Doubting the existence of AIDS: a barrier to voluntary HIV testing and counselling in urban Mali

SARAH CASTLE
Centre for Population Studies, London School of Hygiene and Tropical Medicine, London, UK

Qualitative research was carried out in the Malian cities of Sikasso and Bamako with a view to setting up HIV voluntary testing and counselling (VCT) services and a separate programme to enable young people to improve their sexual health. The most striking finding was that a large number of respondents said they did not believe in the existence of AIDS. Reasons for disbelief were related to the perceived lack of AIDS cases in China, the inability of the virus to be transmitted by mosquitoes and confusion about mother-to-child transmission. Highly educated individuals were very sceptical of the existence of the illness, thinking it to be a Western plot to encourage condom use in order to halt the growth of the African population. Those who were more likely to believe in the existence of the illness were less educated or uneducated people who had personally seen someone sick with AIDS, often when they had been on labour migration to Côte d’Ivoire where HIV prevalence is higher. Respondents thought it likely that this scepticism would limit the use of VCT services. Other reasons for the potential non-use of services included the fact that some people lacked confidence in the competence of the laboratory technicians and were afraid that those testing positive would be highly stigmatized by the community. Thus, widespread awareness-raising campaigns are needed before any centres can be set up. Participatory education programmes are required to address HIV in the context of other health risks. This would allow people to inter-actively shape the debate about HIV/AIDS to fit their own needs. Currently, they are presented with information about the illness in a unidirectional manner via the media or health educators which seems to fuel their scepticism.

Key words: HIV/AIDS, Mali, voluntary counselling and testing, qualitative research

Background

Voluntary counselling and testing services (VCT) for HIV have been set up in a number of African countries. However, they require substantial logistical and technical input and need to create and sustain a reasonable demand among potential clients to become cost-effective (Dabis et al. 2000a; Sweat et al. 2000). It is argued that such services enable people to alleviate uncertainty about their HIV status if they feel they are at risk, to decide whether to have children or to marry and to plan for future child support in the event they are HIV-positive (Muller and Phanuphak 1993). VCT services can also, in principle, facilitate behaviour change, as those who are HIV-negative may subsequently resort to condom use in order to remain so (van-der-Straten et al. 1995; Worthington 1997). By contrast, theoretically, those who test positive can take steps not to infect others, although, in reality, this is not always the case (Tuha et al. 1998; Lutalo et al. 2000).

Many countries with successful VCT services are those where the prevalence of HIV is relatively high and where possibly many (if not the majority of) people believe in the existence of HIV and AIDS. In some high prevalence settings, people may have seen colleagues, friends, neighbours or community members fall sick or die of the disease making them convinced that the illness is indeed a reality (McKinley 1996). In Lusaka, Zambia, for example, which has community prevalence rates of 24–26% (Fylkesnes et al. 1998), the Kara Counselling and Training Trust has been offering VCT services since 1992. At first, it was primarily sick people who came for testing, but now healthy individuals come because they are planning to get married, have children or to engage in unprotected sex having been in a relationship for some time (Chama and Kayawe 2000). In Uganda, AIDS prevalence in urban areas was around 24%, but now appears to be falling due to appropriate and timely awareness-raising campaigns, particularly among young people, which appear to be associated with increased condom use (Kassler et al. 1998; Kamali et al. 2000). In this country, the AIDS Information Centre, established in 1990, tested nearly half a million people by 1998 in Kampala and in a number of satellite centres (Kayawe et al. 1998). Indeed, access to voluntary testing and counselling was seen as a key factor in reducing the spread of the epidemic in Uganda. Unpublished data indicated that clients who participated in the Centres’ post-test clubs were more likely to desist from sex with casual partners and to report abstinence if HIV-positive (Moore et al. 1993). Additional qualitative research showed that VCT service users in this setting were more likely to practice safer sex, abstain or use condoms (MacQuarrie 2001), although more objective quantitative research is perhaps needed to confirm these reported associations.

However, other studies have shown that there is low motivation for the uptake of VCT services elsewhere in sub-Saharan Africa. Reasons for ambivalence are related to the fact that, in most cases, there are no health care services that can monitor and manage the condition of those who test HIV-positive. Even in countries where antiretrovirals are
available, they may not be accessible outside the capital city, and patients may not be able to afford the regular blood tests needed to monitor immune status (Castle 2001a). In many localities, a fear of stigmatization and discrimination makes individuals unwilling to be tested or to know their test result (Baggaley et al. 1998). In others, a concern about lack of confidentiality and a long waiting time for test results discourage people from using VCT services (Muller and Phanuphak 1993).

