



UvA-DARE (Digital Academic Repository)

Safety in the midst of stigma: Experiencing HIV/AIDS in two Ghanaian communities

Kwansa, B.K.

Publication date
2013

[Link to publication](#)

Citation for published version (APA):

Kwansa, B. K. (2013). *Safety in the midst of stigma: Experiencing HIV/AIDS in two Ghanaian communities*. [Thesis, fully internal, Universiteit van Amsterdam].

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, P.O. Box 19185, 1000 GD Amsterdam, The Netherlands. You will be contacted as soon as possible.

“It better be hidden.” HIV testing narratives

Se ani an hunu a, enye tan

It is not nasty as long as the eyes have not seen
(Akan Proverb)

The HIV/AIDS team at St. Patrick’s Hospital had organized a sensitization campaign for residents in Namong, one of the communities in Offinso, where several of the people with HIV who were studied for this project lived. Many people in Offinso perceive Namong (which has a population of about one thousand) as one of the heaviest affected communities with regards to HIV incidence. “Every household has or knows someone who has died of HIV,” Eugene told me during our first encounter. Many residents and non-residents alike participated in the one-day sensitization campaign, which included several speeches from the health personnel in the municipality, and also songs and a drama performance, all to whet the appetite of the audience to undergo HIV testing. In all, more than 150 people volunteered to be tested. In December 2008, more than three months after the campaign, when I finally had access to the list of participants, I observed that (only) five people had tested positive. Cross-checking their names with the records of those undergoing antiretroviral therapy at the Special Clinic at St. Patrick’s Hospital¹, I found that none of them had yet come for treatment, at least at that centre. With permission from the doctor-in-

¹ The Special Clinic is the centre/facility responsible for ART, and other disease conditions such as tuberculosis, diabetes, and hypertension, at St. Patrick’s Hospital. According to the nurses at the centre, the name – Special Clinic – is one of the measures put in place to destigmatize HIV, thereby aiding access to the services.

charge at the centre, I decided to go, together with one of the nurses, to follow up on these five cases.

Only one of the five was reached by phone. For the others, the house numbers that they had provided either did not exist in the community or the calls did not go through. With the one successful call, the man reached said that he remembered taking the test and had expected the team to return after a week to give him the results, as promised. He indicated that, "Since they [the team] did not come back, I thought they were not serious [with their work], and that they did all these [campaigns] to enrich themselves and write more reports for more money." The man was asked over the phone to come to the hospital (St. Patrick's) for a discussion about the test, but he did not turn up on the appointed day and could not be reached again on his mobile phone. The doctor-in-charge at the Special Clinic explained that it was possible that he changed his mobile number since "He may have realized the ramifications of getting to the hospital and being told the worst," i.e. that he is infected with HIV.

Counselling and testing facilities are the usual locations of the revelation of the unwanted news that one is HIV positive. The data gathered from the communities studied, however, suggests that there are several ways and locations through which HIV testing is conducted, including sensitization campaigns (as shown in the above case). This chapter introduces the reader to the available possibilities for finding out one's HIV status in the Ashanti Region in Ghana. It shows how people get to know about their HIV status: the procedure for testing, the clients' immediate reactions after getting the results, and their experiences of the testing facilities. As the case material will show, many people were unwilling to go for an HIV test unless it was mandatory. Using the narratives of HIV positive persons and others in the communities studied, this chapter will conclude by outlining the possible reasons for the widespread hesitation to know one's HIV status.

Getting to know

As in most countries, voluntary counselling and testing (VCT) is the main entry point for accessing ART services in Ghana. VCT in Ghana first commenced with a pilot study conducted in June 2003 at Agomenya and Atua government hospitals in the Eastern Region. Other sites began in December 2003 and February 2004 in the two tertiary and teaching hospitals in Ghana: Korle-bu in Accra and Komfo Anokye in Kumasi respectively. As of 2009, there were 3,222 sites all over the country offering VCT services to the population of over twenty million. At the time of the study, almost 200,000 people in the Ashanti Region (about 3% of the population there) had undergone counselling and testing in the 466 sites offering these services (NACP/GHS 2010). Interactions with people

living with HIV, their families, and general community members showed that the majority of those who had undergone HIV testing did not go for the service voluntarily. The following sections therefore discuss the ways in which people found out about their HIV status in the two communities studied.

Diagnostic testing

The majority of the HIV positive people in this study recalled that they had found out about their positive status when they reported sick at the hospital with a 'normal' sickness, and just like any other patient went through the process of registering at the hospital and getting a patient's card at the Out-Patient Department (OPD). They explained that they then went to the nurses who took their vital signs (blood pressure, body temperature, weight, and height), after which they joined the typically long queue to see the doctor. Some saw the doctor several times before their persistent condition warranted an HIV test; others were asked to do the test at their first appointment with the doctor. Abiba narrated how he came to be tested:

The doctor told me that I needed to do some more tests so he could find out exactly what was wrong with me. This time, he just asked me to go to that room over there and see Mr. Owusu [the counsellor in one of the hospitals]. Well, at first I didn't think about anything ... about this disease, so with the help of my mother I went. When we got there Mr. Owusu asked my mother to leave me, because he wanted to talk to me alone. It was then that he asked whether I knew why I was asked to come to him. When I replied in the negative, he told me that they wanted to check whether I have some of the worms/small animals that have recently been around (*emmoa a, aba yi bi*). My heart skipped a beat when he said that. Why will they have to test me for this? I haven't messed up. And I am also not one who will meddle in the affairs of others, for them to want to hurt me. Why will anyone think about killing me? I just prayed that it should be a dream, and that I would wake up from it at that moment. Mr. Owusu, however, spoke to me at length and advised me to be calm. He then told me that I wasn't going to die if I listened to him and obeyed whatever he and the doctors told me to do. Maybe you are not positive, he said. At that point, all that he was telling me was falling on deaf ears. I was just thinking about the consequences of a possible positive result. My mother would die if she hears about it ... how about my father; already he doesn't even want to see my face. He would just sack me from his house. At that point, I knew I was dead. I didn't have any choice, so they did the test and I was positive, as I expected.

Unlike the case of Abiba, who was informed about the test before it was conducted, analysis of the life stories of those who were attending the two ART facilities in the study shows that the majority of clients were only told about the test *after* it had been conducted and the results were divulged during post-test counselling. This is especially the case for pregnant women. At maternity wards, HIV tests are routine unless one opts out; this constitutes an example of provider initiated testing and counselling (PITC). In many of the cases investigated, however, the pregnant women were not aware of the option to opt out, and the test was done without their knowledge. In cases where the test had not been done by the time of delivery or during a pregnancy-related complication, the woman

was usually tested without her consent. Prevention of mother-to-child transmission (PMTCT) was given as justification for this practice, and was explained as being for the sake of protecting the unborn child, as well as preventing re-infection of the client and/or infection of her partner.

Private clinics and laboratories

The circumstances leading up to getting to know one's HIV status, as explained by the HIV positive informants and described above, was found to be similar in the Quality Care Clinic: a private clinic² in Offinso, where a significant number of those who were on treatment at St. Patrick's Hospital had been diagnosed. The majority of the cases from this private clinic were also provider initiated. Dapaah (2012) reports that it was in the ART clinic that the clients got to know their status after having undergone the dreaded test without their knowledge, let alone their consent.

