

CONCEPTIONS OF AND RESPONSES TO HIV/AIDS: VIEWS FROM TWENTY ETHIOPIAN RURAL VILLAGES

Alula Pankhurst

Department of Sociology and Anthropology
Addis Ababa University

INTRODUCTION

HIV/AIDS has become the most important health problem in Ethiopia and a threat to the social and economic fabric of the nation (Pankhurst and Kloos 2000). Estimates of HIV infections ranging from two to three million were published in 2000 and 2001; AIDS deaths were estimated at more than 200,000 in 2001 alone, and the number of AIDS orphans was estimated at 1.2 million (MoH 2002, UNAIDS 2000, 2002).

Although there is a burgeoning literature on the subject – a recent bibliography (Converse *et al.* 2003) includes over 940 references – two major biases are prevalent. First, the bulk of existing research and publications to date have dwelt on the medical side, notably clinical, laboratory and epidemiological problems. Social and cultural factors, which in fact must be of central importance given the nature of the epidemic as a social rather than a medical problem, have tended to be overlooked and are under-researched,¹ with much of this literature focusing largely on specific groups notably commercial sex workers (e.g. Baardson 1991), People Living with HIV-AIDS (Annania 2000, Sebsib 2002), street children (Getnet 2000), ex-soldiers (Gizaw 1992), and traditional birth attendants (Negassa and Wolde Michael 2001). Other studies tend to be based on rapid surveys of Knowledge Attitude and Practices (KAP), often of college students, and particularly about condom use, and “traditional harmful practices”.²

Second, the bulk of the literature relates to urban areas, and very little is known about rural areas, and especially how people understand the epidemic and react to it in the countryside (Kloos and Damen 2000:14). Even on prevalence rates there is a paucity of data for rural areas. The 2002 estimates suggest that rural HIV/AIDS prevalence was of 3.7 percent, which is almost four times lower than the estimated urban prevalence of 13.7 percent (MoH 2002:9-10).³ However, this data may not be fully reliable as the Ministry of Health acknowledges since it was collected from only six sentinel surveillance sites, in two regions⁴ and on limited data for army recruits.⁵ Information on rural people's perceptions and attitudes is even more limited.

This paper seeks to contribute to redressing these biases, by presenting evidence primarily on social and cultural perceptions from twenty rural sites from the four major Regions of Ethiopia: Amara (four sites), Oromia (eight sites), Southern Peoples' Nations and Nationalities Regional State (henceforth Southern Region, six sites) and Tigray (two sites) (see map).

All 20 sites are ones in which a considerable amount of prior research has already been undertaken. Panel data was collected in 18 of these sites by the Economics Department of Addis Ababa University, with the International Food Policy Research Institute and the Centre for the Study of African

¹ Only 36 out of 942 references in Converse *et al.* (2003) are classified as “socio-economic and demographic”. Notable exceptions to this trend are two MA theses in social anthropology by Annania Admassu (2000) and Sebsib Belay (2002), and two special issues on HIV/AIDS published in *Northeast African Studies* (Kloos and Pankhurst eds 2000, and Kloos and Pankhurst eds *in press*) which bring together 13 papers including several by Ethiopian anthropologists and sociologists.

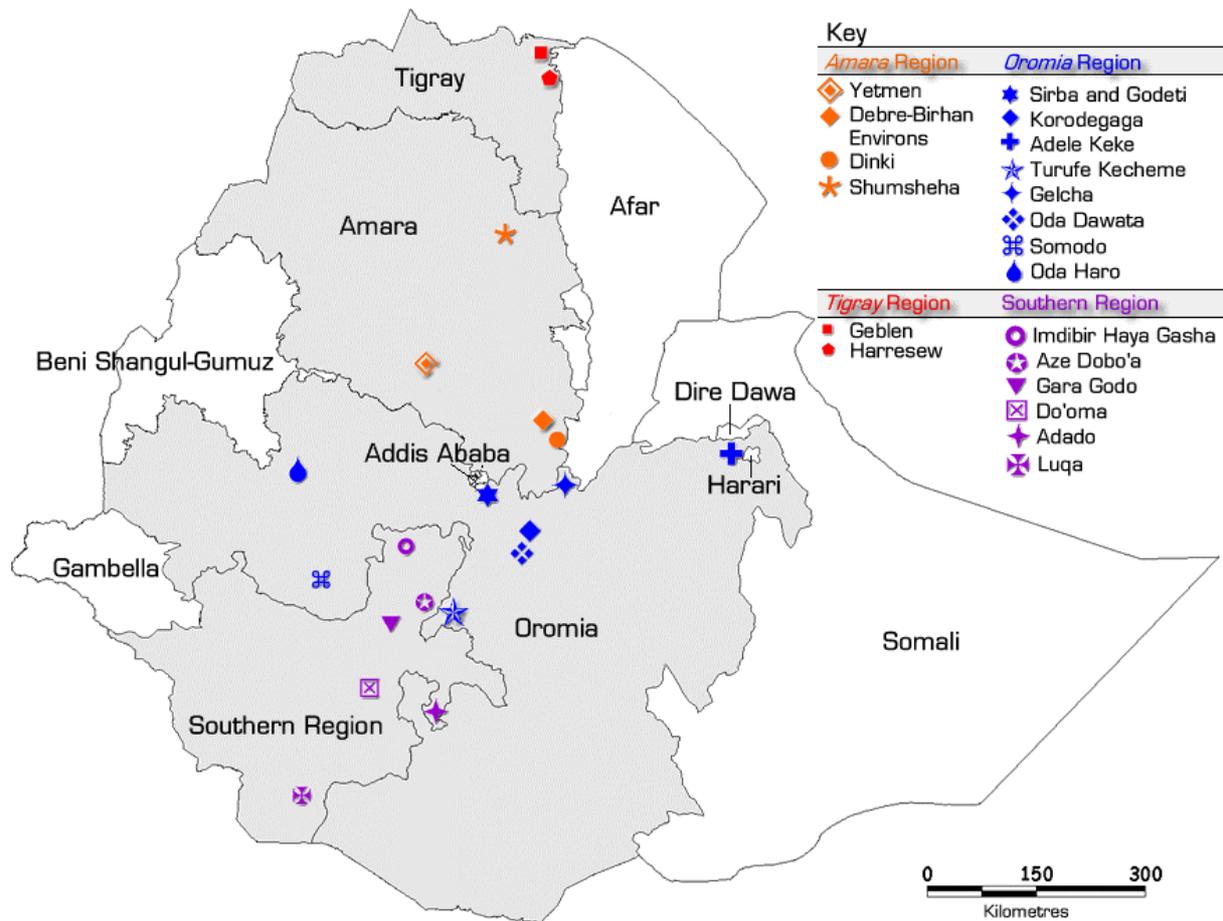
² For a recent review see National Committee of Traditional Practices 2003.

³ The data for urban and rural sentinel surveillance sites are based on the percentage of pregnant women testing HIV-positive in 2001.

⁴ Five of these rural sites were in Oromia and one in the Southern Region, and the overall prevalence was 2.3 percent (MoH 2002:10).

⁵ This was based on 64,000 recruits nationwide giving a prevalence estimate of 3.8 percent (MoH 2002:10).

Economics at the University of Oxford. The household survey data was gathered in five rounds, the first in 1989 comprising six food-insecure sites. By 1995, fifteen sites representing different agro-ecological zones and degrees of market integration were included and community profiles by anthropology students were prepared into villages studies for each of these sites (Bevan and Pankhurst eds 1995). Three further sites were added in 1999 to take account of cash crop producing areas. Since the selected sites did not include pastoralist areas two sites in which anthropologists from Addis Ababa University have conducted intensive PhD research on pastoralism were added in 2003.



The four sites in Amara Region are: *Debre Birhan Environs* and *Dinki* in Tegulet Wereda North Shewa, *Shumsheha* in Bugna Wereda, Lasta, North Wello, and *Yetmen* in Inemay Wereda, Gojjam). The two sites in Tigray are: *Geblen* in Subhsaesie Wereda and *Haresaw* in Atsbi Wereda). The eight sites in Oromia are: *Adele Keke* in Kersa Wereda, Harerge, *Oda Hara* in Bako wereda, West Shewa, *Oda Dawata* in Tiyo Wereda Arsi, *Gelcha* in Fentale Wereda, Kereyu, *Korodegaga* in Dodota Wereda, Arsi, *Sirba and Godeti* in Ada'a Wereda, *Somodo* in Mana Wereda, Jimma, and *Turufe Kecheme* in Shashemene Wereda); the six sites in the Southern Region are: *Adado* in Gedeo, *Aze Deboa* in Kambata, *Imdibir Haya Gasha* in Gurage, *Gara Godo* in Wolayta, *Do'oma* in Gamo, North Omo and *Luqa* in Tsamako, South Omo).

Research methods and limitations

The research on which this paper is based was part of the grounding phase of a research project entitled Wellbeing in Developing Countries (WED) carried out in four countries, Bangladesh, Peru, Thailand and Ethiopia, based at the University of Bath, UK. The central objective of the WED research is to contribute to an improved collaborative understanding of the dynamics of poverty, inequality and quality of life and the interlinkages between them. The project seeks to develop an integrated multi-disciplinary conceptual framework and appropriate methodological tools resulting in an innovative approach to the study of wellbeing in developing countries. Within the Ethiopian context, the WED team is seeking to analyse the production, reproduction and reduction of poverty within inequality dynamics and in relation to the cultural constructions of subjective wellbeing.

To carry out the grounding work 40 students, one male MA student in anthropology and one woman MA graduate, student or BA graduate went to each of the sites for a month in July-August 2003 and asked a range of questions divided into 8 modules to a limited number of respondents. Module 5 entitled "Responses to crises", included a protocol on HIV/AIDS with 29 questions asked of two respondents each. The data was sent to Bath where it was entered into the ACCESS data base which was used to produce tables for each of the questions.

The fieldwork data presents a number of limitations and challenges to interpretation: 1) Although interviewers were expected to provide details of the social status of respondents this was not done systematically nor by all interviewers. 2) The number of respondents was limited to two men and two women per site, and the interviewers had the freedom to choose respondents whom they thought would be willing and knowledgeable. This may have introduced biases, and in some cases some respondents did not answer all the questions. 3) The responses to the questions contain a lot of data, since, for each of the 29 questions (see appendix), there were up to 80 respondents, some of whom made several points, some of which were contradictory, which rendered analysis quite complicated. 4) It was quite difficult to make quantitative analysis of proportions of answers, since the questions tended to be open-ended and the answers were sometimes vague, ambiguous or unclear. 5) Some of the questions were found to be quite difficult by informants, notably those relating to dividing effects of HIV/AIDS into social, cultural and economic factors. 6) The nature of the topic is sensitive, particularly in rural areas, and, even though interviewers were briefed to try to be understanding and sympathetic, the willingness to answer questions frankly was probably constrained. 7) For a few of the questions the interviewers were instructed to ask the question first without prompting and then to ask about specific points; however, this probably influenced some of the answers. 8) Given the amount of data only a limited discussion of differences by gender and by site have been attempted in this paper, although further analysis on this issue will be carried out. 9) Although very interesting quotes have been provided the selection of these had to be limited by space – an arbitrary rule of keeping the quotations to a maximum of three per heading was observed. Some of the quotes were selected because they were striking rather than because they could be considered representative. 10) Respondents were assured that their identity would be kept confidential. Where they mentioned specific named individuals only initials have been used in quotes so that individuals cannot be identified.

This paper is divided into the following five main sections: 1) local understandings of HIV/AIDS, 2) knowledge of AIDS deaths, people living with HIV/AIDS and AIDS orphans, 3) perceptions of differential effects of the epidemic, 4) community involvement in HIV/AIDS prevention and patient care, and 5) perceptions of the effects of HIV/AIDS on social, economic and cultural relations.