Furthermore, in many cultural environments, particularly those with a low prevalence of HIV, there is also sometimes a widespread disbelief in the existence of the AIDS virus. It is discussed here how this may be associated with low motivation for using VCT services in urban Mali. In Zimbabwe (which is currently a high prevalence setting), it has been reported that, particularly at the beginning of the epidemic, AIDS was sometimes dismissed as the ‘American invented disease to stop sex’ (The Economist 1994). In Cameroon, where a survey of antenatal clinic attendees showed comparatively low HIV rates of 4.2% (Mbopi-Keou et al. 1998), SIDA (the French acronym for AIDS) is known by some as ‘ Syndrome Imaginaire pour Décourager les Amoureux’, the imaginary syndrome to discourage those in love (Meekers and Calves 1997). In Côte d’Ivoire (one of the highest prevalence countries of West Africa) official lassitude about the threat of HIV/AIDS, and general ignorance and disbelief among the population about the epidemic, have facilitated the spread of HIV (Husband 1991; Mwadi 1995). The debate raised by South Africa’s President Thabo Mbeki (who questioned causal links between HIV and AIDS) is known internationally, and resulted in many people elsewhere on the continent questioning the existence of the illness (Castle and Konaté 2000; Cohen 2000; Horton 2000). It will be shown that, in the urban Malian setting described here, scepticism concerning the existence of the illness is widespread. This cynicism is linked to the fact that many people’s personal experience of HIV and AIDS is comparatively rare compared with those in East and Southern Africa and may lead to a lack of willingness to use VCT services.

Recently established in Mali, Population Services International (PSI) is in the process of setting up two testing centres; one in the capital city of Bamako and one in the regional capital of Sikasso. In the past few years, PSI has set up a number of VCT centres throughout Africa. For example, in Rwanda, PSI runs the Centre Dushishoze which was set up in January 2001. In the first 3 months open it tested 700 young people with a further 6000 counselled about HIV through a peer education programme (PSI 2001a). In Zimbabwe, PSI runs VCT services from 10 centres, which in May 2001 saw 3616 clients. This increased to over 5000 for August of the same year and totalled nearly 45 000 for the entire 12-month period (PSI 2001b). The centres’ success is attributable to the extensive awareness-raising and promotional activities among urban Zimbabweans, many of whom appreciate the fact that many of the centres comprise anonymous offices in busy commercial centres, thus affording them confidentiality when they visit to be tested.

The prevalence of AIDS in Mali and neighbouring Côte d’Ivoire

Good quality data on AIDS prevalence in Mali are, to date, extremely scarce. Among men, data are available for high-risk groups such as truck drivers, and among women, the prevalence among sex workers has been regularly monitored. Rates of HIV infection in Mali are not, as yet, as elevated as in the neighbouring country of Côte d’Ivoire but have been shown to be increasing among these groups who are systematically followed up. In 1996, 8.9% of truck drivers and 3.8% of pregnant women at antenatal clinics were found to be HIV-positive (Ministère de la Santé, des Personnes Agées et de la Solidarité, 1999). In 1999, research carried out by Mali’s national AIDS programme (in conjunction with the US Centers for Disease Control) among male high-risk groups (comprising truckers) in Sikasso town and Bamako found HIV prevalence rates of 6.8 and 8.2%, respectively. Male medium-risk groups (comprising ticket touts operating around the transport stations) in Sikasso town had a prevalence of 8.2% and in Bamako 6.3%. Corresponding rates among medium-risk female groups (ambulatory vendors) were 4.6% in Sikasso town and 14.0% in Bamako. Female high-risk groups (sex workers) had prevalence rates of 22.8% in Bamako and 36.4% in Sikasso town (Baganizi et al. 2001). The same survey also tested domestic servants in selected urban areas throughout Mali and found low overall rates of infection of 1.7%. These rates among migrant workers (who are likely to be representative of many seasonal rural–urban migrants who comprise a large proportion of Mali’s population) are comparatively low compared with neighbouring West African settings and the East and Southern regions of the continent.

Regional differences do exist, however, in the prevalence of HIV in Mali. Sikasso (where one of the VCT centres will be set up) is near the border between Mali and Côte d’Ivoire. The region has the highest community levels of HIV prevalence of all the regions in Mali, with estimates for pregnant women being 8.5% compared with 4.5% for those attending selected antenatal clinics in Bamako (Ministère de la Santé, des Personnes Agées et de la Solidarité, 1995).

In Côte d’Ivoire, recent estimates have shown HIV prevalence to be higher than in Mali. Data from UNAIDS noted that in 1992–93, HIV prevalence among sex workers in Abidjan was 84%. The mean prevalence for pregnant women in major urban areas was between 12 and 14% (UNAIDS 2000). It should be noted that there is substantial migration from Mali to Côte d’Ivoire and that many Malian household economies count heavily on remittances from migrant family members. Female Malian migrants tend to work as domestic servants in high and middle income households in Abidjan and other cities, while men often work on cocoa and coffee plantations or carry out manual labour in urban areas. It will be shown below that the migration to Côte d’Ivoire of Malian unskilled economic migrants seems to sometimes result in their exposure to people exhibiting the symptoms of AIDS and serves to convince them that the disease is, indeed, a reality. By contrast, more highly educated individuals (who tend to have skilled managerial office jobs within Mali)
Methodology

The study comprised a series of eight focus group discussions which were carried out in May 2001 to capture normative attitudes and beliefs concerning HIV/AIDS and HIV testing. The results were to inform the design of HIV VCT services set up by PSI in Sikasso and Bamako. Another series of eight focus groups was carried out with young people in order to establish their priorities before starting up separate youth-orientated programmes to encourage safer sexual behaviour. Evidence from these groups is also presented here because the issue of disbelief in the existence of the AIDS virus was also strongly evident throughout these discussions.