The situation at the Quality Care Clinic was very different, however, from that of the private clinics and laboratories where people voluntarily walk in with the intention of testing for HIV. However, from observations in some of the private laboratories in the Ashanti Region, it was noted that counselling (both pre-test and post-test) was rarely performed. One technician in a private laboratory explained that there are two main groups that access the HIV testing services in their laboratory:

The first are the cases referred from the hospital. For this group we [the technicians] prefer to assume that they already know about the test to be conducted. If they don't know, then we are not responsible for breaking the news. The majority of the cases are those that the clients initiate themselves.³ In these cases too, the clients already know what they are going in for and therefore did not need counselling.

Generally, although the private laboratories were found not to possess the right personnel to undertake counselling services, many people still preferred their services to those of the hospitals. According to informants, this was mainly because (and unlike most facilities in Ghana), "they are fast," "there are no queues," "they do what you ask them to do and not what they think you should do or what they want you to do," and "they do not condemn you."

² The Quality Care Clinic is one of the few private health facilities in Offinso. This clinic receives important mention in this monograph because of its unique role in referring clients infected with HIV to St. Patrick's Hospital for treatment, care, and support. As observed among the clients at St. Patrick's, a significant number were referred from the Quality Care Clinic.

³ This may be because of their own perception of personal risk, a demand by a church as a pre-requisite for marriage, job placement such as in the military, or to travel outside of the country – to the United States or China (until recently).

Sensitization campaigns and mobile testing facilities

There were cases, as outlined above, where some people walked into VCT facilities to use the services. These cases were found during interviews and focus group discussions (FGDs) with some members of the communities studied. In other cases, the services were brought closer to the people through sensitization campaigns followed by testing and/or use of mobile testing services. Tests conducted after sensitization campaigns (such as the case explained in the introduction to this chapter) and the use of mobile testing services ensure that a number of people are tested without having to go to VCT facilities. A number of the people in the communities studied, including some participants in the two FGDs, said that they had tested as a result of these services. Only one of the HIV positive persons, John, who was casually conversed with, said that he had made use of this means to get tested. None of the infected people studied extensively throughout the period of fieldwork belonged to this group, interestingly. John recounted his experience:

I like listening to such campaigns. In fact, on the said day, I was just taking a stroll when I passed by this group of nursing students who had come into our community to talk to us about HIV. I stood there and listened. After, they asked all those who want to know their status to come over and get tested. I went forward. It was about the fourth time I was doing something like this. Like I said, I like listening and participating in these programmes. But, my brother, that day was not good for me. I regret not walking away. I wouldn't have been going through all these, if I had just walked away.

John was introduced to me by Nurse Josephine during one of my brief visits to St. Patrick's Hospital to meet a respondent. John mentioned that he had experienced many psychological and emotional challenges in coming to terms with being infected. He was concerned with the cause of the infection, and asked why it had happened at the time it did, because he "had been doing this [having HIV tests] all the time and he had never been positive." As with John, it was found that the few respondents who walked in or responded to calls from campaigns without any prior intention to test often felt sure that they would test negative.

Other ways of getting to know

Informal conversations with some members of the communities studied showed that people are wary of thin and consistently sick people, and that such individuals are easy suspects for carriers of the HIV infection. Gossip and insinuation are the main means by which these suspicions are channelled. These accusations made against thin people by community members were found to hold water after observations proved that these people's physical changes (i.e. slimming, wasting) were sudden and prolonged, and were indeed also accompanied by ill health. Eugene explained:

We have been here for long and we know how AIDS treats people. When you get it, you will definitely waste away. How can you continue to defecate, vomit, and be unable to eat, and not grow lean? It is not possible. That is what they all go through. With time, they will start getting sick. They would not recover and then they will die. You don't need a test to know. You already know.

In particular, people who are consistently sick, and especially when it is accompanied by an extreme form of diarrhoea, become suspects. In such cases, it was not uncommon to find community members tracking these sick people in order to find justifications for their suspicions.

The people in the communities also viewed certain behaviours as arousing suspicion regarding HIV infection, notably being rich and having multiple sexual partners. During an interview with Martha, the leader of the Single Parents Foundation, for instance, she narrated the story of a man who lived in one of the communities studied:

He opened a spot [drinking joint], which is still in existence. After he came back from Abidjan, he settled here, got married to a lady he came along with and they gave birth to two children, both of which died. He came with a lot of money. With his money he helped a lot of the boys in the area and he ran several businesses. He had money and helped so many people but he never went to school though he paid the school fees of many of the youths in the community. Due to that, and you know what money and illiteracy can do, he was chasing the girls indiscriminately. So when he finally came with the sickness, he settled with his wife right in the big house down the road where the truck is parked [pointing to the house]. By this time, he had slept and in fact lived with lots of the young girls around. Now he is dead. We are not doctors, but everyone in this village knows that he died of this disease [AIDS]. You can go round and ask everyone in the village and each will confirm what I am telling you.

The sexual partners of suspects are also targeted, especially after a suspect dies. Many people, especially thin young women, resort to the use of medicines to increase their weight. Below are excerpts from the interview with Martha, in which it was revealed that the partners of the rich man described by her above, who were thus also prime suspects of being infected, were rumoured to be taking medicines to keep their bodies plump.⁴

Kwansa: So are you saying that because you people saw that he used his money and influence to get so many women, he might have died of this infection?

Martha: Yes, we know the women he went out with. Apart from his wife, he married two more in the next town and lived about eight years and six years respectively with them. Because he had money too, he lived with some other girls intermittently; some even with the consent of their parents.

Kwansa: What happened to these ladies when he died?

Martha: They are still there. The two he married at the other village have re-married even though we all know the man died of HIV. They are looking more beautiful now because he had given them lots of money. And they are taking medicines too. The one that looked smallish like this is now as fat as this [using her hands to make the small and large gestures].

⁴ In Ghana, many medicines can be bought over the counter and without prescription from a doctor.

Kwansa: Medicines? What for?

Martha: Yes, medicines! I don't know if it is for HIV. But there are medicines on the market to make one fat.

Kwansa: Do you mean blood tonic?

Martha: No! Not necessarily. There are a lot of medicines other than blood tonic on the market to make one fat. Even the ladies go to the extent of injecting themselves to be fat. Even when they give birth, they are given dexacortisone⁵ or something like that, that they take and become very fat. Even when you go to the spot now you will see the woman. Because he is no more, they are living with men. And because the man had money he only went in for beautiful ladies.

Kwansa: So do you think that even when you are infected with this disease and you take these medicines, such as the dexacortisone, you can still grow fat?

Martha: I think so. You see the virus in your system doesn't work very fast, rather they spread little by little, so some people can live up to ten years with the virus without any medication. And for these people they start taking these medicines right after they get a hint of their state. And for these medicines, there are different types. Some ladies even use some injections to make their buttocks fat. So someone who gets the hint can just go and get these injections.

Remarkably, a heated discussion on the issue of thin people being prime suspects for HIV infection cropped up one day in a *trotro*, corroborating the perception that women these days use medicines to camouflage the virus. Some men were also said to be careful in choosing their sexual and marriage partners, based on this perception that thin women are more likely to be HIV positive. They consider a woman's physique before making a move. In the *trotro* discussion, a middle aged man who was obviously the main speaker for the notion stated:

You marry a slim woman at your own peril. Unless you have known this woman for so many years and you know that she sits at one place (*ɔtena faako*) then you can go ahead [and have her as a partner]. Otherwise, play it safe. Go for *oboshie* [a term for fat women based on a television advert where a very fat woman went by that name].