1. LOCAL UNDERSTANDINGS OF HIV/AIDS

This section discusses local understandings of HIV/AIDS in terms of the following four aspects: 1) terms used to describe the illness, 2) when and how people found out about HIV/AIDS, 3) views on the origins and means of transmissions, and 4) similarities and differences with regard to other diseases.

1.1. The Cobra and the Disco: terms for HIV/AIDS

Among the twenty villages there are four ways of referring to HIV/AIDS: 1) simply using a local variant of the English term, which was the most common option; 2) referring to the disease by its symptoms; 3) alluding to its contemporary and/or urban nature; and 4) calling it by terms that indicate its power and dangerousness.

The majority (70 percent or 50 out of 71 respondents) either used the English term AIDS or did not mention any other local terms. However the pronunciation was often adapted to suit local preferences; variants include: *Aidsi*, *Adsia*, *Adisa*, *Ades*, *Adis*, *Aise*, *Edise*, *Eedsii*, *Eski*, *Ekis*, and *Yedis*. This may suggest that AIDS is not generally associated with existing local diseases and/or that awareness of the disease has spread largely through the media and government health services.

A second way of referring to HIV/AIDS is using words that describe its main symptoms. The most common of these were terms referring to the disease's effect of making people thinner. Thus the term *amenmin* in Amharic could be translated as: "makes waste away" and the Oromiffa equivalent is *liqeesa*. Other examples are *lefe ch'ech'ebso* suggesting that AIDS "breaks the bones" mentioned in Turufe in Oromia, and the expression *melesi wedia harge*, meaning "A disease which kills by drying" mentioned in Do'oma in the Gamo area of the Southern Region. Some respondents mentioned other symptoms such as loss of hair and the teeth protruding.

A third way of referring to HIV/AIDS was to emphasise its contemporary nature as a recent arrival and/or as a disease of recent times or the present generation. Examples include terms such as *yezemenu beshita* meaning "the disease of the [recent] times" in Amharic or *yezebareye basha* meaning "disease of this generation" in Gurage, and *dhukuba bera* or *dhukuba addis* meaning "the new disease" in Oromiffa or *bereke tukuba* meaning the "newcomer disease" in the Gedeo language. In Luqa in the Southern Region AIDS was specifically referred to as "the urban disease".

A fourth way of referring to HIV/AIDS is to emphasise its potency, mercilessness, and fatal nature. This is mainly reflected in terms such as the "killer disease" an illness "without medicine", and the expressions: "It kills people when it catches up with them", and "It kills after eating up a person's flesh". In Oda Dawata in Oromia it was referred to as "the Wild One" or "the Merciless". The term that best captures this view is "the Cobra" mentioned in two widely distant sites in Oromiya, in Arsi and in Jimma. The disease was referred to as that of "cursed people" in a site in Tigray, and in the Debre Birhan Environs in Amara respondents referred to it as *meqseft* meaning "a punishment from God".

Perhaps the most intriguing local terms mentioned was "the Disco". This refers to the digital watches, which are popularly known as "Disco" because the dots flash on and off. The connection is that a person with AIDS is at times well and at other times ill, and alternates between the two.

1.2. Time and ways of learning about HIV/AIDS

In 1990, women of our village who were working in the cities came back to get treated by their family and everybody was saying they have Aids and they died in 1992. And the health workers talk about it every time, that is when I heard about it. (Woman in Haresaw, Tigray)

In 1990 here in Adado from people who had been to Shakiso for gold-mining. (Young man, Adado, Southern Region)

In 1999 on the radio when people who were carriers used to speak about it. (Woman in Oda Dawata, Oromia)

Although HIV/AIDS has been known to have existed in Ethiopia since 1984 the data from this research suggests that knowledge of the disease was limited in rural areas until the 1990s and in the more remote sites until after 2000.

Respondents were asked when they first heard about HIV/AIDS, from where and/or from whom. The earliest mentions were two cases in 1986, one being an elderly farmer who was former Kebele

secretary in Korodegaga, Oromia, and the other an old man in Shumsheha, Amhara, who had heard it on the radio while a soldier in Eritrea. The most recent mentions were two cases in 2003, the same year as the interviews, both in remote sites in the Southern Region. Both respondents were women, one in Aze Deboa in Kambata, who heard it from health workers, and the other in Doma, in Gamo, who heard about it when investors came to the area. Out of 47 informants who mentioned a specific year the majority (85 percent) had heard about AIDS during the EPRDF period and only seven respondents had first heard about it during the Derg period.

Regarding information sources the most important were the radio, schools and health services, as well as migrants returning from cities and from abroad. The radio was mentioned by a quarter of informants (16 out of 67). Some mentioned the place where they heard about it on the radio, which included at school, in towns such as Awasa. One person specified hearing PLWHA speaking about their experiences on the radio. The next most important source of information was schools mentioned by 15 percent of respondents (10 informants). Two of these mentioned teachers talking about it, another that a PLWHA came to speak to their school and a third that representatives of an NGO in Kambata came to speak to their school.

Eight respondents mentioned hearing about AIDS in the village from “people talking”, and seven said that they heard about it when migrants came to their villages either ill and returning to die in the villages or coming back with the news. These included women who had worked in towns especially in Northern sites, migrants returning from gold mines in a site in the South, and a migrant from Saudi Arabia in Tigray.

Five respondents heard about it from health workers, four from Kebele or *Wereda* officials, two at meetings in towns, two from churches or missions, two each from relatives (grandfather and uncle), friends, and NGOs (Both in the Southern Region, one was a Kambata women’s NGO, and the other EPARDA a pastoralist NGO working in Luqa). One respondent each heard about it from posters, in a factory in Metahara, and during a training. Six persons said they could not remember where and from whom they had heard about it.

1.3. Local views on the origins and means of transmission of AIDS

It happens due to unsafe sex. For example if a woman have sex with lots of people and have sex with one of the men. She would transfer the disease to this man. This man also have many wives. He could also transfer to his wives. (Married mother of one child, Luqa, Southern Region)

I believe that the 8th thousand has arrived when God will let us know his power. Our religious holidays are now working days, the priests instead of preaching are looking after earthly enjoyment, are armed or involved in politics. God is to punish us through this disease. (Man in Geben, Tigray)

“What we say is that “it is from God in response for our sins”. What we learn from the mass media is that “it is by unsafe sexual intercourse, by touching one’s wound.” (Judge in Oda Dawata, Oromia)

The question: “How/why did the epidemic come about?” was interpreted in two different ways. Most respondents understood the question in terms of means of transmission, and the rest discussed the origins of HIV/AIDS. Out of 67 persons who answered this question, nine said they did not know, probably meaning they did not know how the epidemic came about rather than they did not know about the means of transmission of HIV/AIDS. Indeed one young married woman explained: “I don’t know where or how it started. But I know that it is transmitted sexually through intercourse”.

1.3.1. Perceptions of means of transmission

About two-thirds of the respondents spoke of sexual transmission (38 respondents). Some added qualifications including promiscuity or sex with several partners (5) unprotected or unsafe sex (3), adultery or extra-marital sex (3), unrestricted or uncontrolled sex (3), prostitution (2), and one each mentioned sex before marriage, unnatural sex, and bars and night clubs. Other means of transmission mentioned related to blood contact, including sharing blades or razors (8), contaminated blood (5), unclean needles from injections (4), “harmful traditional practices” (by which respondents referred to

female circumcision, dental or uvula extraction, incisions on the face, tattooing, and body piercing), (4), and contact with wounds (3). One person mentioned beliefs that it is transmitted by touch, and another simply said it was the result of “stupidity”. It is remarkable that unlike some other studies (Getnet 2000) respondents generally seemed to have fairly clear ideas about the transmission and there were no mentions of strange beliefs about transmission unlike in some other studies (Ayalew 2000).

1.3.2. Perceptions of the origins of HIV/AIDS

In terms of the origins of AIDS three views were held by roughly the same number of respondents: 1) that it came from abroad, 2) that it was a form of supernatural retribution, and 3) that it was associated with sex with monkeys. Ten respondents mentioned that it came from foreign countries, two of these specifying America, one of whom claimed that it was specifically meant to kill Ethiopians. Another respondent mentioned that it came from sexual relations Ethiopians had with people living abroad. Two further respondents simply said that it came from towns and cities.

A further ten respondents attributed the origins of AIDS to supernatural sanction, usually mentioning that it was God’s or Allah’s will as a punishment for sins, as a curse, as anger for breaking God’s laws, for indulging in adultery, and in one case as God’s way of reducing the population. One person spoke of AIDS as the apocalypse (referred to as the coming of the “Eighth Thousand”).

Nine respondents attributed the origins of AIDS to sex with primates including monkeys, apes, baboons or chimps⁶. In several cases the respondent specified that it was white men having sex with the primates, and in one case it was attributed to a white man eating monkey flesh. One respondent said that he had heard that it came from chimpanzees but he no longer believed that.

A number of respondents mentioned more than one reason/origin, and others suggested that they were aware of both the official external views and their own different views as illustrated in the quote from the judge at the beginning of this section.

1.4. Similarities and differences with regard to other diseases

Respondents were asked to explain in what ways they thought HIV/AIDS was similar to and in what ways it was different from other diseases. They tended to compare HIV/AIDS with other diseases, notably in terms of symptoms and to emphasize the fatality and seriousness of the disease as distinguishing features.

1.4.1. Similarities with other diseases

You suffer from diarrhoea as with amoeba, and headaches as with TB. Skin changes, as with TB. You sweat, as with malaria. (Man in Oda Haro, Oromia)

It is very different, but it is somehow related with the *Hmam Nefsi* related with the “illness of the spirits”. They order clothes, special kind of food, but there is also continuous diarrhoea and cough. (Woman, Haresaw, Tigray)

All diseases reduce weight. It shows all the symptoms of other diseases. It is like all diseases are within it. (Woman in Somodo, Oromia)

Asked “In what ways is it related to other diseases?” the most common responses were to mention TB, communicability and similarities with other STDs, or to mention symptoms in common with other diseases.

Out of 63 respondents, eight said that HIV/AIDS was completely different from other diseases (one person specifying that it was because it has no cure) and four said they did not know. Eight respondents mentioned that it was similar to other STDs. The most common similar disease mentioned

⁶ This is based on the English translations and it is probable that respondents mentioned monkeys and baboons.

was TB (11), followed by “Diarrhoea”(5), Colds (3), Malaria (2), Pneumonia (1), Cholera (1), and Amoeba (1).

Eight informants noted similarities with other diseases in that it is communicable (8), and that it kills (4) – as one person put it: “if other diseases kill, so does AIDS” -. One respondent mentioned that it is *not* preventable (1) whereas another noted that it *is* preventable (1).

Most informants interpreted the question by mentioning similarities in symptoms with other diseases including weight loss and thinness (5), weakness (2), loss of appetite (2), fever (2), coughing (2), and one each mentioned hair loss, headache, swellings, spots, abdomen sickness, and inability to work. One student from the Southern Region suggested that since it is a virus it must be related to other viral illnesses, while one woman from Tigray suggested it was like spirit possession in that it made “demands”.

1.4.2. Differences from other diseases

It is fatal, there is no medicine to cure it. It affects all people, irrespective of colour, religion, age etc. (Man in Gelcha, Oromia)

It will make a person skinny. Because there is no medicine, it will eat his body alive. Then the person will die. (Married woman, Luqa, Southern Region)

It is a disease that only affects human beings, not other animals. Carriers of HIV/AIDS cannot be identified by observation. It can be transmitted to others. It is not curable. Patients do not tell others. (Young man, Somodo, Oromia)

The most common response to the questions regarding difference between HIV/AIDS and other diseases was to mention that HIV/AIDS did not have a cure. Out of 70 respondents the majority (52) mentioned lack of medicine or vaccination and that HIV/AIDS was fatal. A large number of respondents interpreted this question by simply describing symptoms, including loss of weight and becoming thin (17), loss of hair (6), blisters and sores (4), diarrhoea (4), loss of energy, weakness (2) and one each mentioned vomiting, colds, skin becoming white, and changes in physical appearance.