Table 1 shows the number of focus group discussions carried out in the two cities. In each city, one focus group about VCT services was undertaken with educated and uneducated participants of both sexes. Participants in the VCT focus groups had to be aged between 20 and 34 years and, in the case of the uneducated women, were required to be engaged or married. The rationale behind choosing the latter was so that we could get the opinions of a group who were likely to have the least social power in terms of decision-making, given that the use of VCT services requires a certain degree of autonomy, mobility and time that may not be available to these women.

Table 1. Location and composition of focus groups

<table>
<thead>
<tr>
<th>VCT focus group discussions</th>
<th>Bamako</th>
<th>Sikasso</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men (aged 20–34 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Uneducated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Women (aged 20–34 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Uneducated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Young people’s focus group discussions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men (aged 17–24 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated (currently in high school)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Less educated/uneducated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Women (aged 17–24 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated (currently in high school)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Less educated/uneducated</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

A pre-requisite for participation in the VCT focus groups for educated individuals was to have completed at least secondary school education so that we could get the opinions of those who are likely to read newspapers and be aware of AIDS-related issues in the national and international media. However, in Bamako both the VCT and young people’s focus groups were carried out in an upper class ‘quartier’ (neighbourhood) meaning that most respondents had high school or even higher education. Many were at university or doing some sort of professional training whilst others had managerial jobs or were in business. The discussions with less educated or uneducated groups were carried out in a peripheral low income ‘quarter’ where most people have had little or no schooling. Men tend to work in the transport sector as drivers or apprentices whilst the women either practice petty commerce or travel daily into Bamako to work as domestic servants. Similar high and low income ‘quarters’ were identified in Sikasso. Regarding the interviews with young people which did not explicitly focus on VCT but did discuss HIV and AIDS, pupils were recruited from three schools in the two cities. School children in Bamako who participated in the youth discussions were chosen from two contiguous ‘Lycées’ (high schools). The pupils interviewed in Sikasso were from the same high school but from a selection of classes to ensure a more representative reflection of those in the educational system.

Participants were selected from a purposive sample either by asking community or student leaders to nominate individuals or by the interviewers choosing participants during systematic visits to households, schools, market or transport areas where eligible individuals were likely to be. A screening procedure was adopted which asked potential interviewees about their age, education, occupation and marital status to ensure they met the criteria for participation in the discussions described above. They were then asked if they had heard of AIDS. If they had not they were excluded as it seemed of little use to conduct a discussion about a topic they were unfamiliar with. None of those fulfilling the criteria who were eventually selected for interview refused to participate in the discussions.

The interviewers took care to establish that not all members of the group knew each other. As with all qualitative research, it is not claimed that the results are generalizable more widely (Yoder 1997), particularly given the range of socioeconomic and cultural contexts in Mali. However, it is thought that among the groups interviewed, the opinions are likely to be fairly representative of those of a similar background in urban Mali because of the extraordinary consistency of the results and the independent expression of similar opinions in the two locations.

The focus groups (which comprised 8–10 individuals) were usually convened at night in a ‘neutral’ location such as a home of a community member. Participants were rewarded with gifts of tea and sugar (men) and soap (women). The discussions were carried out in Bambara and tape-recorded. The interviewers transcribed the interviews in French and they were subsequently typed up and analyzed using The Ethnograph computer software. General codes (known as ‘parent’ codes in The Ethnograph) based on the interview guide were attributed to the text. Sub-codes (or ‘child’ codes) were added using grounded theory techniques where important and consistent themes emerge from the text itself to create new categories for analysis (Glaser and Strauss 1967). Verbatim quotations are presented here together with the socioeconomic and educational characteristics of the respondent, whether they participated in a ‘VCT’ or ‘Youth’ focus group and their respondent identifier.
‘Western plot’ theories and scepticism vis-à-vis the existence of AIDS

Each group was asked whether they believed that AIDS was a real phenomenon. In every group convened for discussions about VCT, there were several members who hotly contested the existence of AIDS. Some, particularly men with significant levels of education living in Bamako, justified their disbelief by claiming AIDS was a Western plot to stop the African population growing or an invented fallacy so that the West could make money from the sale of medicines or condoms.