Eugene also noted that changes in the emotions of the suspect, and the loss of a baby during childbirth, are other clues about a person's HIV status. He explained:

I can see a person infected when I look critically at her/him. You see, in my house, I have seen one of my mothers⁶ who became sick and was asked to go and buy some medicines. She has become reserved and emotionally worried this time round. And she didn't get her baby when she went to deliver. She claims the hospital nurses said that she lost her baby because there was lot of water in her stomach. From her behaviour and speeches it seems to

⁵ Dexacortisone is not the correct name for the medication. Checks from the chemical shops showed that prednisolone was the more common type that people bought for this purpose. The clients at these shops referred to it as 'PP'. However, Martha may have been referring to dexamethazone, a type of cortisone used to treat inflammations and allergies, but purchased by clients for the purpose of becoming fat.

⁶ Most people in Ghana refer to their mother and father's sisters also as their 'mothers'. So depending on the age of the person in question, reference could be made to an older mother or a younger mother. In this particular case, Eugene was referring to the experience of one of his mother's younger sisters.

me she does not know and yet she doesn't trust herself. Or maybe she knows but doesn't want anyone to know. When I look critically, I cannot tell where she got this disease. She already has a child. I know it is possible to have this disease and live normally but it can't be so for the child. He wouldn't stay longer on this earth.

Oftentimes, these suspicions and rumours about a person can go on for a long time without the suspect knowing about it. Some indeed may not have even thought about the possibility of being infected until they heard the rumours. Some of the people with HIV in this study noted that it was when they heard about these suspicions that they started fearing that they may be positive. Dorcas recalled that she was getting sick often, and though she is naturally thin, she was getting extremely thin, more so than normal. It became a worry to her when her niece came to tell her one day that, unbeknownst to her, people in the community thought that she had HIV on account of her physical appearance.

I hadn't been well and I was seeking for help [at the hospital and healers], but no one had mentioned this sickness, and I had not thought about it either. All this while, they [the community members] were gossiping about me. Can you believe it? They had already condemned me, even without my knowledge.

After my niece told me, I could hear people talk and point fingers at me as I walk in the community. In fact, I felt bad, and finally stopped going out. But I wasn't getting better, so my niece advised me to go for the test and seek proper help if that was the case. My husband will kill me if he finds out that I have HIV, but I gathered courage and I went. I am positive, but they don't know.

Interestingly, it was found that these suspicions reduce and stop completely depending on the rate of recovery of the suspect. Maakua, who everyone in the community knew to be positive because her husband had died of AIDS and the family had announced it to the community, was at the time of the study living normally with her HIV positive child without the usual suspicions because she no longer looked thin.

Another way that the respondents reported that they first found out about their infection was through the activities of traditional and other religious priests (mainly from the Pentecostal Charismatic Churches), who through various forms of divination and prophetic revelation had 'diagnosed' their infection. This group of HIV positive persons believed that their infection was caused by something supernatural (curses and other malicious powers), and therefore they made use of 'spiritual therapy' to complement medicines from the hospital (Kwansa 2010).

All these ways of getting to know about one's HIV infection notwithstanding, having an HIV test at an official testing site continues to be the only sure way to know one's HIV status, since all the other ways of getting to know one's status have not been proven scientifically. Put differently, it is possible for a person to be suspected and maligned by their community for being HIV positive and nevertheless test negative. The following section discusses the counselling and testing procedure for finding out about one's HIV status.

The counselling and testing procedure

Usually when a client walks in voluntarily or is referred to a counselling and testing facility for an HIV test at the hospital, he or she goes through a standard procedure. Counselling is a relatively new concept, known in the overall health care system in Ghana for around two decades. This is not different from other African countries (see Ego & Moran 1993, Lamptey & Coates 1994). Counselling in most parts of sub-Saharan Africa generally comes in the form of advice from ‘experts’ to patients and their relatives (Awusabo-Asare 1995), and counselling in everyday life is very different from what is found in the health care system. The following discusses the counselling and testing procedure as reported by HIV positive people and other users of such services, looking first at pre-test counselling, then the test itself, followed by post-test counselling.

Pre-test counselling

The pre-test counselling at the facilities is a form of counselling designed to help the client to decide whether s/he wants to have the HIV antibody test. This is usually the first of the procedures in all counselling and testing facilities. Within sensitization campaigns, counselling was also done, though it was not very extensive. Those who had gone for the service at the facilities explained that the counsellor had probed into why they had decided to come for counselling and about their personal history with regards to marriage, sex, risky behaviours, and general health problems. The counsellor had then asked about the clients’ level of knowledge about HIV and AIDS. After assessing this level of knowledge, the counsellor then gave additional information about HIV/AIDS, and enumerated the advantages and disadvantages of having the test. Some of the infected persons interviewed indicated that the counsellor had then explained the test procedure and how one can interpret the results. They also stated that the counsellor had talked about what to do after receiving the results of the test – whether positive or negative – in order to stay as healthy as possible for as long as possible. Abigail, a cashier at one of the banks in Kumasi, who participated in the FGD for young professionals in the town, mentioned:

It was during the pre-test counselling that I felt afraid for the first time to take the test. I knew I hadn’t engaged in any risky behaviour, but it was during the counselling before the test that I felt, for once, that the result is fifty-fifty. That I could be positive! In fact, I wanted to back out at this stage, but it was too late.

She explained later that she had felt compelled to take the test after someone came to their church to give a talk on HIV and the importance of knowing your status. “But at that point, I asked myself whether it was really necessary that I do it. After all, I am not sick.”

Although pre-test counselling is aimed at helping the client to make an informed decision about whether or not to take the test, from the discussions (and exemplified by Abigail's case above) most of the people who went through pre-test counselling felt that the counsellors did not present them with an option. Melissa added:

[It is] as if their only focus is to get you tested. Your feelings and emotions come second. They make it seem like you don't have an option. You definitely have to do the test; [or] else they [the counsellors] may think that you are bad.

Opong, a systems analyst, and also a member of the FGD for young professionals in Kumasi, said:

The counsellors focus too much on the effects of a positive result and that will definitely make you shake. I was asked what impact I thought a positive or indeterminate result would have on my life and how I was going to react to that. I had not given all these the slightest thought, so my heart started beating fast. If fright could cause one to be infected, I knew I was already positive [jokingly].

They even asked me whom I could disclose to, in the case of a positive result, and that really sunk me. I can't tell anybody. I knew I was not positive, that's why I went in for the test. Do you think if I were suspicious of not being negative I would go in for the test?

Most of the respondents did not remember exactly what was told to them at the pre-test counselling. They cited fright, shock, and thoughts of the effects of a possible positive result as preoccupying their minds when they realized that an HIV test was to be conducted. The accounts of the HIV positive persons in this study, and those of the young professionals, could be interpreted to mean that those who utilize pre-test counselling do not find the service very useful. However, Kojo (also a member of the FGD) insisted that as far as he was concerned it was very necessary to undergo counselling before the test. For him, he learnt a lot from the counsellor.

I learnt that a negative result does not necessarily mean that you don't have any HIV antibodies, which should be confirmed some months later [if you had engaged in a risky venture], neither does a positive one show that you are positive since you may need a confirmation test to be sure. In addition, though I knew medicines were available for a positive result, I didn't know much about it – where to get them, how to get them, the daily dosage, how long you will have to take them, whether there were different types or everybody takes the same, and even the problems associated with taking the medicines.