Several informants mentioned the severity of the disease, including that it is difficult to treat (4), that it is “severe” or “cruel” (3), that it doesn’t kill quickly or patients suffer long (3), that patients die in pain (2) and one each mentioned that they die quickly, that it is “the worst of all”, that it “eats the body alive”, and that unlike AIDS other diseases can be cured if you have money.

Only a few respondents identified aspects that they considered specific to AIDS including that: the patients cannot be externally identified (5), it is transmitted through sex (4), it affects only humans (3), no traditional medicine or holy water cures exist (2), and one each mentioned that it is not easily detected, that patients need to take care, and that other diseases can lead to death from AIDS.

A few informants noted purported social aspects including that: it kills both husbands and wives, it affects all peoples irrespective of colour religion, age etc., it affects all age groups, patients do not tell others, and “it does not affect farmers but urban people who drink alcohol and are not religious”.

2. KNOWLEDGE OF AIDS DEATHS, PEOPLE LIVING WITH HIV/AIDS AND AIDS ORPHANS

This section considers knowledge about how the epidemic has affected local communities in terms of the following five areas: 1) people’s knowledge of people who have died or are suspected of having died from HIV/AIDS, 2) Subjective sense of increase of HIV/AIDS, 3) people’s awareness of PLWHA and their relations to them, 4) Behaviour of PLWHA, including migration, involvement in traditional healing, disclosure of status and coming to terms with it, income generating activities and suicide, and 5) awareness of AIDS orphans.

2.1. Personal knowledge and suspicion of people dying of HIV/AIDS

Respondents were first asked whether they knew of anyone dying of AIDS, and then whether they knew of anyone suspected of dying of AIDS, and when the first suspected death occurred in their village. A little over a third of respondents said they knew of someone who had died of AIDS, and a little over half the informants suggested that they knew of suspected AIDS deaths. However, since there has not been testing in practice respondents did not view the two questions very differently. Answers on when the first AIDS-related suspected deaths occurred were obtained in twelve villages.

2.1.1. Knowledge of AIDS-related deaths

Here in Tsamako there were two youths who have suspected of dying HIV. Other diseases also make a person go very thin so it is not proven that these men died of AIDS. Some people who have AIDS rape women and these days men are watching after their wives. (Woman, Luqa, Southern Region)

Yes. G.A. came from Addis Ababa and died in Somodo in 1994 EC. He was intending to go to America but couldn't go due to the HIV/AIDS problem. (Young man, Somodo, Oromia)

No, I don't because the community doesn't openly talk that this person is dead of the disease. (Young man, Imdibir Haya Gasha, Southern Region)

About half the respondents (33 out of 69) said they did not know of anyone who died of AIDS whereas 37 percent (26 respondents) said they knew of someone assumed to have died of Aids. However, a further 15 percent (10 respondents) suspected AIDS related deaths on the basis of rumours or symptoms.

A few respondents suggested rough numbers: in Shumsheha in Amhara a respondent suggested a figure of 10 persons, (one man and nine women), and added that some of the women had come from town, and in Turufe in Oromia a respondent suggested a figure of "about 7 people", 6 of whom were couples.

A few respondents provided some information on the kind of person who died: in Oda Dawata in Oromia a respondent mentioned that two former soldiers and their wives were suspected of having died of AIDS; in Geblen in Tigray a named woman was a returnee from Eritrea, and in Somodo, in Oromia a man who got a DV to go to America was refused a visa since he had AIDS and he came home to die in his village.

2.1.2. Suspicion of AIDS related deaths

Yes. In 2001 when husband and wife died frequently. For instance, by now there are 27 children who have lost their mothers and fathers. (Woman in Oda Dawata, Oromia)

Yes. Woizero Z.C. in 1991 - she came from Harar and she slept one year and she died and she was suspected that she died of AIDS. (Farmer in Gara Godo, Southern Region)

No, I don't know. This is because there is poverty, famine, which makes people so thin. Here it can't be known what the cause is. (Woman in Geblen, Tigray)

A slightly higher percentage of people (56 percent or 37 out of 66 respondents) answered this question affirmatively as compared to the previous question, stating that they suspected people they knew of dying of AIDS, although two of these said that it was in neighbouring villages not in theirs. Only 25 respondents said they did not suspect any AIDS-related deaths or that they did not know. In Oda Dawata, in Oromia a figure of 27 AIDS orphans was mentioned as "proof".

A few respondents gave details on the kinds of persons, notably migrants from towns and from abroad: in Haresaw, Tigray it was a woman who came from an urban area, in Gara Godo, Southern Region a woman from Harar; in Luqa, Southern Region a man from Jinka town; in Oda Haro, Oromia

a woman returning from Ambo town. In two cases the migrants were from abroad: in Geblen, Tigray a man who came from Eritrea, and in Somodo, Oromia a man who had been to Saudi Arabia.

2.1.3. Time of deaths

Answers were provided from 12 sites about when the first suspected AIDS-related death occurred. The earliest suspected deaths were in 1993 in the Oda Haro site, Oromia and Adado, Southern Region, followed in 1994 by Shumsheha, Amhara, and in 1996 by Somodo and Oda Dawata in Oromia, then in 1998 by Gara Godo, Southern Region, and in 1999 by Dinki in Amhara, Doma, Southern Region and Turufe, Oromia. The most recent cases were reported in 2002 in Sirba, Oromia and in 2001 in Geblen, Tigray and Adele, Oromia. There does not seem to be a clear regional pattern to these presumed AIDS-related deaths. However, it is striking that many of these are fairly recent and that the earliest case goes back only 10 years, whereas the epidemic had been around for almost a decade prior to that.

2.2. Subjective sense of increase in AIDS

Yes, it is increasing. First there were only one couple. Now only within this years three people are suspected of being carriers. (Young married woman in Turufe, Oromia)

Yes, because we are hearing that there are new victims day to day. About 2 people in this year only have died.(Young woman student in Geblen, Tigray)

Yes. As TB is prevalent in the village, it is impossible to estimate exactly. No less than 3-4. (Middle aged man, Oda Haro, Oromia)

To the question “Has the number of victims been increasing?” almost the same proportions answered that it was increasing as those who answered it was not. Out of 62 respondents 37 percent (23 respondents) answered in the affirmative, 38 percent (24 respondents) said it was not increasing, (one person adding at least not in their village), three said the numbers were decreasing and six said they did not know, (one person adding that since there was no testing one could not be sure). This suggests that there is a sense that the epidemic is not considered to be all that serious by a large proportion of respondents, and that perception of whether HIV/AIDS is increasing varies between sites and respondents.

In fact there was much variation between respondents, and in a number of sites different respondents gave opposing views. There was a tendency for men to respond that AIDS was increasing and women to say that it was not. It is also clear that the sites where at least one of the men and one of the women said it was increasing were closer to urban centres, notably Somodo near Jimma, Yetmen near Debre Markos, and Oda Dawata near Asela, although the migration factor may be a more likely explanation for Gara Godo and Adado in the Southern Region. Conversely sites where at least one of the men and one of the women said that AIDS was not increasing tended to be the more remote ones, notably Luqa and Do’oma in the Southern Region, Dinki and Shumsheha in Amhara, and Korodegaga in Oromia, although this would not explain responses from Adele in Oromia, which is close to towns.

2.2.1. Number of victims this year

Asked about the number of victims this year, most respondents seem to have interpreted the word victims as PLWHA rather than people dying of AIDS, although in some cases it is not clear which is meant. The largest number mentioned was in Oda Dawata, Oromia “more than 10”, followed by five each in Gara Godo, Southern Region and Sirba, Oromia, then four each in Adado, Southern Region and Somodo, Oromia, and two in Geblen, Tigray. In terms of deaths a respondent from Haresaw, Tigray suggested a figure of 10 in the *wereda*, though none in the village, and there were estimates of three in Shumsheha, Amara and 2-3 in Oda Haro, Oromia.

2.3. Awareness of the presence of PLWHA

Yes, my son. I am his stepmother. He was a labourer in Debrezeit. His condition has gotten worse since he came here, he is very ill now, suffers from diarrhoea and vomiting. He can't take solid food. I take care of him. It is a

taxing job. I don't mind looking after him, but I often fear he may contaminate my other kids. (Old woman, Sirba, Oromia)

I know the son of a relative who lost his wife and is in shock. He stopped working and looks hopeless. (Man, Adado, Southern Region)

No, mostly people with AIDS come from other places, towns, and their families take care of them. (Woman, Haresaw, Tigray)

Only a little over a third of respondents said they knew of PLWHA in their village. Out of 64 respondents 58 percent (37 respondents) said they did not know of anyone living with HIV/AIDS and 36 percent (23 respondents) said they did.

Additional information provided on their occupation was that in one case the young man was merchant, in another site the woman was a trader, and in a third a man was a labourer. Regarding who is caring for them this included parents, wife, children, brother, stepmother, several cases where it was "the family", and two cases where it was stated that "no one is caring for them".

2.4. PLWHA – relationships to respondents

Respondents were asked if they had friends, relatives and/or household members living with HIV/AIDS, and if so to specify the gender and age group. The vast majority of respondents had no PLWHA close to them. Seven respondents said they had friends, one had a relative, and two had household members.

2.4.1. PLWHA friends

Yes. She is female and she is 26 years old. She is making local alcohol but I know that she has many boyfriends. (Woman in Oda Dawata, Oromia)

There is a friend of mine who suspects that he has HIV and he told me his suspicion, but he is frightened to be tested. He does nothing to cope. (Young farmer, Turufe, Southern Region)

Yes. Male friend, aged 35. He went to Oda Haro for treatment. They told him he had TB. They gave him drugs but he did not recover. He went back and they referred him to Nekemte. He is sure that it is AIDS. Now he is sharecropping land and makes tables and chairs when he feels well. His wife is trading coffee. (Man in Oda Haro, Oromia)

The seven respondents who said they had PLWHA friends were in 5 sites, four of which were in Oromia: Turufe, Oda Dawata, Somodo, and Oda Haro, and the last one in Gara Godo Southern Region. This may possibly suggest a higher prevalence in sites in the south.

2.4.2. PLWHA relatives

My uncle was HIV carrier but by now he has passed away when he was 57 years old. (Woman, Oda Dawata, Oromia)

No, since blood test is not known in this community no-one can know who has HIV/AIDS or not. (Woman student, Geblen, Tigray)

The only case of someone with a PLWHA relative was from Oda Dawata, Oromia, the uncle of the woman, who had died. However, the lack of blood tests was mentioned as a main reason why people did not know whether relatives were HIV positive.

2.4.3. PLWHA household members

Yes, a man, aged 35. I am his stepmother. I try to take care of him as best as I can, but I am afraid that my children may communicate the disease from him. (Older woman in Sirba, Oromia)

No, our family are all good Christians so they are free from AIDS. (Older woman, Shumsheha, Amara)

Two respondents said they had PLWHA household members, both in Oromia in Sirba and in Somodo, in the first case a mother's step-son and in the second a woman's mother. The extent to which there are religious prejudices was revealed in the response from Shumsheha quoted above.

2.5. Perceptions of the behaviour of PLWHA

This sub-section presents respondents' perceptions of the behaviour of PLWHA including migration, involvement in traditional healing, disclosure and coming to terms with an HIV positive status, income-generation activities and suicide.

2.5.1. PLWHA and perceptions of out-migration

When things get worse they go to the Tibee town. Others have nowhere to go (Middle aged man, Oda Haro, Oromia)

Yes, they went to town to be cured and some went to the monastery. (Young woman, Shumsheha, Amara)

No. In fact, there are people who came to our area because they are HIV positive. (Old married woman, Turufe, Oromia)

To the question "Have any PLWHA left the community and if so where do they go?" out of 53 respondents 83 percent (44 respondents) said that either there were no PLWHA or they did not know, or PLWHA had not left the community – in fact one person said that on the contrary migrants with AIDS were coming back to the village, and answers from several other questions confirm this trend.

