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

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## To sell or not to sell the sickness

*Se wotɔn wo yadeɛ a na wonya ano aduro*

It is only when you sell your sickness that you get medicine  
(Akan proverb)

On one of my many trips with one of the nurses to visit the people living with HIV in the communities studied, especially those who had not honoured their appointments at the hospital, we missed the only taxi going from town to the village. Since the other taxi that plied the same route had broken down, passengers in need of transport, including some taking their farm products between their house and the market, had to deal with the stress that comes along with such a situation. These taxis, so battered that they would not pass even the most lax test found in Ghana's cities, are considered the passenger's gods. People beg to hang unto them, preferring this to the over fifteen kilometre walk along the untarred pathway that will ensure that you get to your destination smothered in dust. On this day, the only other option was to wait for about an hour for the taxi to make a successful return, by which time the queue would have grown longer and tempers would flare, making it difficult for the weak to board the taxi in a battle of survival of the fittest. Passengers would also have to pray that the driver would not change his mind or become distracted by other things, including calls of nature, or familial or personal responsibilities.

The nurse and I decided to make the journey on foot since we were not sure whether the taxi was coming back, and even if it did, whether we could get on board. Along the way, as we discussed some of the difficulties in accessing treatment faced by HIV positive people, the nurse hushed me and pointed to a

village some few kilometres east across the route to the town we were visiting. “I had one client there,” she said, breaking the silence. “He was the chief of the village.” “A chief with HIV?” I asked. She continued:

Yes, you see, Nana [honorary title for a chief] became ill and after unsuccessfully treating it all by himself, he was brought to the hospital. His sickness became on and off, but after monitoring the situation for a while I suggested to him that we take his blood sample and test him for HIV. He agreed, though reluctantly, and the test was positive, so I decided to arrange counselling and treatment options for him. Later, after I had left and was preparing to go back to him, Nana called and told me it wasn’t necessary that I should come back. He said that since we have found the problem he was going to solve it.

I visited several times to explain to Nana that we could get him medicines that could reverse activities of the virus but he wouldn’t have any of it. He asked me to stop talking about this issue when I came to the palace. I resorted to calling him on phone to convince him to opt for the ART, but Nana stopped me from calling. He said he was sure people were watching him because of my frequent visits, and was sure they would end at nothing to find him out. He never agreed to undergo treatment. He said he preferred to die in dignity, without his people getting to know that he had HIV/AIDS. “Can you imagine how they would react knowing I have HIV/AIDS ... ? Death is worthier,” he said.

So Nana died about a year ago. I was at the funeral but I continue to hate myself for not pushing harder. Maybe, just maybe, he would have changed his mind and [he] would have chosen to live, especially at the time he was dying.

The institution of chieftaincy is greatly revered, so the chief in this case tried to do everything in his control to hide the shame of being infected with HIV. On Valentine’s Day 2009, a paramount chief was alleged to have died after he went with his concubine to a beach resort.<sup>1</sup> Some days after the report appeared in the media, the central regional house of chiefs “threatened to drag a section of the media to court to face the anger of the people of the region for daring to announce the death of one of the chiefs in a bizarre circumstance on St. Valentine’s Day in the Gomoa area.” Because of their position, chiefs in Ghana do everything to protect themselves, to maintain and project a good image, at least to the public. All HIV positive people are faced with this dilemma because HIV/AIDS is perceived as shameful and those who are found to be infected are seen differently; they lose face and respect.

Using the concept of ‘selling your sickness’, taken from the Akan proverb quoted above, this chapter reflects on issues of privacy and disclosure after people find out about their HIV positive status. The chapter also discusses how the people studied developed several strategies to live with the sickness and, to a large extent, get the support of friends and family. It shows how these strategies impact upon their access to ART services and their relationships with family and friends, and discusses their strategies in the context of the high level of stigmati-

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<sup>1</sup> Story on <http://www.ghanaweb.com/GhanaHomePage/NewsArchive/artikel.php?ID=157766&comment=0#com>. Accessed on 19 February 2009.

zation of infected people. In particular, the chapter highlights the issue of death being seen as an option for avoiding stigma and other problems associated with access and adherence to ART.