I would say that I do not believe in AIDS. If I remember in 1989 or 1990 there was a programme on national television that said by 2050 the African population would constitute more than 10% of the world’s population. So they had to invent an incurable illness to put a brake on this development. In other words, an illness that does not have a cure and if you are infected you will die. Knowing that demographic growth is an indispensable factor in human development, they feared a future with an African supremacy. [Bamako, man, 29 years old, unemployed, higher education (VCT, C)]

In reality, AIDS is an invention to sell condoms. The West created the idea of AIDS to put a stop to sexual relations or even better it’s a policy to put a brake on the growth of the African population. [Bamako, man, 23 years old, student, higher education (VCT, E)]

These days, people talk about AIDS too much, to the point where you ask yourself if it exists. Why all this publicity in the media when there are other illnesses that kill more than AIDS? Is it not a plot by the West to get rid of all their pharmaceutical products in our country? [Bamako, man, 24 years old, student, higher education (VCT, G)]

Although fewer women than men cited the ‘Western plot’ theory, the idea still permeated their discussions, particularly in Bamako, with one respondent independently reiterating the view expressed in the men’s group that the illness was invented to encourage condom use.

I don’t believe in AIDS . . . this nonsense about condoms was invented by Europeans to encourage adultery (and thereby their sale) in Africa. [Bamako, woman, 18 years old, high school pupil (Youth, A)]

During all the young people’s discussions, the majority of participants who spoke out on the subject declared that they did not believe that AIDS was a real phenomenon. Some were overwhelmingly of the opinion that it was another illness that had been badly diagnosed (such as chronic malaria or hepatitis).

I don’t believe in the stories of AIDS. I think people mistake jaundice for AIDS. [Bamako, woman, 19 years old, market trader, no education (Youth, H)]

Honestly, I don’t believe in AIDS. People keep talking about AIDS but for me certain people have malaria which turns into typhoid fever. If they die, then the doctors conclude that it is AIDS. [Sikasso, man, 24 years old, stone mason, primary education (Youth, D)]

In my opinion, AIDS is not a reality because they have not been able to find a treatment. For me, AIDS is a complication of another illness. If it gets to a very advanced stage, people say that it is AIDS. [Bamako, woman, 20 years old, student, higher education (VCT, F)]

Like some of the VCT group participants, a number of young people felt that it represented a fictitious plot by Western governments to reduce the size of the African population.

For me there is a political element to this phenomenon of AIDS. I mean that it is an invention of Europeans to reduce the African population. This is why they talk of this illness. [Sikasso, man, 19 years old, high school pupil (Youth, I)]

Both the group of male school pupils and the female school pupils independently argued that one of the over-riding pieces of evidence for the non-existence of AIDS was the perception that it did not exist in China where the population is very large.

Me, I don’t believe in AIDS because the Chinese are very numerous in the world and people say that no Chinese person has ever got AIDS. How is that possible? It is the Africans who are the most affected – not the Europeans or the Chinese. [Bamako, woman, 18 years old, high school pupil (Youth, H)]

I don’t believe in AIDS because I have not had a reply to certain questions such as why are people with AIDS are more numerous in Africa than in Europe? Why are there no people with AIDS in China when it is the most populous country in the world, and why can mosquitoes transmit malaria and not AIDS? [Bamako, man, 19 years old, high school pupil (Youth, G)]

Confusion relating to multiple modes of transmission and reportedly successful traditional treatments

It should be noted that there appears to be a substantial amount of erroneous information circulating among highly educated individuals resulting in their not believing in the existence of the illness. Educated people seem to know more routes of transmission of HIV but, rather than increasing their understanding, it seems to add to their confusion. In addition, the fact that infection (although likely) is not 100% guaranteed during intercourse with an HIV-positive person also led them to doubt the existence of the illness. Similarly, cases where mother-to-child transmission had not occurred led them to be sceptical of the illness’ existence.
AIDS is not real and I am not at all convinced. My reasons are simple. It is said that someone who is HIV-positive and pregnant does not necessarily transmit the virus to her baby and that the rate of infection is 1% when normally the child is nourishing itself with the blood of the mother which will be infected. Another example is that I saw a woman who had come from Côte d’Ivoire to Point G hospital (in Bamako). All the symptoms were visible. A short while afterwards the father of the woman came to get her to treat her traditionally and now she is cured. Even now she is in very good health. Similarly, I heard about a man who died of AIDS apparently and they confirmed that his wife is negative. Is this possible? No! There are so many examples that I don’t believe in AIDS. [Bamako, woman, 26 years old, student, higher education (VCT, J)]

I don’t believe in AIDS because the other day I participated in a debate about AIDS. The doctor said that someone who is HIV-positive can make love with his wife without her being infected. How can this be possible? Furthermore, he said that an HIV-positive woman can give birth to an HIV-negative baby. In both cases it is blood that is transmitted so I don’t believe in AIDS. [Bamako, woman, 18 years old, high school pupil (Youth, A)]

In Sikasso, male school pupils said that the fact that mosquitoes do not transmit the illness made them sceptical of its existence.