However nine respondents said that PLWHA had left. Places they went to included nearby towns, such as Tibe (in Oda Haro, Oromia), Areka (in Gara Godo, Southern Region) and Lalibela (in Shumsheha, Amhara), and in two cases to Addis Ababa, or to monasteries and places of holy water (2 cases from Shumsheha, Amara).

2.5.2. PLWHA and perceptions of traditional healing

Yes, many have. AIDS patients like all others go to traditional healing places and holy-water places. (Young married Woman, Turufe, Oromia)

It is said that the egg of crows and part of a Zegba [Podocarpus] tree are medicines as well as human blood and liver. (Farmer, Gara Godo, Southern Region)

Usually people run to holy water, traditional medication, many have gone and still use it, but their diseases are still not cured. (Woman student, Geblen, Tigray)

To the question "Have any PLWHA sought traditional healing?" out of 61 respondents half (31 or 51 percent) said the PLWHA had not sought traditional healing, six said they did not know and 38 percent (23 respondents) said that PLWHA had sought healing, notably at holy water sites. Examples mentioned were at St John's church in Asela in Oda Dawata, Oromia and Enda Aba Gebir, 10 kilometres east of Geblen, Tigray.

Alleged cures mentioned were crow's eggs, Zegba tree and human blood and liver mentioned by a man in Gara Godo, Southern Region and black and white bark wound round the head provided by witch doctors in Luqa, Southern Region. A woman from Aze Deboa, Southern Region said that there were prayers during healing programmes at the Church, and a man in Oda Haro, Oromia noted that the Kallu religious leaders promise cures.

2.5.3. PLWHA, disclosure and coming to terms with HIV status

No, it is a crime. There is no one who is open and try to teach people saying I am HIV+. Nobody can do it. (Woman, Haresaw, Tigray)

No. They may be thrown out of the community. They are not crazy. If they tell people they have the disease, people will not eat with them. They do not give them the necessary care. (Middle aged man, Oda Haro, Oromia)

No-one is open about this disease. Even if she/he is infected, they will transmit it to other people because they don't want to die alone. (Married woman, Luqa, Southern Region)

Asked “Have any community members been able to be open about their HIV+ status?”, almost all respondents answered negatively and some were horrified at the suggestion as illustrated by the quotes from Haresaw and Oda Haro. Only four respondents mentioned that PLWHA had been able to be open about their status, although in all cases this was limited. In Yetmen, Amara, the person was a school teacher who had been transferred elsewhere, in Geblen, Tigray, it was only in formal meetings initiated by *Tabia* (district) leaders, when PLWHA from town came to teach in schools once, and in Turufe, Oromia, a young man told his brothers and mother. There was clearly an overwhelming sense that openness was not possible.

Asked “Do you know of cases of PLWHA who have come to terms with their HIV+status?” the vast majority of respondents answered negatively. Only six respondents said that PLWHA were doing alright, four of these from Oda Dawata and Turufe in Oromia who explained that if they look after themselves, eat well, go to hospital when they feel ill and do not take alcohol or cigarettes they can manage relatively well. One informant from Gara Godo, in the Southern Region, however, said that it was only by not telling people that they were HIV positive that they could manage.

2.5.4. PLWHA and income generating activities

Yes, many of them fight on to support themselves til the day of their deaths. (Older married woman Turufe, Oromia)

The question of how PLWHA can begin to find means of generating income and not simply depending on assistance has only recently been broached in the urban setting of Addis Ababa (Pankhurst 2003b). In the rural villages in this study there were only five positive responses to the question regarding income-generating activities by or for People living with HIV/AIDS, two each from Turufe and Oda Dawata in Oromia, and one from Gara Godo, Southern Region. The income generating activities mentioned were trading, petty trade, and share-cropping. However, from a further question about whether respondents have friends who are PLWHA we can deduce that a woman PLWHA in Oda Dawata produces alcohol, and a man in Oda Haro, Oromia makes tables and chairs, and two others in Oda Haro work on their fields but when they are sick employ daily labourers to work in their fields. It is therefore clear from the responses that there have not been new strategies developed by or for PLWHA to raise incomes or change their livelihood strategies as a result of becoming aware of their HIV status.

2.5.5. PLWHA and perceptions of suicide

There is one person who has committed suicide because of stigma ha has faced from his family. Whereas she lost her husband because of this disease, her families stigmatised her and she died by drinking medicine. (Woman in Oda Dawata, Oromia)

There was a man known as A. who committed suicide in 1994 E.C.. But this can never be certified. (Women in Geblen, Tigray)

Two women mentioned suicides, one from Geblen in Tigray and the other from Oda Dawata, Oromia, where a woman who lost her husband drank medicine to kill herself. Another man in Somodo, Oromia also mentioned the possibility of suicide in responding to another question about the way AIDS affects social life and how newcomers are excluded because of suspicion of being carriers leading to their committing suicide.

2.6. Awareness of AIDS orphans

Yes, many. Relatives and friends look after them. They clothe them and take them to the clinic. There are already 12 AIDS orphans in the village. They also herd cattle and weed for those helping them. They received aid as a family. The death of the child's parents was attributed to cholera, which was not true. (Young man in Oda Haro, Oromia)

Yes. The remaining family, the extended family look after them. The government is also providing them with food aid, as for any poor person. (Old man, Shumsheha, Amara)

Yes. Their grandmothers look after them. But recently Hiber, an NGO based in Asela is supporting them with 50 birr per month. (Woman in Oda Dawata, Oromia)

Respondents were asked if they knew of AIDS orphans and if so who is looking after them. In almost half the sites respondents knew of AIDS orphans. It is interesting to note that respondents were more aware of AIDS orphans than people dying from or living with HIV/AIDS. Seventeen respondents knew of AIDS orphans in nine sites: Four in Oromia (Sirba, Oda Haro, Oda Dawata and Turufe), two in Amara (Shumsheha and Yetmen), both sites in Tigray, and one in the Southern Region (Gara Godo).

Although they were referred to as orphans by respondents, two of these were not strict orphans since only their father had died and they lived with their mother. The rest were being looked after mainly by relatives including, grandparents, siblings, relatives and friends. In Shumsheha in addition to help from the extended family they were getting food aid. In Arsi an organisation called Hibir based in Asela recently began to give the orphans in Oda Dawata 50 birr per month.

3. PERCEPTIONS OF DIFFERENTIAL EFFECTS OF HIV/AIDS

This section considers differential effects of HIV/AIDS by gender and wealth. Respondents were asked whether men and women were affected equally and whether rich and poor were affected equally. The responses suggest that gender and poverty here combine to make poor women and rich men more vulnerable, and that once people are HIV positive, the rich stand a better chance of longer survival.

3.1. Differential effects on men and women

The cause are men. They will die first and then their wives will follow. So it is almost the same. (Older woman, Yetmen, Amara)

Men could transfer the disease fast but it will kill both the men and women equally. (Married woman, Luqa, Southern Region)

Asked about whether both sexes were affected equally and if not why not the responses were fairly evenly distributed. Only a slightly larger proportion thought that men were more affected. Out of 31 answers where one sex was said to be more affected 55 percent (17 respondents) thought men were more affected as compared to 45 percent (14 respondents) who thought women were more affected. However, men tended to think women were more affected (7 out of 11 respondents) and women tended to think that men were more affected (13 out of 20 respondents). Six respondents said both sexes were affected equally, some arguing that the men were infected first and then passed on AIDS to their wives so that "it came to the same thing"; five respondents said that they did not know.

3.1.1. Men more affected

I believe men are the major transmitter of the disease, Men are highly affected as they catch the disease from going somewhere from somebody. I remember, I was afraid of shaking hands with an AIDS affected person. (Old married woman, Aze Deboa, Southern Region)

It affects men more. That is because men tend to engage in extra-marital sex more than women. (Young married woman, Turufe, Oromia)

Not to the same level. It mainly can attack the males because they use force to satisfy their sexual feelings, rape, sexual harassment are common, males go to the neighbouring town's women, they can have two or more partners. (Woman, Geblen, Tigray)

Reasons given for men being more affected included that they are more involved in extra marital sex, that they migrate more to towns, that they have several wives, that they have more sexual partners, and that they were in the military.

3.1.2. Women more affected

There is great potential of HIV/AIDS affecting women. This is because women are less aware of HIV/AIDS. Furthermore, men from other places come to the *kebele* to work as hired labour during the coffee harvest. (Young man, Somodo, Oromia)

Women, because it is we who get pregnant, give birth, lose blood and work hard in the house and outside, therefore if we get infected with the virus it weakens and kills us very soon. (Woman, Haresaw, Tigray)

If women acquire HIV/AIDS they can reduce its amount through menstruation so they are less affected than men. Women are more vulnerable because women are easily raped during the nights, especially when there are church programmes at nights. (Man, Doma, Southern Region)

The main reason given for women being more affected was that they are the ones who migrate to town to become commercial sex workers; other reasons can be divided into ones relating to men and ones relating to women. The former included that men can attack women using force, rape, sexual harassment, and that men go to prostitutes and have more partners. The latter include that women marry early against their wishes, that they do any job to survive, may marry men who are HIV positive, that they have less energy, are subject to violence and rape, that they get pregnant, give birth, loose blood, work hard in the house and outside so that if they get infected with the virus it weakens and kills them very soon.

Female circumcision was mentioned as a likely reason for women being more affected by a man from Aze Deboa, Southern Region. A man from Oda Haro, Oromia suggested that women were more affected because they are less aware about HIV/AIDS, and that there are male migrant labourers in the area during the coffee harvest. A man in Doma, Southern Region suggested that if women acquire HIV/AIDS they can reduce its effect through menstruation!

3.2. Differential effects on the rich and the poor

I think they are equally affected. The difference is the time of death. (Young man, Sirba, Oromia)

Yes, it affects both kinds of people equally. But sometimes it affects rich people more as they begin to worry about their sexual needs after fulfilling their basic needs. (Young married woman, Adele, Oromia)

The rich people are exposed highly- because of hoarding large amounts of coffee they have many opportunities to go to urban areas. They also have great opportunities to get medicine. The poor have less exposure to the disease but are more likely to die because they are unable to buy medicine. (Young man, Somodo, Oromia)

Asked whether they thought HIV/AIDS affected the poor and the rich equally and if not why not, the responses were fairly evenly distributed: 19 respondents said the poor were affected more, 17 that the rich were more affected and 16 that they were affected equally. As the young man from Sirba put it in the above quote the chances of catching AIDS were seen as equal, but the difference was in the time of death. Once they are HIV positive it is clear for most that the rich have a better chance of longer survival. The reasons can be divided into questions relating to being more prone to catching HIV/AIDS, and questions relating to the ability to cope and resist once they are HIV positive.

3.2.1. The rich more affected

In this community I think that AIDS/HIV attacks more to rich people. Because if one has money he tends to go to recreational places to drink more, to dance and then to go to prostitutes. Rich people think about leisure while the poor don't think about leisure but bread. Poor can't pay money for a cup of coffee and for a prostitute. (woman Student Geblen, Tigray)

No. Rich men can easily get women with their money. Rich people can drink more alcohol so they can lose their tempers. In that case they can easily acquire the disease. (Poor man, Doma, Southern Region)

No, I heard that this disease is a rich man's disease because it is found in bars where sex workers are found, and it is also the sick who go to bars. Poor people do not go out of their houses. (Old poor man, Turufe, Oromia)

The reasons for the rich being affected more were that the rich men are more prone to migrate, to go to towns, to bars, that they have money to spend on prostitutes, and that they have more sexual partners.