### ‘Selling the sickness’ as disclosure

Serovich (2001) notes that before the current millennium, the most common theory about HIV disclosure was the disease progression theory, which posits that individuals disclose their HIV diagnosis as they become ill, because when HIV progresses to AIDS they can no longer keep their status private (see also Hays *et al.* 1993, Kalichman 1995, Mansergh *et al.* 1995, Babcock 1998). Hays *et al.*, for instance, found asymptomatic men less likely to disclose their HIV status to family and friends than symptomatic men. This theory has, however, not been found to be applicable to sexual partners, i.e. there is no significant relationship between the severity of physical symptoms and disclosure to sex partners (see for instance Perry *et al.* 1994 and Mansergh *et al.* 1995). Furthermore, as a consequence of the introduction of ART, and even in resource poor settings, people who enrol on time do not exhibit a standard pattern of declining health, so disease progression on its own does not constitute the prime component of the disclosure process.

More current is the consequence theory, which argues that individuals disclose their HIV status after anticipating the consequences of disclosure. After testing positive, therefore, as the disease progresses, stresses accumulate which result in the need to reveal one’s status to significant others (such as sexual partners), in particular once the rewards for disclosing outweigh the costs (Serovich 2001). The rewards are the positive consequences of disclosure, and may include “pleasures, satisfactions, and the gratifications the person enjoys” (Thibaut & Kelley 1959: 12), as well as social, physical, psychological, or emotional dividends that may please the HIV positive person (Serovich 2001). According to Serovich, these benefits may range from assistance with home-related chores and medical attention to social support and acceptance. Disclosure by HIV positive persons may be a crucial factor in reducing the further spread of HIV (Marks *et al.* 1991); may help PLHIV feel better emotionally (Greenberg & Stone 1992, Derlega *et al.* 1993); reduces stress-related problems (Pennebaker & Beall 1986, Pennebaker *et al.* 1990, Greenberg & Stone 1992); and could provide useful links to education, health care, and the social support needed to improve physical health (Serovich 2001). Serovich (*Ibid.*) further notes that disclosing to family members and close associates and getting their support greatly helps patients adhere to the medical regime. The costs of disclosure are the things of value that must be relinquished in preference for an alternative, equal or greater, reward, or something that would be punitive or distasteful that one would otherwise avoid

(Ibid.). HIV positive persons, according to this theory, disclose to those who pose little risk, while avoiding those who could harm them.

The popular proverb that you must ‘sell your sickness’ literally means that a sick person has to communicate or disclose what is wrong with her/him, how s/he is feeling, and in effect reveal her/his innermost secrets about the suffering, in order to get medicine and other help. The medicine referred to here could range from diagnosis and prognosis to treatment. The person to whom the sickness is being sold may have experienced themselves or known someone who experienced a similar condition, so could ease the fears and frustrations of the sick person by diagnosing the illness, showing the probable course of the sickness (prognosis), or even the best way to treat the sickness. In theory, the more you talk about your problem, the more likely you are to get help. In reality, the sick person is more likely to selectively ‘sell the sickness’ to a person who can offer help – a doctor or a trusted family member – rather than to a stranger or a distrusted person, especially when the sickness is very serious and could stigmatize the individual or the family if an outsider were to know about it.

For the purpose of this chapter, the focus on ‘selling the sickness’ is not about diagnosis (which was dealt with in Chapter 3). Rather, the emphasis is on prognosis, especially treatment and care. The case material suggests that HIV/AIDS is not considered a sickness to be sold, because the ‘seller’ loses the support s/he may have had prior to the sale. Drawing from the consequences model for HIV disclosure, the cases presented here will show the various considerations – the cost-reward analyses – of PLHIV about whether to sell or not to sell their HIV sickness.

## Strategies for selling

After going through the hassle of getting oneself tested (as discussed in the previous chapter), people living with HIV go through another complex stage in their lives – living with HIV/AIDS. Most significant are their thoughts of maintaining or regaining their social status and respect in society, mainly because of the ramifications within the communities of being infected with or affected by the disease (as discussed also in the previous chapter). Fearing what people will think, they employ strategies to conceal their status from those who should not know, and also tactfully deal with those who know so that they do not reveal it. They therefore choose one of four options: some prefer death to shame, others choose to live with the secret; some sell their sickness reluctantly, others willingly.