A few members of the FGD also shared this view that counselling before the test was very necessary, as they had gotten some new information during the process. Though some of the HIV positive people also said that they thought the pre-test counselling was useful, they could not enumerate the benefits they had derived from it.

The test

For those who walk in voluntarily for the test, and for those who go through the pre-test counselling in the hospitals and counselling and testing centres, a sample of blood is drawn in order to test for HIV antibodies. At the time of the research, two testing methods were available: the ELISA test and the rapid HIV test.

Enzyme-Linked Immunosorbent Assay (ELISA) test

From the time that HIV testing became available in Ghana, most of the facilities used the ELISA HIV antibody test. For this service, a sample of blood is taken from a vein in the client's arm, and is sent away to a laboratory for the test to be conducted. The results take between one and three weeks. After the waiting period, the client goes for post-test counselling where the results are declared. If the blood sample tests negative, the counsellor informs the client that s/he has no antibodies for HIV in her/his blood. However, s/he may still be in the 'window period' so is advised to return for a repeat test, usually after three months. If the blood sample tests positive, a second blood test is done on the blood sample so that the result can be confirmed. This is usually called a confirmation test. If the second blood test is also positive, the counsellor will tell the client that there are HIV antibodies in the blood, but s/he is advised to return for another test in a few months' time. If the second test is negative, s/he is told that the result is indeterminate or discordant. This means that it is not sure if s/he is HIV positive or negative. S/he will then be advised to come back to the facility in another few months' time to be tested for a third time.

Some of those who used the ART facility in Komfo Anokye were diagnosed using the ELISA method. In their narratives, two main problems were mentioned. Firstly, due to the waiting period after the blood sample is taken, many people had the opportunity to refuse to go for the test results. Maakua, for instance, recalled that after her husband had died of AIDS she was taken by his family to the hospital for a test, but initially refused to go back for the results:

I worked with my husband in the other town [not too far from her husband's hometown, where she currently resides]. His family was very rich and we [she and her husband] received substantial support from them. When my husband became very ill some few years ago, his uncle took him to several places for medical help until they finally got to 'Gee' [Komfo Anokye] where he was diagnosed as being [HIV] positive.

Probably because he thought no amount of money and/or medicines would help cure his nephew, the uncle immediately stopped all payments for his treatment and so he was subsequently discharged to come home and die. As if this was not enough, he summoned all the family members and announced to them the plight of their son. They subsequently took me back to 'Gee' to also check my status so they could help me if I was also positive. I refused to go in for the results, though it made no difference because the entire community had gotten the news. My husband's family afterwards ejected my children and me from their house and subjected us to public scorn and disgrace. It became worse when my second daughter died some months later also after persistent illness. My first daughter also followed

with the persistent illness and soon it was my turn. That was when I went back for the test and found out I had this thing and started treatment with my daughter.

In particular, in diagnostic cases, where the persons were not certain but suspected that they were being tested for HIV, many refused to return to the hospital or clinic to get the test results.

In the case of sensitization campaigns (like the one described in the introduction), the same problem was found. People who undergo the test can change their mind and decide not to collect the results. On the other hand, they present people like Abigail and Oponong (participants in the FGD) and Maakua (in the case above), who initially had felt coerced into taking the test, with a second chance to decide whether they really wanted to know the results. This opportunity notwithstanding, sensitization campaigns may nevertheless present more public health questions, as people who test positive (as in the case of the five mentioned in the introduction) but who refuse to get their results may instead make use of other treatment options and miss the opportunity to be educated and inducted into treatment.

During data collection, one significant aim was to find and talk to members of the community who had undergone VCT and yet had not followed it up to get post-test counselling and care. A few were found through contacts with other infected people, but they all refused to talk to me. This particular problem of clients not returning to collect results, which arises from HIV testing practices that do not give on the spot results, are found globally. The Centre for Disease Control (CDC) in the United States, for instance, reported that out of the approximately 2.1 million HIV tests that are conducted annually in publicly funded counselling, testing, and referral (CTR) programs, in 2000 thirty percent of persons who tested HIV positive and thirty-nine percent of persons who tested HIV negative did not return to pick up their test results (CDC 2000).

There are also problems associated with negative, indeterminate, or discordant results. Those who test negative may initially go on with their lives unbothered, because in spite of their comparatively risky behaviour, when they find out that they are still negative this gives them a false sense of security. On the other hand, after an initial positive result, some may have lost hope in life and may have already been thinking about the consequences, only to be told later on that they are not positive. Once during a visit to the hospital I witnessed a case where a client was positive in the first test but the confirmation test proved negative. Her countenance obviously displayed how surprised and confused she was with this conflicting news. For greater detail on some of these experiences, see Dapaah (2012).

The rapid HIV test

In order to prevent the problems outlined above, where clients do not go back to the facility for their test results, most counselling and testing sites in Ghana currently use the rapid HIV test, where the test is conducted using blood, plasma, or oral fluid, and the results are ready almost immediately. For instance, if the test uses blood, the tip of a finger is pricked with a special kind of needle (lancet) and a drop of blood squeezed out. Using a thin plastic tube, the drop of blood is put into a small window in the test strip. Drops of special fluid (buffer) are added to this test window to help the blood move up the length of the strip. The test result is often ready in fifteen minutes. If the test shows that the client is positive for HIV antibodies, a second rapid HIV test is done, usually using the fluid around the gums of the teeth. If the second test is also positive, the counsellor informs the client that s/he is infected with HIV. If, however, the client's test shows up negative for HIV antibodies, no further test is done. However, because s/he may still be in the window period, s/he will be advised to return for another test in a few weeks.

During the research period, the rapid HIV test was used in most hospitals, private clinics, private laboratories, and during sensitization campaigns due to the obvious advantages it has with regards to the waiting period for test results. However, it tends to limit the extent of client involvement in the decision to test, especially in the case of diagnostic testing, as the whole process can be over within twenty minutes, during which time the client may have to make a life changing decision.

CD4 T-cell count

Some of the people living with HIV in Offinso also mentioned that the CD4 T-cell count had been used to detect their HIV status. This is not an HIV test but rather a procedure where the number of CD4 T-cells in the blood is determined. A CD4 count does not show the presence of HIV in the system, but rather gives an indication of the HIV trajectory, and is used to monitor the immune system function in HIV positive people. Declining CD4 T-cell counts are considered to be a marker of the progression of the HIV infection, though several factors could account for a low CD4 count, including many viral infections, bacterial infections, parasitic infections, tuberculosis, malnutrition, psychological stress, and social isolation. In the two facilities, St. Patrick's and Komfo Anokye, AIDS is officially diagnosed when the CD4 count drops below 300 cells. In the hospitals, Dapaah followed up on the assertion by HIV positive people that the CD4 T-cell count had been used to determine their HIV status. However, he discovered no confirmation of this among staff. Regular mention of the term in the facilities or during counselling may account for this erroneous assertion.