However, once they have AIDS the rich are able to resist better and live longer since they have enough food, and can afford medication, that they can "buy themselves more days", as a respondent from Oda Haro put it.

3.2.2. The poor more affected

No, the poor die quickly, the rich go to health centres and the rich eat well and live longer. The rich go to cities and stay there and catch the disease. So more probability for the rich to catch the disease but the poor affected most. (Rich old woman, Adado, Southern Region)

Mainly affects the poor. When both contract the disease, the rich will be able to survive for a longer period. "The rich man can buy himself more days." (Young man, Oda Haro, Oromia)

No, but the extent or length of life after being affected, is bound to be different between poor and rich. They poor are likely to die quickly, while the rich can look after themselves and extend the life, eating good food and take good care of their health. (Older woman, Sirba, Oromia)

Reasons given for the poor being affected more were that poor women engage in risky jobs, notably in bars and as commercial sex workers, that poor women are lured to rich men in the hope of marriage; and that once they catch AIDS the poor are less able to afford good food and medication and therefore die faster.

4. COMMUNITY INVOLVEMENT IN HIV/AIDS PREVENTION AND PATIENT CARE

This section considers the awareness of involvement of individuals and groups in addressing the HIV/AIDS issue including, government and non-government agencies, health and education personnel, faith based organisations and individuals and local institutions, including peasants', women's and youth and burial associations, Anti-AIDS clubs, elders, and agricultural agents.

4.1. Awareness of individuals or groups involved in addressing the HIV/AIDS issue

Self-Help had given a 2 days training for about 20 people in the community. These are the only ones who have some idea about HIV AIDS. Otherwise the wider community has no awareness about the disease and HIV is not considered as a serious problem in the community. There also are 2 boys trained by Self-Help to teach the young. (Woman who had taken 2 days training on HIV/AIDS, Korodegaga, Oromia)

Yes, there are associations like the Farmers Association, Women's association, and now Anti-AIDS club, But they don't work effectively. They can't transfer the needed information to the people particularly the woman have done nothing regarding HIV/AIDS although it is one of their aims. (Woman student Geblen, Tigray)

The *Kebele* organisation, the Orthodox Church and youth associations called 'save your holy land' are providing advice, information, education and communications to the local people. In particular, 'save your holy land'

provides information and communication through music, drama, theatres and in other creative ways. (Young man Shumsheha, Amara)

The importance of community based organisations in HIV/AIDS awareness, care for PLWHA, and AIDS orphans has been indicated in a number of studies (Damen 2003, Kloos et al. 2003, Kloos and Damen *in press*, Pankhurst and Damen *in press*). The main actors include the Kebele, health workers, community health agents and extension workers, community based reproductive health agents, traditional birth attendants, women's and youth associations, Anti-AIDS clubs and schools, faith-based organizations, *iddir* burial associations, development agents, and traditional healers. This study found that many of these community based organisations and agents of government or non-government programmes, did play a role. Furthermore this study provides a sense of how rural respondents view their relative importance.

Out of 60 respondents who answered the question "Have there been any individuals and groups addressing HIV/AIDS?" a large majority, 80 percent (or 48 respondents) said that there were some individuals or groups involved in the HIV/AIDS issue, and the remaining 12 respondents from eight villages said there were none. The latter included some of the remote villages (Haresaw in Tigray, Shumsheha in Amhara, Gelcha and Oda Haro in Oromia, and Do'oma in Southern Region).

The groups involved included Anti-Aids clubs, generally of youth (7), one of which was called "Save your Holy Land", Kebele Anti Aids committees or clubs (5), the one in Geblen, Tigray including farmers and clergymen, Anti-AIDS religious groups and NGOs, including Tesfa Goh and Hibir in Oda Dawata and Self Help providing training in Korodegaga both in Oromia, the women's NGO known by the name of the founder Bogalech in Aze Deboa in Kambata, and the pastoralist NGO called EPARDA in the Luqa site, both in the Southern Region. Other actors were associations including farmers, youth and women's associations.

One of the most important agents of raising awareness that were mentioned were religious leaders, priests, churches and mosques who were said to address the issue by 28 respondents. Other agents included health agents, posts, centres (14 respondents), notably at times of vaccinations in Yetmen, Amara, Kebele officials (9), schools and teachers (3), *iddirs* (3) in Oda Haro under direct orders from the *wereda*, family planning services (2), elders (2), drama groups (2) in markets and public gatherings in Imbidir, and even the agricultural Development Agent in one case. The Kalehiwot church provides counselling for AIDS orphans in two sites (Turufe in Oromia and Adado in the Southern Region). In Korodegaga in Oromia three individuals had been on trainings to the *wereda*.

Although some sort of HIV/AIDS activity seems to be carried out in the majority of sites, there is a need for caution. It should be noted that many of the respondents expressed scepticism about the effectiveness of such interventions, as two of the above quotes suggest. In Geblen, Tigray, a respondent said that teachers hardly gave any advice, that the church leaders were weak and more involved in politics, and another respondent noted that the farmers association and women's anti-aids clubs do not work effectively. A man in Imdibir Haya Gasha, Southern Region mentioned that there were drama shows and education given on market days and at public gathering but he did not know who organised them. A woman from Aze Deboa, in the Southern region who participated in an Anti-AIDS club stated: "What I have observed is that they [the people] have the knowledge of what AIDS is and how it is transmitted. But the main problem is that they can't implement it and save their lives."

4.2. Possible effects of HIV/AIDS on *iddir* burial associations

I can't say HIV/AIDS has affected *iddir*. Our contribution fee has increased but I do not know whether it is because of HIV/AIDS or not. It may be because we buy more things from the market or because more money is given to mourning households. (Young woman, Aze Deboa, Southern Region)

It didn't affect *iddir* because most of them are not members of *iddir*. The main reason is that they don't have financial capacity to pay what is required by the *iddir*. (Woman, Oda Dawata, Oromia)

Actually HIV/AIDS cases are not clear in this community; people are dying due to different epidemics and HIV/AIDS has been discovered within this situation. But our *iddir* has been attempting to help orphans. (Old woman Gara Godo, Southern Region)

Iddir burial associations are some of the most widespread local indigenous and independent social institutions (Pankhurst 2003a), which evidence from Addis Ababa suggests have been affected by the HIV/AIDS epidemic (Wubalem 2003, Pankhurst and Damen *in press*). However, little is known about how rural *iddirs* have been affected. Respondents in this study were asked whether they thought HIV/AIDS had affected *iddir* burial associations, first without prompting. They were then asked whether there had been any effects in terms of increase in deaths, in fees to be paid, reduction of members, disintegration of any *iddirs* and attempts by *iddirs* to help PLWHA or AIDS orphans.

The vast majority of respondents (51) who answered and understood this question asserted that HIV/AIDS was not a significant problem in their site, that it had not affected *iddir*, or that there were no *iddirs* in their area (in 3 sites, the two pastoralist sites and Haresaw in Tigray).

Only seven respondents in five sites (Adado, and Gara Godo in the Southern Region, and Adele, Oda Haro and Oda Dawata in Oromia) suggested that *iddirs* had been affected, in terms of rising deaths, increased fees, declining numbers of members, (although these responses may have been affected by prompting). A respondent from Oda Haro in Oromia implied that the increases in deaths resulted in the increase in fees. In two of these cases in Adele and in Oda Dawata in Oromia respondents suggested that once one member of the *iddir* was infected then others were affected, suggesting that they understood *iddir* as equivalent to the community, and in two cases from Adado in the Southern Region it seems that the answer was that there was an increase in fees, but not necessarily that this was due to AIDS. Indeed, several respondents said there had been increases in fees and/or in deaths, or *iddirs* disbanding but this was *not* due to HIV/AIDS. One respondent noted that there had been an increase in deaths but it was not possible to be certain that this was due to HIV/AIDS. Another noted that some of the poor PLWHA were not members of *iddirs*. Only in two cases, in Gara Godo in the Southern Region and in Turufe in Oromia did the *iddir* try to help orphans, and only in the latter did the *iddir* provide money to PLWHA.

In general the responses suggest that burial associations in rural areas have hardly become aware of the HIV/AIDS threat, and have therefore not responded to it. This finding is different from the findings of Pankhurst and Damen (*in press*) on urban *iddirs* where awareness of HIV/AIDS is fairly prevalent. It is significant that the exceptions are fairly close to urban centres in the South. Turufe is very close to Shashemene town where anti-HIV/AIDS activities are well developed and Gara Godo is fairly close to Areka and Shone towns where missions are involved in anti-HIV/AIDS work.

5. PERCEPTIONS OF THE EFFECTS OF HIV/AIDS ON SOCIAL, ECONOMIC AND CULTURAL RELATIONS

This section considers the perceived effects of HIV/AIDS on social, economic and cultural relations. Respondents were asked early on in the interview about how HIV/AIDS is related to social life and to cultural norms (questions 6 and 7, see Appendix). At the end of the interview respondents were asked whether HIV/AIDS had affected social relations, economic relations and cultural norms and rules (Questions 27, 28, 29). The answers to the two sets of social and cultural questions have been presented consecutively.

Although some respondents found dividing effects in these ways difficult to conceptualise, it is clear that the majority of respondents thought that HIV/AIDS had effects on all three types of relations, with slightly more seeing cultural effects (60 percent) than economic effects (53 percent) and social effects (51 percent).

5.1. Perceptions of relations of HIV/AIDS to social life

People do not approach a person who has AIDS because they think that the disease can be transmitted by social contact like shaking hands, social kissing and sitting on the chair that an HIV infected person sat on. (Older man, Dinki, Amara)

It causes ex-communication of the victim and his family from the community. If one of the spouses is also the victim of HIV/AIDS it will also affect the other partner. The death of spouses causes child headed families (orphans). (Man from Gelcha, Oromia)

It is killing the workforce of the country from 18 - 40 years. So the loss of this force to a country means poverty. (Farmer, former *Kebele* secretary, Korodegaga, Oromia)

The main effects noticed can be divided into two: those on the PLWHA and their families, and those on the community and society at large.

5.1.1 Effects on PLWHA and their families

Thinks infected person has no social life. Social exclusion. "Tirefetamu" - a strong word implying exclusion - avoiding something due to its stinking smell. Treat them as if they stink. T. H. died of AIDS. She was excluded from society. She remained a widow. (Young man, Oda Hara, Oromia)

Parents worry and frustrated, get ashamed. The sick person is hated and excluded, she cannot talk and play with others, people get afraid of her. (Woman in Haresaw, Tigray)

It relieves people of parents, sons, daughters and relatives. Causing them pain, financial problem and stigma. (Woman in Somodo, Oromia)

The most common response to the question "In what ways is HIV/AIDS related to social life" mentioned by 22 respondents was that PLWHA are segregated, ostracised, outcast, alienated, or marginalized.⁷ Only two informants said that HIV-AIDS was unrelated to social issues, and two others that they did not know since AIDS was not around in their area. Several respondents mentioned kinds of discrimination and stigma including not shaking hands, not greeting the person, not talking to them or talking about them behind their back, not entering their house, keeping a distance, not sharing clothes or lending utensils by neighbours and burial associations. An extreme form was the suggested that the PLWHA was avoided because they are considered to smell bad. Some respondents spoke of fear or of hatred of the PLWHA, in one case it was suggested that the person was almost considered a dead man; others spoke about how the person feels isolated, lonely and faces stress, lack a social life or have a deteriorating social life since people will not approach them and fear to expose themselves; in one case a respondent mentioned that it can lead to suicide.

Some respondents mentioned that even friends, neighbours and family may stigmatise the PLWHA. Others suggested that not only the victim but also their family may be "excommunicated" or "outcasted". Several respondents mentioned how the fact that someone has AIDS can affect others: parents worrying, feeling frustrated or ashamed, that death affects the spouse, partner, parents, children who become orphans, causing child-headed families, that HIV-AIDS sometimes leading to divorces, and in one case a respondent mentioned how a woman whose husband died remained a widow since no one wanted to marry her.