*Not selling the sickness*

As discussed in the introductory chapter, stigmatization of HIV positive people leads to labelling, stereotyping, separation, loss of status, and discrimination. The fear of these consequences causes some PLHIV to completely fail to disclose their status and to live in total secrecy. Usually, those who weigh the risks of the consequences of their infection – loss of respect, shame, the breakdown of relationships with friends and relations, etc. – consider not selling their sickness to be the best option. In the case of the late chief, discussed above, he considered the ramifications of his subjects knowing about his infection – which may have even included destoolment – and thought that the better option was to hide the infection and not to start therapy. Thus, in the case of Nana and some of the HIV positive people studied, as a consequence of their considerations of the negative ramifications of disclosure, they consciously decided not to let anyone know about their HIV positive status. Some settled on refusing to treat the infection with ART, perhaps resorting to other alternative therapies, while others accepted ART but were vigilant not to give away any clues about their infection. In the majority of the cases investigated, the choice they felt they were faced with was between ending it all or living with the secret; a choice that was, from their perspective, a rational one.

*Preferring death to shame*

Almost all of the HIV positive persons I met said that their first reaction after getting the result was to “end it.” After considering the possible reactions from family, friends, and the general public to their HIV status, they thought that death was “worthier,” as Nana put it, and thus a better option. During the course of the study, a number of the clients from the two facilities died by committing suicide, or were rumoured by fellow HIV positive persons to have killed themselves. An example is Rahim, discussed in Chapter Three. In the cases investigated, the means used to carry out these suicidal intentions were taking a poisonous concoction (mainly *nkura aduro*), starvation, and in one case hanging. Several also said that they did not carry out their intentions to commit suicide only because they did not have the means and/or the courage to do so. Mama Sɔfo explained:

I know how Ama Donkor is a public disgrace in this community because she is infected with that illness (*saa yadeɛ no*). Even children do not respect her. So when I found out that I was also positive, I could not imagine myself in her position. I decided to end it. I decided to buy poison for rats (*nkura aduro*) and mix it in a bottle of Coca Cola. It was going to be fast. I know several people who had died using it. I just did not get the courage that time. You know I’m a Christian, and it is not good ...

Kaakyire: I got some money from my sister and bought *nkura aduro*. I tried three times but I didn’t get the courage to drink it. I always thought about how my children would be ridiculed

because their father was not manly enough to live and look after them. That was the only reason why I did not end it.

By not selling the sickness and choosing to die, these HIV positive people on the one hand succeed in concealing their positive status. Nevertheless, death by suicide is detested. It is considered a bad death, and “normal funeral rites are not performed to honour the coward,” as Kaakyire put it. To those who opt for suicide, however, it is a choice between two evils – enduring the shame of HIV while still alive or going through the same while dead; the latter was deemed more suitable. Considerations of the effects of shame as a result of the suicide on family and children, however, made some of the HIV positive persons choose to live, as shown in Kaakyire’s quote above.

From observations and the accounts of some nurses and peer educators (who were part of the home-based care team) and some of the people living with HIV, it was clear that although some of those who refused ART did regain their health, the majority did not, and thus had to go back to the facility when they became seriously sick. Some of them, like Nana, died before they could go back. By choosing not to enrol in ART, to keep quiet about the infection, and/or to pursue other treatment options, some of the HIV positive persons did eventually kill themselves. In preferring death to shame, therefore, two forms were identified from the case material: the active form, which is death by suicide; or the passive form, which involves refusing to go for ART and resigning oneself to death in the long run.

#### *Choosing to live with the secret*

Among the HIV positive people in this study, those who chose to live but still keep their status secret were mainly those who were diagnosed while they were relatively healthy. A few had walked in voluntarily to do the test, others had tested because of offers made after sensitization campaigns. The fact that they were healthy and not in a critical or incapacitated state meant that their HIV test results were divulged personally and privately to them alone. The initial shock and confusion notwithstanding, these persons were in a better position to choose critically between the options available to them. The majority decided to follow the ART regimen and/or other options offered, which might help them to manage their situation while concealing their status from others. Due to the fact that they had no overt symptoms of the progression of the disease, little change occurred in their everyday lives after testing positive. They were therefore not compelled to sell their sickness in order to get medicines for it. For those who were married or in sexual relationships, especially the women, although they felt uncomfortable about not selling the sickness, the consequences of their partner knowing – such as divorce and loss of the relationship, loss of financial support, and further disclosure to others who they did not want to know – made them remain silent.