(The fact that) an insect bite can transmit malaria and not AIDS – I mean from someone infected to someone who is healthy – seems very surprising. There should be more information given to people on this subject. [Sikasso, man, 17 years old, high school pupil (Youth, D)]

What bothers me a bit is that it is not transmitted by the anopheles (mosquito) when (people say that) it is passed on through the blood. [Sikasso, man, 19 years old, high school pupil (Youth, I)]

Some individuals were convinced they knew of cases where a person had been diagnosed with AIDS and then, more often than not using traditional medicine, had been miraculously cured. This led them to believe that the illness had never existed in the first place.

I do not believe in the existence of AIDS because sometimes you see people and people say they have AIDS but afterwards modern medicines don’t seem to help. Then they go and seek a (traditional) treatment in the bush and come back cured most of the time. So I’m not really convinced of the existence of this plague. [Bamako, man, 23 years old, student, higher education (VCT, E)]

My best friend became seriously ill in Côte d’Ivoire. In all the health centres where we took him, they said, having analyzed his blood, that he had AIDS. Not being discouraged, we took him to his village in the Wassalou region where he underwent a traditional treatment. After this he recovered. Now he is in very good health and the father of two children. This is why I do not believe in AIDS. [Bamako, man, 28 years old, blacksmith, no education (VCT, B)]

The participants themselves recognized the need for more and better quality information about HIV/AIDS and for HIV testing, and for a better exchange or dialogue with the information providers.

Certain people do not believe in AIDS or they have a doubt. This is due to the fact that there is a lot of debate concerning this illness and many different theories . . . in the end we don’t know who to trust. Certain co-ordinators and project workers who fight against AIDS get annoyed with people who ask questions so they can get clarification and convincing arguments about the illness. In any case, to convince me I need more hard proof like the test for the virus. [Sikasso, man, 28 years old, businessman, secondary education (VCT, F)]

Personal experience of knowing someone with HIV or AIDS as a factor in ensuring belief

In most cases, those interviewed who believed that AIDS was real were those who had some personal contact with someone who was sick or who had died from the disease. Interestingly, for some it was the blood test itself which contributed to the proof they needed to believe in the existence of the virus.

AIDS exists because I personally saw a woman who was sick from AIDS. After the first symptoms, the doctor confirmed it via a blood test and even informed her husband. And recently (on the 1st December) I had a relative who died of AIDS. [Bamako, woman, 24 years old, secretary, secondary education (VCT, D)]

I believe in AIDS because my uncle said he had seen someone with AIDS and accompanied him to hospital. There the doctors confirmed that he had AIDS in his blood. Me, I didn’t believe in it but after my uncle told me this story I believed in the existence of AIDS because I really believe in what my uncle says. He told me that he had seen three people die of AIDS. It was this proof that made him believe in AIDS himself. [Sikasso, man, 25 years old, photographer, no education (VCT, F)]

Those who had seen someone sick with the illness seemed more likely to be uneducated, with scepticism predominating among the highly educated classes.

I believe in AIDS because I have heard about it on the radio and on the television. Also I have seen a lot of people die from AIDS in the ‘quarter’. [Bamako, woman, 19 years old, market trader, no education (Youth, H)]

Yes I believe in AIDS because I saw someone die from it in the ‘quarter’. People were afraid of him and he was
The readiness of those with little or no education to believe in the existence of the illness may be connected to the fact that, unlike their more educated counterparts, they had often been on labour migration to Côte d'Ivoire where the disease is more prevalent. Alternatively, they were more likely to know returned migrants who had fallen ill.

I can say that I do believe in AIDS because once, in Côte d'Ivoire, someone said that there was someone HIV-positive around and I went to look with my own eyes. [Bamako, man, 23 years old, driver, no education (Youth, A)]

A couple who were from the same ethnic group as me came back from Côte d'Ivoire sick with AIDS. Their diagnosis of AIDS was confirmed by a doctor. Later they died, first the man then the woman. [Bamako, woman, 27 years old, no education, fabric dyer (VCT, E)]

We believe in the existence of AIDS. One of our compatriots came back from Abidjan sick with AIDS. Her (diagnosis of) AIDS was confirmed by a doctor and later she was dead. [Bamako, woman, 27 years old, trader, no education (VCT, I)]

It is also possible that the educated classes have had less contact with someone who has contracted the disease because they belong to a group that is more likely to use condoms. Indeed, the DHS for Mali (1995–96) indicated that, among men, 12% of those with secondary education were currently using the condom as a method of contraception compared with 6.2% of those with primary schooling and 1.8% of those with no education (Coulibaly et al. 1996). However, condom use was not central to the focus group discussions described here. Further exploration of this hypothesis could be done in the future, perhaps using in-depth individual interviews.