On a positive note one respondent noted that PLWHA were not excluded from church and religious associations such as *mahiber* and *senbete*, another mentioned that they can take part on all activities including funerals (although people are tense in their presence and even wary of shaking hands with them), and a third argued that since a PLWHA can live up to ten years and the disease cannot be transmitted if one takes care they can continue normal social relations.

⁷ These are the terms used by the interviewers, which may not correspond exactly to terms used by respondents.

5.1.2. Effects on community social life

AIDS affects social life. It affects *iddir* and other social institutions due to high number of deaths. On the other hand a man with HIV/AIDS may be secluded from the community. (Young woman, Gara Godo Southern Region)

There is a problem to accept and respect newcomers who are suspected [of having the disease?] and this can lead to suicide. Friends stigmatize the patient. Divorces occur within families. Neighbourhood and *iddir* could not lend house utensils, or drink coffee together, or visit each other. (Young man in Somodo, Oromia)

Some respondents mentioned that HIV-AIDS affects social life since it kills the younger generation, and the educated leading to shortage of manpower, that it affects not just families but society as a whole and exacerbates poverty, and that it is worse where there are insufficient social services. Several respondents mentioned the financial costs both to the family and to the society since AIDS patients occupy hospital beds.

Other social problems mentioned were that AIDS had led to a fear of newcomers, especially from urban centres and Arabia, that there are problems to do with sexual relations in general and rape, premarital sex, adultery, polygyny and prostitution in particular. One respondent stressed that it affects burial associations and other social institutions.

5.2. Perceptions of the effects of HIV/AIDS on social relations

Of course, the victims do not participate in culturally valued activities, particularly labour sharing networks - *wonfel, debo* (etc) and they become incapable of contributing money for *iddir* and other local institutions. (Older man, Shumsheha, Amara)

Yes, everyone will take a test before marriage which was not before. Parents changed their attitude, they send their children to school rather than send to a husband, take test before marriage (Man, Adado, Southern Region)

Yes, they get condoms from their association. People start to be strict in this matter, they go to the church and they prefer to be loyal to their wife. Polygamy is declining because people are in fear and migration to cities have declined. Men start to keep condoms in their pocket. Everybody talks about it. (Woman in Haresaw, Tigray)

Out of 65 respondents who answered the question: “Has HIV/AIDS affected social relations?” half (33) thought that it had, a third (21) thought that it had not, five thought that it had not yet, or not in the village, or not much, and two did not know. However, two of those who said they thought AIDS had not affected social relations and two of those who said “not much” went on to make suggestions as to how it did affect social relations.

Although half the sample thought that there had been social effects, what these were seen to be varied quite widely. Some of the responses might well have been affected by the prompting, in which respondents were asked about 1) relations between spouses (including polygyny and migrant labourers), 2) relations between generations, and 3) relations between unmarried men and women (e.g. courting behaviour).

5.2.1. Effects on relations between spouses

The apparently most noticed effect was suspicion between spouses (11 cases) out of which most (7) suggested women suspected their husbands. As one young woman from Turufe in Oromia put it: “Lately women are increasingly suspicious of their husbands. I myself feel more nervous on market days when my husband comes home a bit drunk”.

A further four respondents suggested that people were asking for blood tests before marriage. A woman from Oda Dawata in Oromia even said: “I know a person who got a divorce after engagement because when they test their blood one of them was positive”, and another respondent also mentioned divorce.

Five respondents suggested that there had been a decline in polygamy (5), in Gebelen in Tigray those with more than one wife were criticised at a public gathering.

5.2.2. *Effects on relations between unmarried youngsters*

Other alleged effects included less courting (7), in one case the respondent mentioned that sex was excluded and another that intimacy was delayed, and a third that faith between prospective partners had been destroyed.

5.2.3. *General effect on social relations*

Other social effects mentioned were an avoidance or discrimination of victims (5), more fear and reduced social relations (4), one person adding that there was less visiting; suspicion of migrants (4). In one pastoralist site this affected the way that young men who move with the camels are viewed; tensions between the generations (3), the presence of AIDS orphans (2), PLWHA being left alone and feeling stress (2), and less trust and interaction between neighbours (2). Social effects mentioned by a single respondent included less involvement in local associations, decrease of migration to towns, and revenge by PLWHA engaging in sex.

5.2.4. *Positive social effects*

On a more positive note respondents mentioned more faithfulness between spouses (3), more open talk about sex notably between generations (2), parents keeping girls at school longer, and more use of condoms (1).

5.3. Perceptions of the effects of HIV/AIDS on economic relations

Many are affected. The sick cannot work all the time. They can become impoverished within a year. The inability to work land, children leaving school to work land and need for more labour to look after sick are common occurrences. (Middle aged man, Oda Haro, Oromia)

Yes it has. Unhealthy people cannot be productive. There has not been that much a serious problem in our village. But I guess that we won't escape it if things go the way they are. (Woman, Imdibir Haya Gasha, Southern Region)

They have lots of expense at hospital, holy water, magician's home. If they were making traditional alcohol they stop it as they become ill. (Woman, Oda Dawata, Oromia)

To the question; "Has HIV/AIDS affected economic relations?" out of 34 respondents, the majority (53 percent, or 18 respondents) claimed that it did have an economic effect, 35 percent said it did not, two respondents said "not much", and one did not know.

The details may have been affected by the subsequent prompting which asked about: 1) loss of jobs and income from remittances; 2) inability to work the land, 3) children leaving school to work land, 4) need for more labour to look after the sick, 5) children leaving school to look after the sick.

5.3.1. *Effects on ability to work the land and loss of jobs*

The most important effects mentioned were loss of ability to work the land (11), and loss of job or work (10), although there was an overlap between the two and several respondents mentioned both. This also had the consequence of the need for more labour to look after the sick (8).

5.3.2. *Effects on children*

The effects on children included leaving school to work (6), in one case the person adding that this particularly affected orphans, and children leaving school to look after the sick relatives (4).

5.3.3. *Effects on livelihood*

Other effects included additional expenses, notably for medicine and medical care (4), fall in living standards or impoverishment (4), loss of remittances (2). In addition there were single mentions of having to contract out land, sale of assets (cattle) to pay for medical care, inability to do even housework, that the most productive (the young) die, and that domestic workers who were suspected of AIDS were isolated.

5.4. *Perceptions of relations of HIV/AIDS to cultural norms and rules*

For example our culture gives greater independence to young people (men) to have free relation any woman they choose. Hence these men can be easily attacked by the disease. While women become (recipient) victims of STDs including AIDS. (Woman Geblen Tigray)

On the 'evangady' or 'kibrko' dance a person could have sex with a girl. If he has slept with another girl when he went to the city, he could transmit the disease to the girl. This girl may sleep with another guy on the next dance. This thing will increase the speed of transmission of the disease but you can't stop the dance because it is a custom here. (Woman Luqa, Southern Region)

Respondents found this question rather difficult by informants who gave a wide range of answers which can be grouped into 1) issues to do with discrimination of the victims, 2) loss of cultural values, 3) the role of "traditional harmful practices", and 4) marriage and sexual customs.

5.4.1. *Discrimination against PLWHA and commercial sex workers*

The one who is suspected carrier or sick of HIV-AIDS would be categorised as normless. Because he is caught by the disease through sexual intercourse with many women. Instead of giving care and love the society discourage him as guilty. (Young Man in Yetmen, Amara)

and of ways in which PLWHA were blamed or ostracised, how women who went to towns were assumed to be prostitutes, that others were branded as adulterers and considered guilty or sinners. Some suggested that family friends, and neighbours would not help, as one respondent put it that "no one is sorry".

5.4.2. *Loss of cultural values*

Things which are considered as illegal (bad) in the society are means of transmitting HIV/AIDS. Adultery, sex before marriage. (Older woman Adado, Southern Region)

Some respondents spoke of the way that the cultures of cooperation were eroded by the fear of HIV/AIDS and how cultural norms which if followed would help avoid HIV/AIDS. This included not allowing pre-marital sex, valuing virginity, condemning adultery and prostitution. It was suggested that these values were becoming eroded, and that a return to cultural values would be a good protection against HIV-AIDS.

5.4.3. *The role of "harmful traditional customs"*

Traditional harmful practices (circumcision, pulling out teeth, making incisions near the eyes *mbtah*) increase the spread of the disease. (Man in Geblen, Tigray)

It is related to circumcision, uvulotomy, piercing ears, blood contact, incision of eyelids and tattooing. (Man in Aze Deboa, Southern Region).

Many discussed "harmful traditional customs". Several respondents suggested that female circumcision could spread the disease, but others challenged this on the grounds that the same blade was not used for many babies. Other practices mentioned included uprooting teeth, incisions at the side of eyes, cutting out tonsils (uvula) piercing ears, tattooing. Other issues raised were abduction and

rape, and widow inheritance, one person suggesting that there was less wish for the latter due to the danger of HIV-AIDS.

5.4.4. Marriage and sexual customs

One to one marriage helps prevent the disease. Polygamy accelerates the spread of the disease. (Man in Geblen, Tigray)

In the case of Muslims it is allowed to marry more than one woman and this has contributed to the disease. But in the case of Christians - lack of discipline. (Woman in Gonde, Oromia)

On the question of polygyny and adultery, some suggested that these were factors, and that monogamy and strict one-to-one relationships were an important way of avoiding HIV-AIDS whereas others claimed that there was no connection and that these were just customs. Only one respondent pointed to the gender differences in sexual mores, with men having more sexual freedom and women then becoming the victims. A few respondents mentioned that there was developing a culture of blood tests prior to marriage, and others expressed the view that this should be done.

5.5. Perceptions of the effects of HIV/AIDS on cultural relations

Yes, it decreases early marriage, it is highly respected to be virgin. Everyone is afraid to have sex with people urban women or commercial sex workers. Early marriage decreases because of HIV/AIDS. Men stop going to commercial sex workers. Everyone is afraid of the future. (Young woman, Adado, Southern Region)

In the previous time marriage is without checking HIV but now if somebody wants to survive it is a must. Although there are people who marry without check-up. In the previous time virginity was important but now what is more important is being free from HIV not virginity. (Woman in Oda Dawata, Oromia)

Yes, women have the chance to go to school and to attend meetings, to talk about their own situation and fight against violations of all kinds. This was not part of our culture. But the disease has created a chance for this. Another change is the churches have started to make the HIV issue as part of the teachings of the church. Customs regarding sexuality have become more strict and premarital sex is forbidden, and early marriage has changed from 9 years to 20 years. Regarding female circumcision even the traditional health attendants have been given a training and are using sterilized implements. (Woman in Haresaw, Tigray)

To the question “Has HIV/AIDS affected cultural norms and rules?” out of 55 respondents, the majority (60 percent or 33 respondents) said that it had affected culture. Just over a third (19 respondents) said that it had not; however eight of these then went on to suggest that it had affected aspects of culture. Two respondents said that they did not know and one said that it had not affected culture much. If we include the last of these and the eight respondents who responded negatively at first but went on to show examples of cultural effects, over three quarters (76 percent or 42 respondents) did acknowledge some cultural effects.

When we look at the detail of the effects it is likely that the prompting might have affected some of the answers. Interviewers were asked to check about: 1) rules and norms about first and subsequent marriages, 2) attitudes towards virginity, 3) attitudes towards sexuality, 4) attitudes towards early marriage, 5) attitudes towards Female Genital Mutilation, 6) attitudes towards education (especially of girls), 7) attitudes towards commercial sex workers, 8) attitudes towards alcohol and *chat*, 8) attitudes towards urban areas and migration, and 9) attitudes about hope for the future.

