because of this disease therefore we have to thank those who are very intelligent. Though people cannot get recovered with ARVs, many of them are living longer. Their lives still exist because of the ARVs. We have to appreciate that.”

(Alice, 6/11/2007)

The second woman’s position shows a dramatic shift in thinking from the early ART era when some people speculated that the entire population of Malawi would be eliminated due to AIDS. Despite the presence of more optimistic beliefs about ART’s transformative effect on personal lives and on the epidemic in general, rural Malawians still expressed reservations regarding the implications of ART on HIV prevention. In the final section, we conclude with an example of cautious optimism, in particular, how ART created difficulties for rural Malawians to socially diagnose HIV and determine who was a safe sexual partner.

### **Antiretroviral therapy alters the local diagnostic process**

Using the same set of ethnographic journals, Susan Watkins (2004) described how rural Malawians came to collectively diagnose people with AIDS based on their physical appearance (e.g., loss of weight, diarrhoea and failure to recover) and what may be known about their sexual history (e.g., multiple partners, a partner who died or is ill with symptoms associated with HIV). In the absence of testing, people used these socially constructed diagnostic techniques to warn each other about risky sexual partners and to identify partners perceived as safe. Once testing became available, some people learned others’ HIV status through their disclosure (Anglewicz and Chintsanya 2011). Nonetheless, people still frequently relied on diagnostic tools because they provided a more publicly accessible form of information than someone’s private HIV test result.

The journals charted how these local diagnostic tools started to evolve over time with the spread of ART. In 2006, a female journalist named Alice conversed with a man she knew while he was on his way to the funeral of a nearby village headman. He told her that a certain Mr. Ozumba ‘has not many days living in this country. That man has AIDS and it is showing that he took it from Chisomo’s mother or that the woman got it from the man.’ A few days later, Alice followed up on Mr. Ozumba, who she learned has since died. Her conversation partner, Jacob, reported:

Chisomo’s mother is left alive but she is not feeling well. Since she started bearing children they die, up to four children have died. She was also not feeling well. Her body was not looking nice, after some days we saw Mr. Ozumba’s body as well that it was also not fine. But people were exaggerating that the woman was bewitched by people for her not to have some children. Now today, the people from the hospital have revealed that it was AIDS and not HIV. Everybody knows that the woman as well has AIDS and it is what she is suffering from.

AIDS is like all other diseases only that it is more dangerous than other diseases. Every person will die though with AIDS or not. People were talking that the teacher Mr. Chomba died of AIDS and his wife was really showing that she had it. But since they are rich, they are just buying the ARVs and now she is very fat.

Other people who don't know her can think that she was born like that since she is fat and she is looking very beautiful.

(Alice, 5/12/2006)

The conversation reveals that in the ART expansion era local diagnostics continued to have utility – the two speakers knew the sexual history and symptomatology of the first couple and concluded with confidence that both had AIDS. As they moved on to discuss the second couple, however, Jacob described how ART allows people's health, and particularly their weight, to rebound. While the recovery of health was generally perceived as a virtue of ART, the fact that people returned to a healthy weight made it difficult for those who did not know their history to discern an individual's true status. This point also emerged in the following quote. Here, a male journalist named William overheard a group of people gossiping about a man who was perceived as being particularly promiscuous. One of them said:

Eeeh! So it is true that it [ARVs] even makes people look healthier than those who don't have it. I was wondering why these days he is growing fat while the rest of this family they are now turning bony. I didn't know if it is because of this February [meaning hunger season].

But, why doesn't he share his drugs with his wife because still more people will be suspicious with them through the looks of his wife, they will know that he is on the dosage though he looks strong and healthy. [said the old man in trying to compare his looks with those of his wife].

(William, 9/1/2006)

The participants of the conversation were not confused by the fact that this man looked healthy despite his sexual proclivities and prior physical symptoms; they knew he had AIDS because of this history. The older man's comment demonstrated that even people who did not know the man's past might still have suspected he had AIDS because of his wife's poor health – such is the nature of AIDS, it is not something to be diagnosed just by looking at an individual but also by assessing his or her partners. But this exchange also suggested that these diagnostic tools were evolving as the list of symptoms once associated with AIDS became less clear-cut. Indeed, in 2010 when a survey project in the town near where many of the journalists lived asked a random sample of more than 2000 young people whether ARVs make it hard to know who has HIV, just under three-quarters of respondents strongly agreed or agreed with the statement.<sup>4</sup>

As ART became more widespread in rural areas, the journals charted even more changes in and challenges to old diagnostic techniques. As long as one knew someone's sexual history and long-term symptomatology, the old methods could work, but in the absence of that history, people came to realise that it was difficult to tell if someone had AIDS based on their physical appearance alone. In 2008, a journalist named Diston described a conversation among his male friends as they sat on his brother's veranda. The men were talking about the wife of a bar owner who they all observed growing thin but had recently started to get fat. Dalitso said:

Those ARVs are not good because they do make someone who has got AIDS to look just as healthy as someone who doesn't have that AIDS which is also one way of promoting the spread of that disease as those people who don't know the background of such a person do have unprotected sex with such people as they do think that that is how that person naturally looks like.