More than eighty percent of the HIV positive people followed, and a slightly higher percentage of the clients in the two ART facilities, had not disclosed their status to their family and/or friends. Instead they resorted to several schemes to keep their status private, chief among them being the pursuit of spiritual therapy. Kwagyei's sister (who did not know the biomedical explanation for the continuous ill health of her brother), for instance, explained how she earnestly helped her brother in fasting and prayers. She also took him every Wednesday for prayers with one prophet, since "No one knew what [was] wrong with him, and only God can help out." By not selling their sickness, Kwagyei and other PLHIV do not jeopardize the support of family and friends throughout their ill health.

Prior to becoming seriously sick, Kwagyei was very supportive of his family, so when he fell ill he moved to his hometown in order not only to get proper treatment but also to receive the support of his family. From conversations and observations, it was clear that his family believed that his predicament had supernatural underpinnings, and though comments from some people in the community suggested that he was suspected of having 'that disease', the family thought otherwise. Once Kwagyei's niece told me that she had heard people saying that her uncle has AIDS, but she said "They don't know what they are talking about. Can't they see that he is getting better every day? We do everything with him, and then we should be infected too by now." It was remarkable how clearly the treatment given to Kwagyei at home confirmed that his family did not suspect that he was infected with HIV. For example, they ate together with him, using the same plates, cups, and other household utensils, unlike what was seen in the majority of households where the PLHIV had sold their sickness. In choosing the alternative to selling the sickness, HIV positive persons could rely on the effects of the HIV infection conforming to people's perception of a 'spiritual' attack, including the work of witches, curses, and other malicious powers (see below, and also Kwansa 2010).

#### *Selling the sickness: The only option*

The study also found some PLHIV whose family and friends knew about their positive status. These HIV positive persons did not choose to die, yet their secret was now in the open. In some of the cases, they explained that they had reluctantly sold their sickness because they had no other option. In a few cases, however, they had willingly confided in a few trusted people.

#### *Selling reluctantly*

As a consequence of people being reluctant to know their HIV status, those who test HIV positive often find this out at the end stage of their illness trajectory, when they are in the worst condition. They therefore need help to get to the facilities where they are then tested and their status determined. Most of the

people in the study for whom this was the case explained that, at this stage, they were compelled to inform their caregivers, at least those who were with them when the test results were given. Some of these caregivers were the first ones to be told about the result by the health care workers, because of the state of helplessness of the client.

In a case observed during the early part of the fieldwork in St. Patrick's Hospital, Mary's family had already suspected that she was infected when they brought her to the facility because of "how slim she had gotten" (*na wafɔn dodo*). I was shocked by her fragility when I assisted her brother and mother, who had brought her to the hospital, to get her into a wheelchair so that she could be aided to the Special Clinic. Her hands were very frail, and I was scared when I held onto her arm to get her seated. It felt like it was going to fall off. When we finally got her there, I could observe that she was in real pain. Her difficulty in breathing was obvious, and she was very unstable in the chair. When her HIV positive status was confirmed, her family refused to have her admitted. In fact, I later realized that they had been coerced by the nurse in the unit to get Mary to the hospital this time round after she (the nurse) had received messages that Mary had not responded well to the treatment given to her after her last visit to the hospital, and that she was dying.

The nurse at the hospital explained that since Mary's family had suspected that her ill health was caused by 'that sickness', when it was confirmed they refused to "spend an extra penny since she was going to die anyway and the money would go [to] waste." About three weeks later, I saw Mary's 'one week' obituary notice<sup>2</sup> all around the community. Mary had expired. A very grand funeral was held for her.<sup>3</sup> They had rejected the living body infected with HIV and were celebrating the dead one. For Mary and some other infected people, they were not lucky enough to receive the test results directly and in private, so it was not possible for them to decide for themselves whether or not to sell the sickness. It had already been sold and they had to live with the ramifications.