5.5.1. Attitudes towards virginity and pre-marital sex

The most important effect mentioned was a reinforcing of the values of virginity. Fifteen respondents suggested that HIV/AIDS has contributed to a greater concern for virginity of women. However, a few respondents suggested that valuing virginity had been a custom beforehand and that it continued to be important, and that it was therefore not affected by HIV/AIDS. One respondent from Oda Dawata in Oromia, even pointed out that what was important was not virginity but being free from AIDS.

Related to the question of virginity was the suggestion that there was stronger feeling that pre-marital sex should be avoided owing to the threat from HIV/AIDS. This was mentioned by three of the respondents. However, the exception was Luqa in the Southern Region where the local custom apparently expects girls to have had sex to become desirable marriage partners.

5.5.2. Attitudes towards early marriage and girls' education

Regarding the question of early marriage there were mixed opinions. Six respondents suggested that early marriage had decreased as families did not want their girls too be exposed to HIV/AIDS. However, five other respondents said that the HIV/AIDS threat was reinforcing the demand for early marriage. Moreover, five further respondents suggested that the increase in the age of marriage was due to other factors, notably to government legislation which decreed that the minimum age of marriage should be 18, to the death of women who had children too early, to the education of girls and other social changes. Two respondents said that although there had been an increase in the age of marriage it was not possible to tell if this had anything to do with AIDS. Five other respondents said early marriage was still practiced and AIDS had not had any effect on this. One respondent from Imbidir in the Southern Region said that as long as there were blood tests the age of marriage was not an issue, and early marriages could go ahead.

The education of girls in particular was one effect that was mentioned by eight respondents, one of whom added that parents think that by sending girls to school they will learn about how to avoid HIV/AIDS. Three other informants suggested school attendance had increased due to HIV/AIDS for both sexes. Only in Luqa in the Southern Region was it mentioned that there was not an interest in girls' education as they were seen as a means of acquiring bridewealth by marrying them off.

5.5.3. Attitudes towards norms of marriage and sexuality

Concerning norms about marriage seven respondents suggested that there was pressure for people to keep to one wife. In Geblen in Tigray people with more than one wife were denounced publicly. However, it seems that this issue is largely linked to religion; in Luqa it was only converts to Christianity who stick to this norm, and in several sites a decline in polygyny had to do with other factors, notably poverty, although several respondents suggested polygyny continued in Muslim sites and was not affected by AIDS.

However, nine respondents suggested that there was less adultery, illicit or extra marital sex, more abstinence and less general promiscuity, although in three sites respondents suggested that behaviour had not really changed and that people continued to have affairs. Two respondents suggested that HIV/AIDS meant a decrease in divorce as people feared remarriage. In Gelcha, the pastoralist site in Oromia it was mentioned that the custom of widow inheritance was being questioned.

One of the important changes concerns blood tests for HIV/AIDS. Six respondents suggested that this was an important issue. In Harresaw, Tigray it was seen as the concern of parents at the marriage of their children; in Aze Deboa, Southern Region it was the concern of religious leaders, in Imbidir Haya Gasha Southern Region it was considered a must before marriage.

5.5.4. Attitudes towards stimulants

Regarding alcohol and *chat* only two people said alcohol consumption had been reduced and three that *chat* consumption was reduced. However, it was not clear that this was related to HIV/AIDS. In Haresaw, Tigray a reduction in alcohol consumption was attributed to drought and poverty. A woman from Turufe in Oromia said "Now women don't want their husbands to drink alcohol or chew chat, before they were indifferent". However, many respondents suggested that there was no link with HIV/AIDS and that attitudes towards stimulants was determined by religion: Islam condemning alcohol, and Christianity condemning *chat*.

5.5.5. Attitudes towards urban areas and commercial sex workers

Regarding attitudes toward urban areas and commercial sex workers there was a clear sense that this was an area of change. Seven respondents said that people feared urban areas as the source of HIV/AIDS. Seven other respondents said that migration has been reduced, although one added that people still went to town but go less to bars, another that people go to town but do not spend the night, and a third that urban migration had been reduced due to other factors. In several sites respondents suggested that migration still continued and was not affected by HIV/AIDS.

Eight respondents said that people feared commercial sex workers and that men frequented them less, and seven said that prostitutes were ostracised. In Haresaw, Tigray commercial sex workers were encouraged by their associations to become involved in other trades. However, three respondents suggested that male behaviour had not really changed.

5.5.6. Attitudes towards Female Genital Mutilation

Regarding Female Genital Mutilation five respondents suggested that this had decreased. However, this was not seen as directly resulting from the AIDS threat, and three further respondents said that the practice had been declining even before. A respondent from Turufe in Oromia said that there had been education in this respect and that the practice had stopped three years earlier. However, several respondents suggested that the practice continued, one suggesting that as long as new blades were used there was no danger, and another in Haresaw Tigray saying even traditional birth attendants had received training about safe circumcision practices using sterilising blades. A respondent from Adele in Oromia said that HIV/AIDS was not a problem in this respect at the moment but that it might become one soon. In several sites there was no FGM practiced so that the issue did not arise in the first place.

5.5.7. Attitudes towards the future

Regarding hopes for the future, eleven respondents said that people had lost hope and were worried, one mentioning that it was particularly the youth who were desperate, another suggesting that it was infected people who were distressed, and a third stating that he did not know how God would help them overcome the threat. A respondent from Haresaw, Tigray said that prayers were said, and people were swearing not to sin; another respondent said people would leave the country.

More hopeful attitudes were much rarer. These included a respondent who said that the main hope was the anti-AIDS clubs and another that he hoped that vaccinations would soon be discovered against HIV/AIDS.

On the whole there were very few respondents who expressed positive aspects. A man from Oda Haro, Oromia suggested that HIV/AIDS had resulted in more self-restraint in sexual matters, which he saw as positive. A woman from Debre Birhan Environs said that even the children were now able to talk about sexuality, which was not previously in the culture. As noted in the quote at the beginning of this section, one woman from Haresaw, Tigray suggested that the epidemic had a role of empowering women as they could use the disease to fight against male violations of all kinds and assert their rights.

CONCLUSIONS

This paper has sought to provide insights into how local people in twenty sites in the four main regions of Ethiopia conceive of the HIV/AIDS epidemic and their responses to it. Respondents tended to refer to HIV/AIDS by using local variants of the English term, by describing its symptoms, by referring to its current or urban origins, and by emphasising its fatal nature. The vast majority of informants had heard about HIV/AIDS during the EPRDF period, and knowledge about the disease was limited in the more remote sites until around 2000. The most important sources of information were the radio, schools and health services; other sources included migrants returning from cities and abroad, missions and NGOs. Respondents had fairly clear ideas about the sexual transmission of HIV/AIDS, as well as other forms of transmission through blood, notably the role of sharing blades, unclean injections, and the possible role of contamination through “harmful traditional practices”, such as female circumcision, dental or uvula extraction, incisions, tattooing and body piercing. HIV/AIDS was

seen as having come from abroad, was believed by many to have originated from sex with monkeys, and was often described in terms of divine retribution. In comparing and contrasting HIV/AIDS with other diseases, respondents noted similar symptoms, notably with TB and other STDs, and emphasised the lack of cure, the severity of AIDS, the fact that patients cannot be externally identified and sexual transmission as the main distinguishing features.

Concerning AIDS deaths, over a third of respondents knew of someone who had died of AIDS, and over half suspected people of having died of AIDS. The highest figure mentioned was ten people. In particular respondents mentioned former soldiers and women returning from towns and abroad. The earliest suspected deaths were in 1993 in two sites in Oromia and the Southern Region and the most recent in 2001 and 2002 in three sites in Oromia and Tigray. There does not seem to be a clear regional pattern to the AIDS related deaths; however, it is striking that although the epidemic has been known in Ethiopia since 1984 the first suspected death were not until 1993 in a couple of sites. It is also notable that about the same proportion of respondents though the epidemic was increasing as those who thought it was not, suggesting that there is not a very strong concern about the spread of the disease. There were important gender and site differences with men and respondents closer to urban sites tending to view the epidemic as increasing as opposed to women and respondents from more remote site who did not consider the epidemic as increasing.

Regarding people living with HIV/AIDS the vast majority of respondents did not have close relations with any; only seven respondents had friends, one a relative, and two household members who were PLWHA. Concerning perceptions of the behaviour of PLWHA a few respondents mentioned that some come home to the village to die, and others go to towns and monasteries or places of holy water in search of healing. Only two respondents mentioned other alleged traditional cures, and two others mentioned prayers and promises of healing by religious leaders.

From the responses it is clear that PLWHA are generally not able to be open about their status, with only four cases mentioned, one of whom was a teacher who was transferred elsewhere, another PLWHA coming from elsewhere to teach, and in one site a young man telling his brothers and mother. Only six respondents said PLWHA were doing alright, if they looked after themselves, ate well and went to hospital regularly; one informant said that it was only by not disclosing their status that they could manage. In terms of how they survive, respondents mentioned petty trade, share-cropping and producing alcohol as strategies though it is clear that there were not specifically income-generating activities devised to cope with HIV/AIDS. Respondents from two sites mentioned cases of PLWHA committing suicide.

Whereas there was not much awareness of AIDS deaths and PLWHA there was a much greater awareness of AIDS orphans, who were reported to exist in nine sites in all four regions. In one site a respondent claimed there were 27 AIDS orphans. The orphans were being looked after by relatives and friends. In one case they obtained food aid and in another assistance from an NGO.

Regarding differential effects of HIV/AIDS by gender and wealth, there were mixed views. About the same proportion thought men and women were affected more, though men tended to think women were more affected and vice versa. Reasons for men being more affected included that they are more involved in extra-marital affairs, have several wives, migrate to towns and visit commercial sex workers, and were in the military. Women were seen as more affected because of migrating to towns and become involved in commercial sex work, marrying early against their wishes, marrying HIV positive men, being subject to male violations, rape, etc, working hard and becoming weakened fast once infected.

Concerning differential effects by wealth, almost the same proportion thought that the poor and the rich were more affected, and roughly the same proportion that they were affected equally. Reasons for the rich being more affected related to rich men having more sexual partners or more wives and going to town and visiting commercial sex workers. The poor were seen as being more affected because poor women engage in risky jobs, in bars and as commercial sex workers, and are lured to rich men in the hope of marriage. Once infected, though, respondents noted that the rich had more chances of longer survival by “buying days” through better nutrition and health care. It is clear from the answers that there is a synergy of gender and wealth with rich men and poor women being most at risk of being

infected. Some of those who argued that men and women were affected equally, suggested that men who go the disease in towns brought it home and spread it to their wives.

Regarding community involvement, a majority of respondents from 12 villages said that there were some individuals and groups concerned and active in anti-HIV/AIDS work. The sites where there were no activities were mainly the more remote ones. Groups involved in anti-HIV/AIDS activities included Anti-AIDS clubs generally of youth, *Kebele* Anti-AIDS committees, some involving farmers and clergymen, Anti-AIDS religious groups and NGOs, youth and women's associations, faith-based organisations and preachers, health facilities and personnel, schools and teachers, *iddir* burial associations, drama groups, and agricultural development agents. The most important of these were religious and health personnel.

Despite a number of organisations and individuals involved, several respondents expressed considerable scepticism about the effectiveness of teachers, religious leaders, women's and Anti-AIDS clubs and committees, and the quotes suggest that respondents are not convinced that such interventions are having a significant effect. Unlike in Addis Ababa where *iddir* burial associations are becoming increasingly aware of the epidemic and responding to it, the evidence from this study suggests that this has not yet happened in rural areas. The only two exceptions of *iddirs* helping AIDS orphans and one assisting PLWHA are close to towns where anti-HIV/AIDS activities are developed.