As described above, the region of Sikasso is the region in Mali with the highest prevalence of HIV according to national statistics (Ministère de la Santé, des Personnes Agées et de la Solidarité 1999). This means that young people in Sikasso are more likely to have been in contact with someone infected with HIV than their counterparts in Bamako. Thus, in Sikasso some educated young people, particularly women, who had had personal contact with someone infected by the disease were also more ready to believe in its existence than school pupils in the capital. One noted, however, that young men in Sikasso still remained sceptical; a fact which indeed emerged from the discussions with the male pupils cited above.

I believe in AIDS because I have seen a lot of people die from AIDS. But, by contrast, there are a lot of young men who say that AIDS does not exist and that it is hepatitis in an advanced stage. [Sikasso, woman, 17 years old, high school pupil (Youth, H)]

Like the educated participants, those uneducated respondents who had not actually seen someone die from the disease were sceptical of its existence. Thus, it seems that the phenomenon of believing in the existence of AIDS due to personal experience of its consequences transcends the effects of education. Disbelief among educated individuals is because they are likely to hold jobs that do not regularly take them to Côte d'Ivoire like their uneducated counterparts. Alternatively, as discussed above, they may have different patterns of condom use and be more likely to protect themselves from infection. Educated or not, individuals seem reticent to perceive AIDS as a reality if they have not known someone to contract the illness.

I don’t believe in AIDS as I have never seen someone die from AIDS. [Bamako, woman, 18 years old, fish seller, primary education (Youth, C)]

I have heard of AIDS but I don’t believe in it because I have never seen anyone ill with my own eyes. It is for this reason that I don’t believe in it. [Bamako, man, 17 years old, trader, no education (Youth, D)]

Disbelief and other barriers to the uptake of VCT services

Disbelief in AIDS was perceived by some educated participants to be a barrier to the potential use of VCT services.

I am part of that group who do not want to know if I have the AIDS virus or not. Because to do something, first you have to believe in what you are doing. As I don’t believe in it (AIDS), I won’t go. [Bamako, man, 23 years old, student, higher education (VCT, E)]

Certain young people and adults who don’t believe in AIDS will not want to know their HIV status. [Sikasso, woman, 17 years old, student, secondary education (VCT, C)]

Those who don’t believe in AIDS – why would they go and do a test? It’s not worth it. They have no reason to go. For me it is these kinds of people who would not go and do a test. [Sikasso, man, 25 years old, unemployed, secondary education (VCT, C)]

However, the majority of uneducated respondents, who, as shown above, appeared to be more likely to believe in the existence of the virus, said that they would go and be tested.

I am not afraid of being tested so that I can protect myself subsequently. If you are negative you are reassured. If you are positive . . . well . . . [Sikasso, woman, 20 years old, trader, no education (VCT, I)]

I am brave enough to get tested so that I can know my (HIV) status. If I turn out to be sero-positive, that will enable me to adopt behaviours that can save others’ lives. [Sikasso, man, 28 years old, mason, no education (VCT, E)]
I am ready to go and be tested because I am faithful but I can’t count on my husband being faithful. [Bamako, woman, 20 years old, trader, no education (VCT, G)]

One sceptical uneducated male respondent saw HIV testing as something to go through to confirm the existence of the virus. In other words, as also described by another respondent above, the test itself became a means of verifying whether the virus was for real or not.

I want to be tested to know if I am affected or not and to know if I should or should not believe in the existence of this illness. At this moment I would be able to get to the bottom of all this. [Bamako, man, 18 years old, carpenter, no education (VCT, B)]

The other major reason for the potential non-use of services by educated respondents included a fear of rejection by society and by family if an individual was found to be HIV-positive. The research clearly showed that there was likely to be a high level of stigmatization and isolation of those found to be carrying the virus and thus it was better not to know if one had been infected. It is probably not a coincidence that one had been infected. It is probably not a coincidence that the sense of stigmatization seems greater among educated individuals who are unfamiliar with the disease compared with uneducated respondents for whom the illness often touches upon their daily lives.

In our society, people are rejected when they are infected with HIV and I think it is due to a lack of information . . . When someone is rejected by his entourage because he is ill, he will find himself confronted with two illnesses instead of one – because exclusion is also an illness. [Bamako, man, 28 years old, manager, higher education (VCT, H)]

In my opinion it is better to be surprised by falling ill rather than knowing that one is HIV-positive because I could not bear being rejected and marginalized by my entourage. I am sure that I would kill myself. [Bamako, man, 29 years old, unemployed, secondary education (VCT, C)]

Others did not have confidence in the health services and perceived the staff to be incompetent, leading to the giving of a positive result when in fact the person tested was HIV-negative.