Some of the PLHIV said that even though circumstances (mainly their ill health) at the hospital compelled them to disclose to someone – usually the caregiver who was present when the results were declared – they still expected that person to be very discreet about it. Osei explained that though his sisters and some of his uncles and aunties were present when he was asked to do the test, he was so sure that he was negative that he told them that they should not worry; he was going to come clean. He had earlier been rushed to Komfo Anokye on four

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<sup>2</sup> Among the Akans, after the demise of a member, there is the gathering of close family and friends to discuss the aftermath and funeral arrangements. This is usually done exactly a week after the death of the member. Notices are usually posted, and this is the first information given to the general public regarding the member's death. Currently, this practice is gradually spreading to other ethnic groups.

<sup>3</sup> See in-depth discussions of funerals in De Witte (2003) and Van der Geest (2000).

occasions with severe stomach aches. He had grown so thin over a period of four months that all his family members were worried. The idea of having the test was suggested to his maternal uncle who worked at the hospital, and he openly discussed it with Osei in the presence of his other family members. Later, one of his sisters explained to me how scared she was of the test, though she had already thought that the nature of his suffering could be attributed to HIV.

No one said anything to me about the test. However, after about two weeks, I heard that the test was positive. Ei, I couldn't believe it was true. My sister [a younger and relatively wealthy one and the major financier of Osei's medical expenses] was telling someone on phone how Osei had been asked to do the test and how the positive result was given to him and his uncle. I suspected that she was talking to our sister in Europe. I eavesdropped and I was right. That was how I got to know. No one has said a word about it. And they think I don't know anything.

Later, I heard our brother was complaining a lot that we were not visiting him as often as we did before the surgery that led to the diagnosis, so he inquired from our uncle whether he had mentioned anything about the results to us. I'm told that he confirmed that he had mentioned it to our younger sister. Since then he became so disturbed, he refused to eat anything. His health deteriorated very much, and he finally passed on.

I had spoken to Osei a few days before he died on one of my visits with a peer educator to his house. He had told us how disappointed he was in himself that he was going to leave behind his two children, the younger only eight months old. Though we tried to reignite his desire to live, it was clear that the thought that his sisters had got the news, that they had not bothered to care for him unlike before hearing of his positive status, and also that they would not be tight lipped about it, was too much to bear. He told us he wanted to drink poison and end it all, but did not have the strength to get it. His wife later told me that he starved himself to death.

In some other households that I visited, families who learned from the hospital that their relative had been diagnosed HIV positive began to maltreat them. Most families and friends tried not to broadcast the positive status of their relative or friend, probably because of the resulting shame that would be cast on the family, though they were nevertheless the major culprits in the maltreatment of the HIV positive person. In one case, a family kept their relative in a room and barred her from speaking to anyone. No one could visit her, not even her own children and the staff from St. Patrick's Hospital. On one of our visits to the house, the nurse demanded to check the patient herself. Every time she came, the door to the room was slightly open, but she was told that her client was travelling. When the family vigorously refused, the nurse decided to make a scene by shouting and accusing them of preventing people from seeing their sick family member. Probably because of the fear of the consequences of the nurse's action, they decided to shut her up by allowing us to go to the room and see for ourselves. They had lied. The woman was lying on the only mat in the virtually empty

room, with only a few cover cloths, two eating plates, a cup, a tablespoon, and a chamber pot. She explained that she had seen us every time that we had come there and had not travelled anywhere. She had been denied any visitors, and only saw the world through the opened door. She sobbed:

They open the door in the morning when my sister comes in with my food and to empty the chamber pot. They don't talk to me; they don't even ask me about my health. I have run out of medicines and when I told her she says what good is the medicine if I am going to die anyway. They don't care whether I take my medicines or not. They are waiting for me to die, but even death would not come and visit me. I am tired.

Considering the possible consequences of selling the sickness, it was unusual to find HIV positive persons who willingly did so,<sup>4</sup> though there were some.

### *Selling willingly*

As part of the requirements for enrolling in ART in the two facilities, the HIV positive persons have to bring along another person, a treatment or adherence monitor, who will also partake in the adherence counselling and help the sick person at home when needed. The monitor should preferably be someone who lives in the same household as the infected person. Josephine, one of the nurses at St. Patrick's Hospital, clarified:

... the main task of the monitor is to monitor the client and ensure that she follows the regimen religiously. In case the client is so unwell that she is unable to make it to the hospital, it is the monitor's duty to ensure that the client is not taken anywhere else for treatment but to the ART centre.