<sup>4</sup>Data come from the Tsogolo la Thanzi project (details are available at: <http://projects.pop.psu.edu/ltt>).

Then, Issac said:

That is true, just imagine how Agnes grew thin because of AIDS in the past years. But these days when she is using these ARVs, she has become so fat so that when she has come in the bar, those men who can see her for the first time, they can just think that that is how she looks like without knowing that she has become fat because of the ARVs. I agree with you Dalitso that these ARVs can surely promote the spread of that AIDS because it is going to be difficult for people to know who has got AIDS and who doesn't have AIDS because we have seen someone growing thin, we do know that that one has got AIDS like how it is with Ruth, the wife of Wilson, where it is easily seen that she is infected because she is growing thin.

(Diston, 24/12/2008)

Over time, people's initial surprise that someone who once had AIDS symptoms could look healthy again was supplanted with concern that one could no longer easily tell who had AIDS and therefore might be drawn to an unsafe partner. This change also prompted the more general concern that without identifiable symptoms the epidemic would continue.

## Discussion

Our analysis charted the historical trajectory of beliefs about AIDS as access to ART unfolded throughout Malawi. While the journals presented a wide variety of opinions, understandings and reactions to ART, we highlighted the predominant underlying sentiment in each of the three treatment eras: AIDS fatalism, uncertainty around ART and the rise of optimism. Brown (1995) argues that treatment and outcomes of illness often operate as feedback loops to revise the original social construction of a disease. Similarly, we found that the dominant belief of AIDS as a death sentence slowly became less prevalent (although still present) as more people became convinced of ART's therapeutic payoffs.

Through their social interactions with each other and with larger ART structures, stories from the journalists revealed that rural Malawians systematically filter and process complex health information about AIDS and its treatment and respond accordingly. Rather than immediately reacting to the news of life-prolonging drugs with optimism and hope for the future, the journals showed that people reacted with caution and scepticism until the benefits appeared to outweigh the costs. Even in the later ART era, accounts of scepticism were still present despite the rise of more optimistic beliefs about AIDS. These findings may help to explain the low levels of treatment optimism found in a recent population-based study from southern Malawi (Yeatman et al. 2012).

We also found that shifts in the physical presentation of AIDS affected the strategies that Malawians used to determine who was HIV infected and considered a safe sexual partner. Our findings from rural Malawi are similar to those found by Ezekial and colleagues (2009) in Tanzania. They described ART as interfering with what people knew about the symptoms of AIDS and therefore contributing to HIV transmission. In the journals from rural Malawi, it was clear that local diagnostic strategies were not discarded with the introduction of ART. Rather, the diagnostic process was forced to evolve alongside the changing therapeutic environment. In other words, people cautioned each other not to read too much into current physical appearance and, where possible, to look further back into someone's physical and sexual history in order to assess their risk as a partner. This was not without challenges, of course, and these strategies were frequently recounted and debated in the journals.

Our data and methods are subject to a number of limitations. First, it is possible that journalists were biased in what conversations they chose to document, such as only documenting conversations they deemed interesting. While such bias is possible, the large

number of journalists that participated in the project should compensate for some of this. Second, the journal project was scaled back significantly in 2007 and as a result, it is possible that saturation points may not have been reached for findings during the later ART era. More qualitative research is needed to supplement our findings in order to evaluate how attitudes and perceptions towards ART shift in response to improved access to treatment in sub-Saharan Africa. Additional weaknesses of the conversational journals are discussed in depth elsewhere (Watkins 2004; Tavory and Swidler 2009; Watkins and Swidler 2009).

We contribute to a growing body of literature that examines how HIV interventions are interpreted by the recipients of such services (Angotti et al. 2009; Tavory and Swidler 2009; Angotti, Dionne, and Gaydosh 2010; Kaler and Watkins 2010). Antiretroviral therapy has been widely promoted by global health institutions as a critical response to the AIDS epidemic (WHO 2003; UNAIDS 2010). Despite the unchallenged accolades of ART in the West, perceptions of ART among the rural Malawians in our study were less straightforward. The recent collapse of the global economy has significantly scaled back existing drug supplies in many African settings (UNAIDS 2009) and threatens to reverse any gains in optimism around ART. Only time will tell if ART is a sustainable treatment option in Malawi and how future access will impact the population's perception of AIDS. We recommend that researchers continue to monitor perceptions and beliefs about ART and the implications for sexual behaviour given the looming challenges that remain for ART programmes in rural Malawi.

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