I know a lot of people who have done the test and who have been declared negative. But in my case, I would never even dream of doing the test. I wouldn’t even think about doing it once. They do not have reliable (laboratory) materials to prove that someone has AIDS. They say that a lot of people have AIDS when they don’t. Under these conditions I would not go because of fear that they would say that I am HIV-positive and that I would die of fright before the time I was supposed to when in fact I only had malaria. I won’t go. [Sikasso, man, 23 years old, student, higher education (VCT, D)]

I believe in the test but I think that the health workers themselves are not qualified. The HIV test is not a simple blood test . . . You should give the responsibility for such a job to someone who has graduated from EPS or ESS (Ecole Primaire de Santé and Ecole Secondaire de Santé). Ordinary health technicians are not qualified to do this. In addition, the human brain can make mistakes if it is tired. Under these conditions someone could conclude that an individual is HIV-positive when in fact he isn’t. It is an error of interpretation and shows incompetence in the subject. [Sikasso, man, 25 years old, unemployed, higher education (VCT, C)]

**Strategies to combat scepticism**

Scepticism about the existence of HIV/AIDS together with the perceived quality of testing services and the probable stigmatization of those testing HIV-positive are likely to serve as a barrier to the utilization of VCT centres. The evidence presented above shows that belief in the existence of HIV appeared to be strongly associated with having known someone who has contracted the disease. A widespread and comprehensive awareness-raising campaign will need to be done before the VCT services are operational. As yet, particularly among intellectuals, there are important gaps in their knowledge, erroneous beliefs, confusion or simply incomprehension, which need to be rectified if VCT services are going to be successful.

While this finding is not new, its implications for the setting up of VCT services in a comparatively low prevalence country such as Mali merits further attention. In non-programme settings, it has been clearly shown that experience of knowing someone with AIDS is a good predictor of behaviour change (Kipp et al. 1994; Gregson et al. 1998). It may therefore potentially be useful to engage people living with HIV as educators – a tactic that has been tried before through the media in Mali. However, referring to this, several educated respondents thought that the individuals shown as having symptoms of AIDS or saying they were infected with HIV actually had another illness and had been paid to say they had been infected.

One day I listened to and watched a programme where they showed people with HIV. People did not really believe it because these were people who were in good health. Me, personally I didn’t believe it and thought that they had given money to these people so that they would give a statement. [Bamako, woman, 20 years old, high school pupil (Youth, F)]

However, in many settings stigma against people who are infected with HIV or who exhibit symptoms of AIDS is often high and their lives could be put in even greater danger if they admit to their condition. This is particularly true where the overall prevalence of the virus is low, where it has been shown that ‘people with HIV and AIDS, whose involvement in prevention interventions is known to support behaviour change, are often not available at the early stages of an epidemic when their participation is needed most’ (Family Health International/UNAIDS 2001).
As the respondents point out, rather than simply receiving this information unidirectionally, people require direct and personal contact with those suffering from AIDS and the chance to exchange opinions with them and to ask questions. To date, the debate has been very one-sided with people receiving (often contradictory) information from many sources but with very little opportunity to ask questions or to express their own concerns. Either people gain information from the television or radio without the chance to ask questions, or they are told about the virus by health workers who, as several participants noted above, frequently do not allow them to probe for answers or to request additional information. It is clear that the media, in all its forms, together with the health sector, needs to involve people in a participatory way in accessing information so that they cannot only listen and observe but also get involved in the debate and shape it to fit their own needs.

In settings where sexual health interventions have been carried out, psychologists have shown that sexual health education programmes that are experiential (that is to say they draw on the experiences of the participants) are the most successful in inducing safer sexual behaviour (Aggleton 1996). Theories such as the Adolescent Development Theory recognize that information and services are not enough to make people adopt safe sexual behaviours. Rather, they need to be able to draw on their own experiences, express their fears and concerns in a non-judgemental environment and form positive relationships to address their own priorities (Hughes and McCauley 1998). Such a theory can be adapted, both for adolescents and older individuals, to persuade them to accept the existence of HIV and AIDS and to use VCT services. It is possible that, among the educated groups, interventions that draw upon susceptibility to other risk behaviours, such as smoking, or other aspects of sexual health risk (such as the association of multiple partners with STIs) may need to be developed. This may potentially facilitate the introduction of the idea of risk in other areas of their lives that can then be applied to HIV. In tandem with these participatory activities, the formal media needs to be more finely tuned to the informational needs of the general public, and in particular should present comprehensive, consistent and understandable messages to the educated population who actively seek out information and question the facts they are presented with.

In addition, there may be a need for focused interventions with those at particularly high risk. In this study, the sub-sector of the population expressing a greater degree of disbelief in the illness was that with high levels of schooling. Ironically, it is these individuals who may make greater use of preventive and curative health services compared with their uneducated counterparts. For example, Demographic and Health Survey data (1995–96) show that educated families are more likely to use allopathic medicine for the treatment of childhood and other illnesses, are more likely to utilize antenatal services and to immunize their children (Coulibaly et al. 1996). Thus, it may be necessary to capitalize on their use of existing services to disseminate correct information about the nature and transmission of the HIV virus with the aim of ultimately attracting them to the VCT centres.