The monitor must therefore know when the client has an appointment at the centre and remind her. She must also know when the infected person takes her medicines, in order to constantly remind her. In general, the monitor will have to know everything about the client's condition and what she does, in order to help her in times of need or when she forgets.

The person living with HIV must sell her/his sickness to the monitor in the first place in order to get her/him to the hospital. This requirement chiefly accounted for how other people got to know about the PLHIV's 'sickness'. Mr. Nkansah explained:

... after getting to the hospital, I realized that if I am to live, I will have to tell someone else. So I looked around ... I cannot tell my parents. They are already old. They will die. They will be disappointed in me. I cannot tell my sisters ... they cannot be trusted. They may tell their husbands and that would be it. My wife? Hmm! She will say that I went behind her. I therefore confided in my friend at church. As for him, I know I can trust him.

Kaakyire, telling about how he decided to sell his sickness to a treatment monitor, also recalled:

I remember when I was first asked to bring a monitor; I told the nurse categorically that I won't do it. If that is the only condition to get treated then I'll go and die. So the doctor

<sup>4</sup> It must be noted here that based on the understanding of the proverb, the use of the word 'willingly' only means that the act of selling comes from the person with HIV him- or herself.

called and explained the need for a monitor to me. What convinced me was the fact that I may be bed ridden and still need the medicines, so the monitor would just have to be present and he could take them on my behalf. You could also fall sick suddenly and various people could give different suggestions but if the monitor is around, he would just take charge of the situation and get you where you can be treated, because he knows your condition. This could prevent the many people who rush you to the hospital in such critical conditions from finding out.

So after pondering on it for a while, I knew my sister [his main caregiver] could not be considered. However, there was no other person in mind, so I asked to be given more time to think about it and get someone. The next time I went alone but they [the nurses and the doctor] insisted that if I had no monitor, then there would be no medicine. So I went home and decided that between disgrace and death I rather choose death (*Fereɛ ne owuo deɛ, anka fanyinam owuo*).

However, one day I decided against all odds and called Nsiah, my nephew. I told him that, if God permits, I would want him to accompany me to the hospital to see the doctor. On the said day, he didn't go out but rather asked that I let him know when I was ready. I told him that the appointment has been rescheduled to a later date so I would keep him informed. So when I went to the hospital I lied that I didn't get to bring my nephew because he was busy, but I still wasn't attended to. So the next week, I went with him. On our way to the hospital I told him exactly why I needed to take him with me. And I warned him that it should remain a secret between us ... and that when a third person gets to hear, we would both end it there.

I know my nephew as someone who is discreet and thus capable of keeping such issues to himself. I told him I was placing my life in his hands, so if he wanted to kill me then he could go ahead and do that. So I told him that when I went to the hospital, the doctors said that I had TB, and that is the first one, the second is this disease. He was shocked and kept looking into my face, sheepishly. And I told him that the doctors have told me that they would give me medicines, and I would be fine. "If I had not told you about this, I'm sure you wouldn't have had any idea about that, so I don't expect that now that you know we will behave in ways other than we used to. If you would be infected, it would have been before now since we have been doing everything together. I therefore do not expect that you refuse to sit on the same seat I do, or avoid to be with me and touch me. When such things happen you will make me very sad (*wo bema me were aho*). So note that we can continue eating together and you won't be infected. It is when we share blades and tooth brushes, etc. that we can transfer my contaminated blood that you can get infected. And that is why the doctors have asked that you come so that they can educate you on this, so if you come back and decide to tell everyone, then it's up to you (*ese wo ara*)" ... I told him all that.

So he said he had understood the situation. You know, when I was working and he was in school I was providing a lot for his needs (*na meye no fine*). I was his only uncle and they are six [nephews] but I helped all of them.

Brothers sold it to sisters, wives to husbands, children to parents, nephews to uncles, and vice versa. However, the main criteria for divulging the information were trust and how safe the HIV positive person would be afterwards. Where there was no trust that the monitor would be discreet, and it was felt that they would act contrary to the expectation of the HIV positive person, the latter decided to not sell the sickness at all or waited until s/he had to sell reluctantly, as discussed in the earlier section.