Post-test counselling

Post-test counselling, according to the HIV positive persons, is an occasion where clients are again asked to express their feelings about and expected reactions towards the possible results of the HIV test. Those who test voluntarily are then shown how to interpret the results on the rapid test kit, and are therefore able to tell the result just by looking at it. However, in the case of clients who take an HIV test as part of a diagnostic procedure, and who do not know that the test had been conducted, they are taken through some of the issues that should have been discussed during the pre-test counselling stage before the results are declared. Esther explained that even though she did not know that an HIV test had been conducted, when the counsellor started talking about and putting stress on managing physical and mental issues, better social relations, and safer sex practices, she feared the worst. It was still a surprise though when she was finally told that you have “some of the small animals/worms in your blood” (*emmoa no bi wo wo mogya mu*).⁷

The result is then declared and the various options available to the client discussed, whether they are HIV negative or positive. Counselling for those with HIV negative results was found to be used to (re)educate clients on HIV prevention, and clients with problematic high risk behaviours were referred to specialized organizations such as the Planned Parenthood Association of Ghana (PPAG) for ‘treatment’. For clients with a positive result, the counselling was used to educate them on issues including partner notification, and for referral for medical and psychosocial support and care. The facilities are also mandated to offer follow-up services to clients to enable them to access and utilize existing care and support services, including ART and home-based care services. Mapanyin expressed her feelings after the test:

For me, after the results were declared, I didn’t remember anything that the counsellor said again. I started feeling dizzy. I was confused. I knew that was it ... I am done.

Some of the clients had issues with how their positive results were explained to them during post-test counselling. In almost all the cases investigated, the PLHIV said that they were told that “worms or small animals were in the blood/system” (*emmoa wo me mogya mu oremmoa wo me mu*), as in Esther’s case above. This was probably considered the best way for counsellors to communicate the situation to the infected persons, since in the local language HIV/AIDS has no direct name. The logic is that the virus is like a small animal that gets into the blood and then works its way out. Other terms such as “extreme form of

⁷ The literal translation of the phrase commonly used to disclose test results – *emmoa no bi wo wo mogya mu* – connotes (small) animals; however, the people I interviewed usually referred to them as ‘worms’. For in-depth discussion of this and its impact on the pursuance of alternative therapy, see Kwansa (forthcoming).

gonorrhoea” (*babaso wenfo*), “that sickness” (*saa yadee no*), “a sickness whose name cannot be mentioned” (*yadee a yenmmɔ din*), etc., were also used to identify the virus. These latter phrases, however, bring up negative sentiments, especially for people who are quite unwell. These latter phrases are therefore regarded as being quite harsh, so people (including counsellors) prefer the much softer ‘worms’, which is often ambiguous and arouses less shock in reaction to the news. Others, however, explained that such ambiguities as to whether it is “this worm or that worm” lingered on in their minds, and so they did not fully grasp the implications of the post-test counselling; it was not until they were referred to the ART clinic for care and support that they actually realized the “magnitude of these worms.” ‘AIDS’ was found to be more commonly used by community members but less often by counsellors, probably to lessen the fears of those found to be positive after the test.

“It better be hidden”: To test or not to test?

As noted earlier, the majority of people in the communities did not want to know their HIV status. Statistics from UNAIDS some years ago suggest that despite the enormous number of HIV infected people worldwide, less than ten percent are aware of their HIV sero status, mainly because of fear of stigma and discrimination, fear that the test will be positive, and lack of access to treatment or testing services (UNAIDS 2006). Some of those who test through the initiative of hospitals decide to end their lives so as not to live knowing that they have the disease. Rahim’s case brings this issue to the fore.

Though worn out because of the very long hours walking through the various communities visiting the clients who accessed ART services at St. Patrick’s Hospital, I was rejuvenated when the little boy we met at the entrance of the house told us that his father was at home. Nurse Rose (with whom I was travelling) had spoken a lot about Rahim, but we had not yet met him on any of our home visits. Rahim had been to the hospital two months earlier and had been diagnosed as HIV positive after referral for the test by the doctors. He was asked to come back a week later for a confirmation test, but that was the last time he was seen at the hospital. In retrospect, I reckon he did not accept the test result because he was not bed ridden and could go on with his usual schedule unhindered, though with difficulty because of his ill health.

Rose asked me to meet and talk with Rahim since by then she was too tired, and wanted to relax under the huge neem tree just in front of the house. When I sat with Rahim, he gave me one of the warmest receptions for a person who we later found out had deliberately refused to go back to the hospital. He explained to me that he did not know that he was supposed to have gone back to the hospital, and since he was doing so well he did not presume it was necessary. I

asked him what test he had done, the results, and what he was asked to do next. He made clear to me that they never really explained anything to him, but that they had told him there were “worms in his system” and he was asked to come back later if he still felt unwell.

So when I came home I prepared an herbal concoction to de-worm. I later realized that what I was suffering from was spiritual since I have never had worms in my system so I resorted to prayers and it has worked tremendously. Can't you see I'm doing very well now?

It was the first time that I had met Rahim, but to say that he was doing well in his current state meant that he was either exaggerating or had previously been seriously sick. He looked thin, dehydrated, and malnourished, and his skin was shining with the maps of shingles all over his body. I encouraged him to go back to the hospital on the next clinic day and promised to visit him (alone) very soon so that we could talk in-depth about his general health condition. I was very convinced – by his warm smile, candid nature, and unswerving commitment and promise to go back to the hospital – that he was going to get better. I went to see him two weeks later only to meet his little boy and the other members of the household, as well as some relations and friends, in black clothes. “Rahim is no more ... he is dead!” It was rumoured, but later confirmed by his eldest son who I was earlier introduced to by Rahim as a worker in the hospital, that he had committed suicide.

Like Rahim's case, the study found that the immediate reaction of people who had undergone testing, especially in diagnostic cases, was one of shock and an attempt to explain away the results. In Rahim's case, he continued to live normally because he had killed the ‘worms’ that had led to him needing to do the test in the first place. As found in other cases, quite a number of those who had a choice – in particular, the cases where there was a longer waiting period – also refused to go in for the test result and continued to live without knowing that they were positive. Unfortunately, quite a number too, like Rahim, decided to ‘end it’ by committing suicide.

Until May 2003, when the Family Health International START programme, in partnership with the National AIDS Control Programme/Ministry of Health, started the first large scale delivery of ART services in St. Martin's and Atua Government Hospitals in Manya Krobo District, HIV had been untreatable, and people had little to gain from knowing their status. The majority therefore did not see the need to get tested for HIV. However, HIV has turned out to be treatable in many cases, though access to testing facilities remains very poor. Those who do the test sometimes refuse to go for the results. In cases where they are told the result, some still refuse to accept it. “Getting to know what is actually wrong with you, as a patient, is already finding a solution to your problem,” one infected respondent told me. However, the case material suggests that oftentimes

people just do not want to know about their HIV status. “What will happen if I don’t see [or find out my status]?” (*Se mannhunu a, na aye den?*), one respondent in Namong asked. The following sections discuss the possible reasons why the majority of people do not want to find out their HIV status, and at times refuse to go for their test results.

Public projection of HIV: The fear factor

Travelling the major road from Offinso to Akomadan, I saw several Ghana AIDS Commission advertisement boards. These boards, placed at key vantage points and displaying the names of the community you are entering or leaving, all carry similar messages about HIV/AIDS. For instance, at Anyinasuso, the board had the inscription “Welcome to Anyinasuso, I fear AIDS, what about you?” (see pictures of some of the boards below). This message, in accordance with most HIV/AIDS slogans and campaign messages, is obviously meant to press home the idea of AIDS being a killer disease and thus something to be ‘feared’. A cursory look at most of the advertising boards about HIV/AIDS in Kumasi and Offinso reflected this stance. Over the years, HIV/AIDS has gained notoriety as a killer disease: it is dangerous, deadly, a menace, something which instils fear and revulsion in people. Also with public health personnel and other medical staff involved in HIV/AIDS information, education, and communication, there has been a conscious motif to emphasize the destructive abilities of the virus. The objective is to put ‘positive fear’ in people so that they flee from contracting this toxin. These messages are in contrast to those regarding other diseases, such as tuberculosis, though only a couple of decades ago they would have also given the same scare to the populace (see for instance a picture of a TB signpost below).