Regarding perceived effects of HIV/AIDS on social, economic and cultural relations, about half the respondents identified such effects, with slightly more mentioning cultural effects. HIV/AIDS was perceived as being related to social affairs in two ways: 1) through the segregation and ostracisation fear, and hatred of PLWHA and their families, which affects the ways that the victims and their families feel and more generally through effects on social life in that it creates social problems through financial costs, shortage of labour, exacerbating poverty and problems related to sexuality, and affection social institutions. Asked specifically about social effects the main ones noticed included suspicion between spouses, notably women of their husbands especially when they go to town, requests for blood tests before marriage, and less or more circumspect courting behaviour. Other alleged effects were reduced polygyny, avoidance or discrimination of PLWHA, the presence of AIDS orphans, fear and general reduced social interaction, suspicion of migrants, tensions between generations, stress felt by PLWHA, and less trust and interaction between neighbours. Very few respondents mentioned positive effects, including more faithfulness between spouses, more open talk between the generations, parents keeping girls at school longer, and more use of condoms.

The main perceived economic effects were loss of jobs and income from remittances and inability to work the land. Children were mentioned by a few respondents as being affected by having to leave school to look after sick relatives and work the land. Other effects mentioned included high medical expenses, fall in living standards and impoverishment, sale of assets, having to contract out land, inability to do even household, the young and most productive dying, and domestic workers being suspected of AIDS and being isolated.

Concerning how HIV/AIDS relates to cultural norms and rules respondents mentioned discrimination against PLWHA and commercial sex workers, loss of cultural values notably regarding sexuality which worsens the problem, the role of "harmful traditional practices" such as female circumcision, incisions, uvulotomy, etc as possibly spreading the disease, and cultural practices regarding marriage and sexuality, notably polygyny and adultery, alleged by some informants to increase the risk of HIV/AIDS whereas others rejected this assumption. Only one respondent mentioned gender differences in sexual customs. Asked directly about the impact of HIV/AIDS on cultural relations, the main perceived cultural effects concerned alleged reinforcing of values of virginity, and less pre-marital sex; although some respondents suggested either that these had not changed or had changed as a result of other factors. Likewise views about early marriage were said to have changed by some respondents whereas others challenged this view. A greater concern with girls' education was, however, stressed by several respondents, although some suggested that this resulted from other factors. Regarding norms about sexuality and marriage respondents suggested that there was less adultery, illicit or extra marital sex and that there had been pressure to stick to one wife, although this was partly linked to religion, with more concern in Christian areas, and less in Muslim areas. Concerns with blood tests prior to marriage was mentioned as an issue in six sites. Regarding stimulants

changes were attributed to religious values, Christianity opposing *chat* and Islam alcohol, rather than HIV/AIDS. Attitudes towards urban areas were said to have become more negative and in particular commercial sex workers were avoided and ostracised, although a few respondents suggested that male behaviour had not really changed. Regarding Female Genital Mutilation, a decrease in the custom was observed in several sites but this was due to education and changing values and was not to be related to HIV/AIDS; respondents from several sites suggested that the custom continued, and as long as safe procedures were used, HIV/AIDS was not a threat. Only one respondent suggested that this could become an issue, and in several sites there was no practice of FGM in the first place.

Concerning attitudes towards the future respondents tended to suggest that they were pessimistic, and that in particular PLWHA were desperate, and the young worried. Hopeful views were rare. One respondents suggested that Anti-AIDS clubs could make a difference another hoped that vaccinations would be discovered. Other isolated examples of more positive views included that more sexual restraint was positive, that the ability to talk about sexuality, which was not in the culture, was a positive development. A single young woman suggested that the epidemic was empowering women to fight against male oppression.

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References

- Annania Admassu 2000. "Coping with the challenges of AIDS: The experience of persons living with HIV/AIDS in Addis Ababa and their relations with institutions rendering health and counseling services". M.A. thesis in social anthropology, School of Graduate Studies, Addis Ababa University.
- Ayalew Gebre 2000. "Community knowledge and perceptions about HIV/AIDS and other sexually transmitted diseases in Bahr Dar". *Northeast African Studies* 7(1):127-146).
- Baardon, P. 1991. "Female survival strategies in Ethiopia: the case of commercial sex workers". Doctoral thesis, Department of Anthropology, University of Oslo.
- Bevan, Philippa and Alula Pankhurst eds 1995. *Ethiopian Village Studies. 15 studies*. Department of Sociology, Addis Ababa University and Centre for the Study of African Economies, University of Oxford.
- Converse, Paul, Tadesse Wuhib, Mesfin Mulatu, and Helmut Kloos. 2003. "Bibliography on HIV/AIDS in Ethiopia and Ethiopians in Diaspora" *Ethiopian Journal of Health Development* 17:33-85.

- Damen Haile Mariam 2003 “Indigenous social insurance as an alternative financing mechanism for health care in Ethiopia (the case of eders)”. *Social Science and Medicine* 56(2003): 1719-1726.
- Getnet Tadele 2000. “Sexuality and HIV/AIDS risk and perception among male street youths in Dessie”. *Northeast African Studies* 7(1):109-126.
- Gizaw, G. 1992. “Health aspects of repatriation of ex-soldiers”. *Ethiopian Journal of Health Development* 6(1):55-61.
- Kloos, Helmut and Damen Haile Mariam 2000. “HIV/AIDS in Ethiopia. An Overview”. *Northeast African Studies* 7(1): 13-41.
- Kloos, Helmut and Damen Haile Mariam *in press*. “Community Based organisations in HIV/AIDS prevention and Control in Ethiopia. A preliminary survey”. *Northeast African Studies* 7(2).
- Kloos, Helmut and Alula Pankhurst *in press*. “Introduction: HIV/AIDS in Ethiopia. Part 2. Community-based Organizations, Prevention, Patient Care, Research Aspects and the Epidemic in the Diaspora”. *Northeast African Studies* 7(2).
- Kloos, Helmut, Tadesse Wuhib, Damen Haile Mariam and Bernt Lindjorn 2003. “Community-based organizations in HIV/AIDS prevention, patient care and control in Ethiopia.” *Ethiopian Journal of Health Development* 17:3-31.
- National Committee on Traditional Practices of Ethiopia 2003. *Old beyond Imaginings: Ethiopia, Harmful traditional Practices*. National Committee on Traditional Practices of Ethiopia. Addis Ababa.
- Ministry of Health 2002, *AIDS in Ethiopia*. Disease Prevention and Control Department. Fourth Edition. October.
- Negassa, A. and Wolde Michael K. 2001. “Knowledge, attitude and practice of training traditional birth attendants on HIV/AIDS prevention in Jimma town, southwest Ethiopia.” *Ethiopian Journal of Health Sciences* 11(2):123-9.
- Pankhurst, Alula 2003a. “The role and space for *iddirs* to participate in the development of Ethiopia” in Alula Pankhurst ed. *Iddirs: Participation and Development. Proceedings of the Ethiopian National Conference, 20-21 December 2001*, Addis Ababa: Agency for Cooperation and Research in Development, pp.2-43.
- Pankhurst, Alula 2003b. “Income-generating activities for People Living with HIV-AIDS: Opportunities, constraints and potential strategies. Report submitted to Concern, Addis Ababa, October.
- Pankhurst, Alula and Helmut Kloos 2000 “Introduction: HIV/AIDS in Ethiopia, Part I: Risk and preventive behavior, sexuality and opportunistic infections”. *Northeast African Studies* 7(1):1-12.
- Pankhurst, Alula and Damen Haile Mariam *in press*. “The *Iddir* in Ethiopia: Historical Development, Social Function and Potential Role in HIV/AIDS Prevention and Control”. *Northeast African Studies* 7(2).
- Sebsib Belay 2002. Socio-Cultural Aspects of AIDS among Young Adults in Bahir Dar Town, Northwestern Ethiopia. M.A. Thesis in Social Anthropology, School of Graduate Studies, Addis Ababa University
- UNAIDS 2000. *Report on the Global HIV/AIDS Epidemic*. UNAIDS. Geneva.
- UNAIDS 2002. *Report on the Global HIV/AIDS Epidemic*. UNAIDS. Geneva.
- Wubalem Negash 2003. “The Role of Indigenous Voluntary Associations in Community Based HIV/AIDS Intervention Activities (The case of *Iddirs* in Addis Ababa)”. Masters Thesis in Regional and Local Development Studies, Addis Ababa University.

**APPENDIX:
MODULE 5: CRISES AND LOCAL RESPONSES:
PROTOCOL 2M AND 2F - CONCEPTIONS OF AND RESPONSES TO HIV-AIDS**

Respondents protocol 2M: 2 individuals: young man, older man

Respondents protocol 2F: 2 individuals, young woman, older woman

Reassure respondents that you will respect anonymity and NOT ask any names

RESPONDENT 1: Note details about respondent's status

Q1. What are the local terms for HIV-AIDS? If different from the English what are its connotations.

Q2. When did you first hear of HIV-AIDS, and from where/whom?

Q3. How/why did it the epidemic come about?

Q4. In what ways is it different from other diseases?

Q5. In what ways is it related to other diseases?

Q6. In what ways is it related to social life?

Q7. In what ways is it related to cultural norms?

Q8. Do you know of anyone known to have died of HIV-AIDS within your community?

Q9. Do you know of anyone suspected of dying of HIV-AIDS within your community?

If yes, when was the first case of death suspected?

Q10. Has the numbers of victims been increasing? If yes, how many estimated this year?

Q11. Do you know of anyone who is currently living with HIV-AIDS in your community?

If yes in what ways has their lives changed? Who is caring for them?

Q12. Have any left the community? If yes where did they go?

Q13. Where is the nearest testing available?

Q14. Have any sought traditional healing (holy waters etc)

Q15. Has there been any suspected cases of HIV-AIDS related suicides?

Q16. Do you know of cases of PLWHA who have come to terms with their HIV+ status and are coping well? If yes, what do you think the reasons are?

Q17. Have any community members been able to be open about their HIV+ status?

Q18. Have any become involved in income-generating activities? If yes describe.

Q19. Do you have a friend who is living with HIV-AIDS?

If yes specify gender and age group. How has the person tried to cope?

Q20. Do you have a relative who is living with HIV-AIDS?

If yes specify gender and age group How has the person tried to cope?

Q21. Do you have a household member who is living with HIV-AIDS ? If yes specify gender and age group. How has the person tried to cope?

Q22. Do you know of any AIDS orphans or suspected AIDS orphans?

If yes who is looking after them?

Q23. Do you think that HIV-AIDS is affecting men and women in your community to the same extent? If not describe and explain differences.

Q24. Do you think HIV-AIDS affects poor people and rich people equally?

If not describe and explain differences.

Q 25. Has HIV-AIDS affected *iddir*?

First ask without prompting, then check for the following: increase in deaths, decision to increase fees, reduction of members, disintegration of any *iddirs*, attempts to help PLWHA or AIDS orphans, changes in rules?

Q26. Are there any individuals, associations, institutions, networks, groups addressing the HIV-AIDS issue? If yes describe their activities. (check for youth and women groups, religious groups, health agents etc)

Q27. Has the HIV-AIDS issue affected social relations?

First ask without prompting then check for the following and elicit examples:

- relations between spouses (check about polygyny and migrant labourers)

- generations: parents and children (especially girls),

- unmarried young men and women (e.g. courting behaviour)

Q28. Has HIV AIDS affected economic relations?

First ask without prompting then check for the following with examples

- loss of jobs and income from remittances

- inability to work land

- children leaving school to work land
- need for more labour to look after sick
- children leaving school to look after sick

Q29. Has HIV-AIDS affected cultural norms and rules?

First ask without prompting then check for the following with examples:

- rules and norms about first and subsequent marriages
- attitudes towards virginity,
- attitudes towards sexuality
- attitudes towards early marriage,
- attitudes towards FGM.
- attitudes towards education (especially of girls)
- attitudes towards commercial sex workers
- attitudes towards alcohol, chat etc.
- attitudes towards urban areas and migration
- attitudes about hope for the future

Repeat for Respondent 2

Use this space to comment on the Protocol – does it work? any problems? suggestions for improvement
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