Conclusions

The study indicates that a comprehensive awareness campaign is needed well in advance of the opening of any VCT centre. The discussions found that there was widespread scepticism about the existence of HIV/AIDS, particularly among the educated groups. Reasons for disbelief were related to the perceived lack of AIDS cases in China, the inability of the virus to be transmitted by mosquitoes and confusion about mother-to-child transmission. Many intellectuals thought that the virus was a Western plot to encourage condom use so that Africa’s population would not grow and dominate the developed world.

Those who were more likely to believe in the existence of the illness were less educated or uneducated young people who had personally seen someone sick with AIDS, perhaps when they had been on labour migration to Côte d’Ivoire or had had friends and relatives return sick. When talking about the consequences of a positive diagnosis, it became clear that an HIV-positive individual was likely to be highly stigmatized. In such a social climate it is unlikely that people will want to go for testing and much must be done to support those who test positive for HIV.

People had many unanswered questions and preferred to engage in an active debate with those who had had first-hand experience of the disease. However, such discussions should be carefully prepared and monitored as it is not useful if their testimonies comprise shock tactics or scare-mongering which may backfire and even put those living with HIV/AIDS at risk. Nor is it useful if their testimonies are the only or main form of raising awareness about the issue. Rather, a comprehensive experiential approach is needed with individuals drawing on perspectives from their own lives to evaluate their own risk in terms of HIV and other health-related issues. It appears to be crucial to use a variety of media to reinforce safe sex and VCT messages and that health workers engaged in awareness-raising and testing have a welcoming and patient manner.

In addition, the study revealed some other important findings relating to the potential non-use of VCT services. The perceived lack of competence of laboratory technicians and fear of stigmatization were also given as reasons for avoiding testing. The testimonies of those interviewed point to the need for a holistic approach to awareness-raising, not only targeting individuals but also health service personnel and their clients together with community organizations to talk about what the test entails, the means by which it is verified and the need for support for those who have a positive result.

Clearly, Mali is at an important threshold in terms of the evolution of the AIDS pandemic in the country. Whilst medium- and high-risk groups exhibit moderate to high levels of infection, the overall prevalence in the general community remains low. Nevertheless, unless campaign activities seek to combat the evident scepticism, particularly among the highly educated, the epidemic risks taking hold rapidly, which would result in the devastating social and economic consequences seen in many other parts of the continent.
Endnotes

1 However, it has been documented in some settings that those who know they are HIV-positive do not use condoms for fear of raising their partner(s)' suspicion (Meursing 1999) or because they want to deliberately infect others as a revenge on society and on the opposite sex in particular (Ayiga et al. 1999; Castle 2001b).

2 It should also be noted that in other high prevalence settings, scepticism still exists about the existence of the illness, with many believing it to be a fictitious invention of the West (McGrath et al. 1993; Meekers and Calves 1997). This view was shared by many of the Malian respondents taking part in the discussions described here.

3 The Demographic and Health Survey for Mali (1995–96) showed that 98.3% of men and 91.3% of women in urban areas had heard of HIV (Coulibaly et al. 1996). Thus it is likely that those selected into the study described here are representative of the general population.

4 Two blocks of industrial soap (highly valued for domestic laundry) were offered to each woman to compensate them for their time lost for market or trading activities. This may explain why few refused to participate.

5 These young women may have over-estimated the likelihood that an HIV-positive mother would give birth to an HIV-negative baby. Without intervention the likelihood of HIV transmission is 25% but this risk can be reduced to 8% with the use of drugs such as Nevirapine (Dabis et al. 2000b). The participants may not be aware that this low risk is due to the use of antiretrovirals.

References


Bamako: Ministère de de la santé, des personnes agées et de la solidarité.


Acknowledgements

This work was funded by USAID grant no. 688-A-00-01-00042-00. The author is grateful to M. Mouhamadou Kamisoko, Mamadou Faramba Camera, Mme Diallo, Djeneba Boro and Mme Mallé, Safiatou Coulibaly who carried out the discussions and to M. Modibo Samoura and Mme Bamba who greatly facilitated the work in Sikasso. I would also like to thank Rodio Diallo of PSI Mali and Dominique Meckers of PSI, Washington DC for the chance to carry out this research. The article has greatly benefited from Dr Meckers’ insightful comments for which I am grateful. In addition, Chelsea Treadwell and Amy McInnis of PSI, Washington DC were very helpful in furnishing additional information for the article.

Biography

Sarah Castle is a lecturer at the Centre for Population Studies, London School of Hygiene and Tropical Medicine. She has carried out research in Mali for the last 14 years specializing first in child health and nutrition, and more recently in young people’s sexual health. Her interests lie in qualitative methodologies and in the application of research findings to programme design and evaluation.

Correspondence: Sarah Castle, Centre for Population Studies, London School of Hygiene and Tropical Medicine, Keppel Street, London, WC1E 7HT, UK. Email: Sarah.Castle@lshtm.ac.uk