This fear of HIV/AIDS has led people to fear anything associated with the disease, thus leading to a very high level of stigmatization and discrimination of PLHIV. Communities look down on people who have HIV/AIDS. Some employers sack their employees, others are refused their rights to life chances, and children whose parents are known to have HIV/AIDS bear the scorn of their peers, at times encouraged by the latter’s parents. Awusabo-Asare *et al.* (1993) note that the fear and ignorance associated with HIV/AIDS have led to various reactions such as panic, scapegoating, stigmatization, and denial.

The fear of HIV/AIDS is also channelled to the fear of infected people, which influences the public’s reactions to people living with HIV/AIDS. Ephraim, for instance, was stopped from using the same facilities that he had hitherto used with his siblings when his family found out that he had HIV.

It was so pathetic. They [his family] treated me with disdain, as if I was no more a human being. I was not allowed to eat or drink from the same eating and drinking utensils. Rather my [step] mother bought plastic plates and cups similar to what we fed our dogs with for me to use. I was stopped from using our water closet, our bathroom, and was even moved from

the main house to the boys' quarters. We did not have any WC and bathroom at the boys' quarters so I had to make use of the public facilities outside the house. People [in the community] started asking questions. I couldn't stand it anymore, so I moved to Kumasi.

It is not unusual at all to see families disown a member who is HIV positive, or to refuse to give the necessary help to her/him because "s/he has brought shame upon the family" or "s/he is going to die anyway," but also for fear of becoming infected themselves. Due to the observed plight of PLHIV, many people do not want similar experiences to befall them and therefore do not want to know if they are themselves infected.

One fundamental issue in counselling and testing discourses is that of disclosure, and the fear that others will find out about one's status, because of the fear of discrimination and marginalization of those infected and affected. According to the International Labour Organization (ILO), fear of losing employment often discourages individuals from using available testing services.

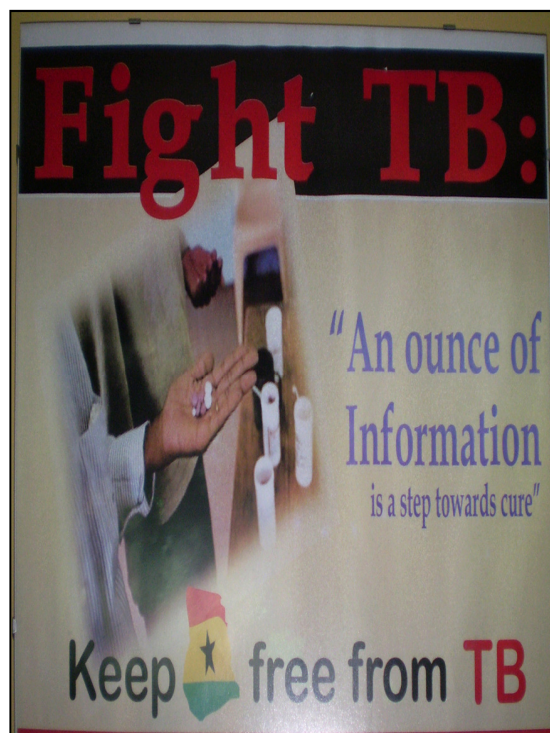
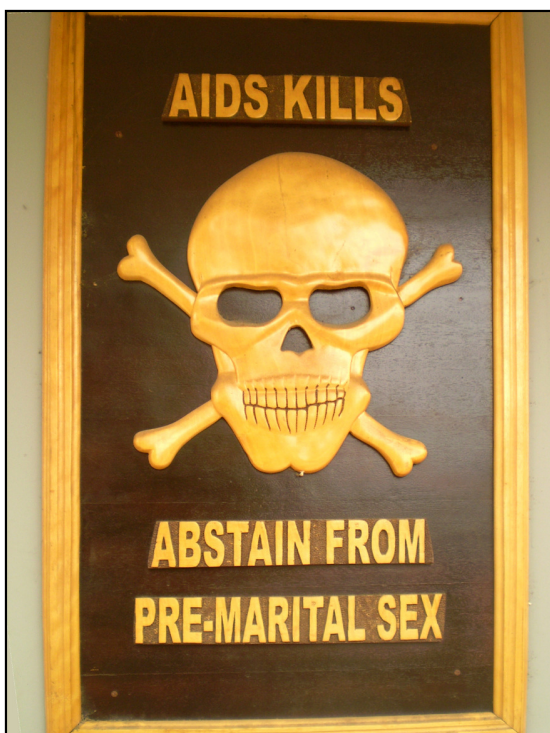
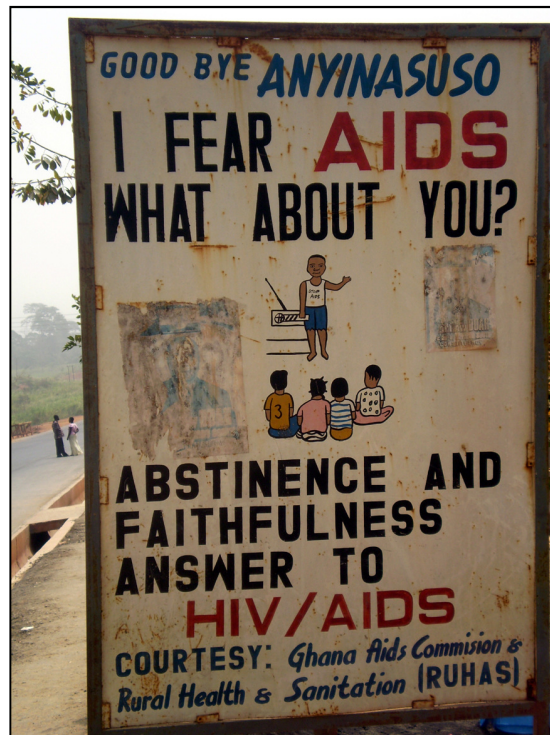
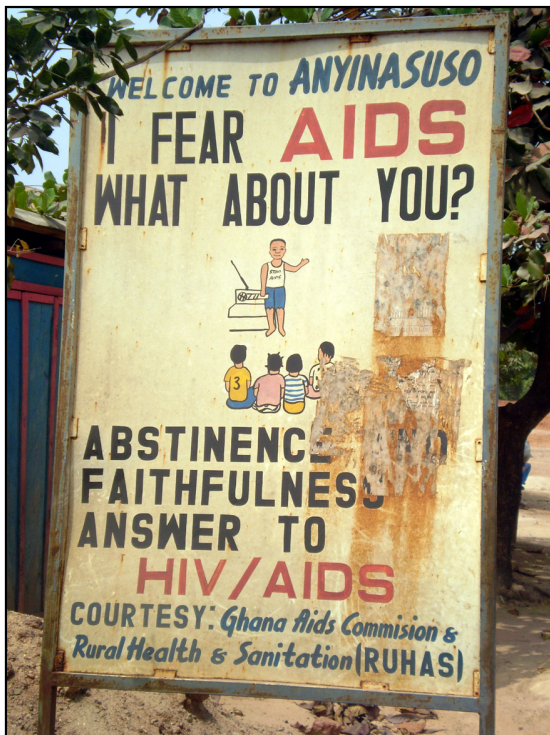
The fear of HIV/AIDS has thus led to the fear of knowing one's status. More than ninety percent of respondents had taken the HIV test upon the initiative of the doctor or medical personnel looking after her/him. Others reasons for having the test, as far as the people in the community were concerned, included the test as a prerequisite for marriage, entry into the military, or for travelling outside the country. Generally, people felt reluctant to access counselling and testing services unless they were compelled to do so, and under such situations they still did whatever they could to avoid getting to know their status.

During the period of interaction with people in the two communities, it was not uncommon for me to receive a negative reaction when I asked whether a person may want to know her/his status if the opportunity was given. In response to the question of whether they would want to test and know their HIV status, a number of people in the communities, such as Abigail (a member of the FGD), replied by saying "I am not sick, so why would I want to know?" Massa, a teacher, predictably though philosophically linked having the test to writing an examination. He indicated:

Going for the [HIV] test is like going to sit for an exam. The result could be a pass or a fail. If you fail, your family would be disappointed in you. For this exam, however, you cannot re-sit and pass if you fail the first time. You fail once and you are doomed.

For others too, such as Eugene, "It is not nasty as long as the eyes have not seen" (*Se ani an hunu a, enye tan*). This is a popular proverb in the area that is used to explain situations where curiosity is found to be a vice. It is okay to be curious, but too much curiosity, or when it is pursued unduly or at the wrong time, brings problems to the prying eye. "Why do you have to go for a test to tell you whether you are sick or not, when you don't feel sick?" my carpenter

Picture 3-6 Some HIV/AIDS and TB sign posts in the Ashanti region



informant also questioned. “If you pry too much into the eyes of a corpse, you see a ghost” (*Se wo feefee efunu ani a, wo ahunu saman*), was another expression used to explain the irrelevance of going for the test if you do not feel sick.

Most striking was the association people drew between getting to know one’s status and “starting the dying process.” ‘Death’ talked about here was not limited to physical death, but also referred to emotional, psychological, and especially social death. Due to the fact that families and acquaintances alike discriminate heavily against people known to be HIV positive, just the thought of possibly being infected makes people start to waste away.

The fear of HIV/AIDS also leads to fear of certain groups known to be more likely to be infected. From 1986, when the first recorded case of HIV was found in Ghana, several linkages were drawn regarding the origin of the infection and higher risk populations. For instance, earlier reports of the disease, which linked HIV to migrants from neighbouring Cote d’Ivoire (Abidjan), brought about antagonistic behaviour towards migrants, especially those who had gone to Cote d’Ivoire and had come home sick. Due to the worsening economic and political state of Ghana in the early 1980s, a lot of people migrated to the neighbouring countries of Cote d’Ivoire, Benin, and Nigeria (Anarfi *et al.* 2000, Atobrah 2005). With male migrants who did not have their partners around, many had sex with sex workers, while some of the women migrants practiced sex work themselves. Many of these migrants made much wealth. However, when they came home around the mid to late 1980s, they were sick with what is now known as HIV/AIDS. Even today, since several migrants come home sick, it is not unusual for people to refer to AIDS as “those people’s sickness” (*yaanom yadee no*) or “sickness for sleek people” (*apremanfoɔ yadee*).

In public health campaigns, these high risk mobile populations are targeted and their behaviours discouraged. Going for the test and being diagnosed positive will therefore undoubtedly align the person to these groups, including the migrants who are feared. They will therefore refuse to find out their status. “AIDS is real” is currently the main campaign message in Ghana, with the intention that the general populace will come to know about HIV/AIDS and desist from risky behaviours. But how these messages impact upon and work for most Ghanaians remains unclear, though it is clear that people make their own interpretations. To a very large extent, people in the communities still associate the infection with these higher risk groups. In Offinso, for instance, there is the major association of the infection to travels to Cote d’Ivoire, Benin, and Nigeria, since the community has a very old history of travel. This was made clear in one of my interviews with an opinion leader, Eugene, in the community:

Kwansa: I remember the last time we talked you told me there are lots of people with HIV in this community.

Eugene: Yes that's true!

Kwansa: How come this is the case?

Eugene: Hmm, you see, we don't have many people going to school in this community although we have a secondary school right here. And also it is very difficult to see a young guy, above twenty, who has not travelled.

Kwansa: Travelled? Where to?

Eugene: Oh, Benin, Nigeria, Abidjan, etc. If one has not travelled at all, at least, he may have been to these places. You wouldn't get a fifteen, sixteen, or seventeen year old boy who hasn't been to Accra in this community. In this community people make fun of you if you are of this age and have not travelled. They can even insult you with it. 'Fool, have you ever travelled?' (*Kwasea, wo koraa watu kwan da?*). And this can be from a fifteen or eighteen year old boy, because they travel a lot to Abidjan and all these other places. It is a very old system that is still in place. In time past, our mothers travelled and lived in Abidjan and some other places and they got this sickness. I say it is predominant here because they are often brought home when they are seriously sick.

Kwansa: So are you saying that no one gets infected here?

Eugene: Not at all [I am not saying that] ... when these people come they spend a lot because they bring money. If you don't go to school, what else will you do in this community? For a young girl, you will just take one of these boys in order to get twenty or thirty pesewas [about twenty or thirty US cents]⁸ to buy some food and also some needs. Those who stay together with these guys last for at most two months because the guys will have to leave for their next trip. He will have to go look for more money to come and spend, so they leave to Abidjan, Benin, and Nigeria. Today being Sunday, you will see a lot of them coming back to spend their monies – at least ten people will come to town today.

Other people in the community corroborated this story. HIV/AIDS was therefore linked to these migrants – both men and women. The females who had travelled and had money were, for instance, thought to be prostitutes and therefore carriers of the infection. Unsurprisingly, people in the surrounding towns and villages 'know' that this community has many infected people (see introduction).

Significantly, however, unlike earlier days of the epidemic when people attributed the origin and transmission of HIV in Ghana to witchcraft, an act of God, punishment, and insect bites (see Ametewe 1992, Anarfi & Antwi 1993, Radstake 2000), this study suggests that today there is direct competition between explanations related to behaviour and 'spiritual' causes (see Kwansa 2010). These HIV positive people considered the former (behavioural causes) as derogatory while the latter (spiritual causes) were used as a coping mechanism.

Personal risk perception

Available statistics show that the personal risk perception for HIV infection is low in Ghana; fifty-four percent of women and fifty-eight percent of men believe

⁸ During the fieldwork period, one Ghana Cedi (100 Pesewas) – GHS (the Ghana currency) – was equivalent to one United States Dollar (100 Cents) – US\$.

that they have no chance of contracting HIV (GDHS 2008). These figures may be this low because of the low prevalence rate in the country (1.9% as of June 2008). The low risk perception may also be due to the fact that relatively few people (37% of men and 38% of women) personally knew of someone who had died of AIDS compared to other countries, especially those in East Africa. People who believe that they have no risk of contracting HIV are less likely to change their risky behaviours compared to those who believe that they have a moderate or greater risk of contracting HIV, and this belief may be channelled into their (un)willingness to go for HIV testing. This assertion was shared by most people in the communities studied, who thought that since they were not engaged in risky behaviours they were not at risk and thus did not need to go for an HIV test. A typical example was that of my very critical informant Eugene:

Kwansa: Do you know your HIV status?

Eugene: How do you mean?

Kwansa: I mean, have you checked whether you are positive or not?

Eugene: No, I haven't! But I trust myself that I am not infected. My girlfriend claims that she checks hers at least quarterly because she is a final year nursing student in Kumasi.

Kwansa: Did you ask her how often she does the test?

Eugene: No! I didn't but she always does it, I think it was only the first time when she started having clinical for her course that I suggested to her to do it, since she had access to it. But subsequent ones, she does it on her own volition.

Kwansa: So why don't you do it too?

Eugene: Well, I don't chase girls. I have been together with my girlfriend for not less than seven years so I think if she does it, it caters for us both. Or is it possible that she wouldn't have it and I will?

Kwansa: I'm not implying so. I wanted to know why you haven't tested. More generally, why do you think people do not want to know their status, and thus do not go for testing?

Eugene: I think it is lack of education. And come to think of it, when you go for the test and you find out that you are positive, I think you die earlier when you know it. So when you ask anybody around, her/his answer would be what happens if I don't have the test (*manyɔ a ebye den*)? You see, it is not nasty as long as the eyes have not seen. If he dies, that's it.

Others who appear to have the knowledge and even sometimes the resources to prevent the infection do not protect themselves because they do not see themselves as at risk. These groups are the least probable candidates to go for HIV testing. Not surprisingly, therefore, and as discussed above, people refer to HIV/AIDS with phrases that do not include themselves, such as "that illness" (*saa yadee no*) and "those people's illness" (*enkrɔfoɔ no yadee no*). People do not want to be associated with the whole caboodle.

Others questioned available statistics. For instance, at a point in time during the late 1990s to early 2000s, the Ghana AIDS Commission had advertisements on radio and television that said, "Every day, there are 200 new HIV infections in

Ghana.” One respondent asked how this can be true and yet most Ghanaians are still alive. He calculated that at least 70,000 new infections should be recorded every year, and for at least fifteen years about a million and half people should be infected. This is, however, not the case since as of the end of 2009 less than a third of this figure was estimated to be living with HIV. In 2000, the South African Ministry of Health estimated that roughly four million South Africans carried the HIV virus and about 1,700 people were becoming newly infected every day (Epstein 2007). If the purpose of these exaggerated figures in these campaigns is to scare people so that they become cautious not to infect themselves and thus become part of the statistics in the advertisements, the impact of this approach may be questioned. These messages may instead contribute to turning the fight against HIV/AIDS onto infected people, and, due to the fear factor, reinforcing the general communities’ reluctance to have anything to do with HIV/AIDS, even at the peril of their own lives. As noted by Epstein (Ibid.), these traditional prevention campaigns were too depressing: they tried to scare people into changing their behaviour, and this turned many people off.

Awareness of HIV/AIDS in Ghana today is nearly universal among men and women of reproductive age (GDHS 2008, Antwi & Oppong 2003), which is largely the product of the massive public education campaign aimed at prevention of the infection. Nevertheless, the reality is that since the majority have no firsthand experience of knowing an infected person (unlike in Eastern and Southern Africa), there is an apparent exhibition of ignorance and apathy, which is channelled into stigmatizing behaviours towards those infected and affected by HIV/AIDS. Many people in the communities still question the reality of the disease among the populace. In one instance, during the celebration of World AIDS Day 2007, a middle aged woman who stood at a distance to observe proceedings answered thus when I asked why she would not take a seat at the durbar grounds:

All this [the durbar] is a waste of time. Do you think if people are truly infected with HIV they would come around and give their testimony? It is not possible. These [the PLHIV who own up during such programmes] are all fake. They just come and say these things to scare us. No one in the right sense would truly come out and say ... I have HIV. What for?

“What for?” remains a very pertinent question for the majority of Ghanaians. During our conversation this woman acknowledged that she did not know about the availability of medicines to manage the HIV infection, and did not know that the medicines were available at the local hospital (St. Patrick’s). Most pertinent, she did not know anybody who was infected, and did not think that those who claimed to be infected indeed were. Total lack or inadequate knowledge of HIV, in addition to the ‘fear factor’, therefore contribute to stigmatizing behaviour, which translates into the majority of people refusing to know their status.

Conclusion

This chapter was about the general public's perceptions and experiences about HIV counselling and testing. Due to the levels of stigmatization of HIV, particularly directed towards those infected and affected with the virus, many people do not want to find out their status. There is a strong connection between not testing and stigma. On the one hand, if people are found to be HIV positive they will be stigmatized and lose their respect in society; so they resort to not finding out their status and to leading a normal life, even if they suspect that they may be infected. On the other hand, because of the shame associated with and the stigmatization of PLHIV, some do everything possible to conceal their status by going for the test early on and starting antiretroviral therapy, which will mean that their status will not be given away because they will appear 'normal'. The case material suggests, however, that the majority of people chose the former option – of not finding out their status.

The belief is that it is better to suffer the disease quietly and hidden than to find out through HIV testing, because of the stigma associated with receiving a positive test result in addition to the feeling that "what you don't know can't harm you" (Skinner & Mfecane 2004: 160). What Skinner and Mfecane show is expressed in the proverb "It is not nasty as long as the eyes have not seen." People do not want to be 'harmed' and they do not want to see anything 'nasty', so they do not go for the test. Even though this chapter discussed people not wanting to know their status – not wanting to lay their eyes on nasty things – the argument transcends the individual. Others are afraid that other eyes will see them. That is, in order for other people not to find out about their infection, they suffer the disease quietly.

The consequences of not wanting to know one's status because of shame and fear of stigmatization are that by the time it becomes evident, most people are in a very advanced stage of the disease process, making it difficult for treatment to be successful. This poses a paradox. Many make it to an HIV treatment centre in a late stage of their disease. By this time, because of the noticeable wasting of the body, the situation would likely have become obvious to people in the community, those who made the person hide from testing in the first place. At this late stage, however, there is nothing to hide from anymore; neither the test nor the prying eyes. Many of the infected people followed in this study were, in retrospect, regretful of not having started ART earlier.

Knowledge about HIV/AIDS must generally be channelled into behaviours and behavioural change. People who get to know that 'AIDS should be feared' are supposed to change their behaviours in order not to become infected. They will therefore be wary in their sexual encounters, be careful not to be pricked or cut by infected objects, and pregnant mothers will be very cautious not to

become infected in order to protect their unborn child. The majority of people in the communities are aware of these preventive behaviours, and are in fact very alert regarding them. However, since education is inadequate and the fear of being stigmatized is great, people still question what will happen if they do not get to know their status.

There is a serious implication for HIV prevention efforts when people do not want to go for VCT owing to HIV/AIDS stigma (Greeff *et al.* 2008), in particular when it concerns people who are more likely to engage in high risk sexual behaviours. This has dramatic implications for the spread of HIV/AIDS (Gilmore & Somerville 1994, Duffy 2005). Educational messages may therefore have to shift from using scare tactics to spreading messages that the majority of people can relate to, such as informing people about the dangers of having long term concurrent relationships and how this sexual system puts all sexually active people at risk, even though most people may have few sexual partners (Epstein 2007). Most pertinent is the fact that those who go for testing and find out their positive status do not disclose their HIV status, not even to their sexual partners. Hiding behaviour therefore transcends the fact of going for an HIV test. It goes beyond people who do not want to know if they are infected. The following chapter explores the issues of disclosure among the infected people.