The HIV positive persons in the study mentioned that for the first few days to weeks after they had ‘willingly’ sold their sickness, they watched out for the reactions of these trusted people and those they associated with to be sure that they had made the right choice. Kaakyire continued:

But after a week, I invited my nephew out to a popular joint where we used to eat and I bought some yams and palava sauce [*kotomire* stew] in separate bowls for us to eat together. I deliberately drew the sauce from the same bowl he did, to know his reaction. He seemed okay with it and we finished the meal. Another time I had just told him I was going to that joint to eat, when he offered to go, so when we got there I told him we should buy in separate bowls but he insisted we eat together. I tried this on about four different occasions and he passed the test. Even at home, he didn’t mind coming home to finish a meal I had started. So I realized I could trust him. If it were to be someone else, he would not tell anybody perhaps, but would try to protect himself by not touching things that I had touched or by not eating from the same plate.

Though a few were able to trust their monitors and could keep their status private (as Kaakyire’s case with his nephew shows), the fear of a possible negative attitude from people to whom the sickness is sold is not simply a *worry over nothing*, as the cases have shown so far. In other cases, the HIV positive people explained that their treatment monitors’ reactions had been a mixture of casting insinuations, suspicion, and at times blackmail. Many more of the people living with HIV who willingly told their trusted folks were shunned, rejected, and “some [confidants] even acted as vehicles for broadcasting the news.” Elizabeth, for instance, was tested through the PMTCT programme when she went to deliver her child. She informed her husband about the positive test result and encouraged him to go for the test as well. He tested negative and, as she explained, that “was the beginning of the end of our marriage”:

My husband was so loving until his test proved negative. For the first weeks he wouldn’t talk to me. He even didn’t want to hold our child. He said that I went behind him and that is why I had been punished with this illness. He later on stopped giving us money, even to the extent that at a point we had nothing to eat. When I complained he drove us away from the house and hasn’t bothered to look for us. It has been more than three months.

One category of infected persons who had relatively little difficulty in selling their sickness was the group who were ‘lucky’ to have had an earlier sickness – in the case of my study participants, tuberculosis (TB), leg pains, osseous meningitis (inflammation of the bone tissue), severe stomach aches, etc. – or various forms of surgeries, which later led to the HIV diagnosis. These people were therefore able to sell their sickness by proxy: they sold the non-stigmatizing sickness and thus were able to receive regular familial and collegial support. These people continued to claim that the ARV medications they were taking were for the earlier sicknesses. This was particularly so for those suffering from

TB prior to testing positive for HIV (note that about two out of three of all HIV cases in Ghana are co-infected with TB).<sup>5</sup>

## Strategies for managing the sickness

For the HIV positive people – whether they sell their sickness or not – strategizing about whether to sell or not to sell is not the end of their bid to keep their HIV status hidden. Instead, it ushers in another level of strategic lifestyle, often more complex than that of the previous stage: strategizing to manage their private lives, including going to the ART facilities and also living comfortably at home.

### *Strategizing to get to the ART facility*

Two factors accounted for the way in which these HIV positive people strategized in order to get to the ART facilities for treatment: communal and institutional.

#### *Communal factors*

For new clients, going to the ART facility is usually a very difficult undertaking. They fear that others will see them going there and thus give them away. They are careful about which routes they take and also literally watch their backs in order not to leave any trace. Especially in a rather small community such as Offinso, positive persons who enrol at the ART facility are most scared of the threat to their privacy. Amina, for instance, had gone to the hospital one morning for her ARVs. Some friends, hearing that she had not been well for some time, went to visit her at home. There they were told that she had gone to the hospital. The traditional care and support system in the community makes it imperative that they either follow her up at the hospital or come back later to make sure she is or will be fine. Amina's friends chose the former. Amina got a hint of their arrival through a close relative who had gone ahead to inform her so that she could be ready to meet them. The visit, however, put Amina in a dilemma, because she could neither receive her visitors at the ART facility where she had gone to get her medicines nor get herself into another ward. She nonetheless managed to arrange with the nurse on duty to go to the main OPD, to create the impression that she had not yet been taken care of although she had already spent about four hours at the hospital. As part of the arrangement, when it was her turn for treatment she would be called personally by the nurse and would go with her

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<sup>5</sup> The influence of HIV on TB has been increasing, such that while in 1989 about fourteen percent of TB cases could be attributed to AIDS, by the year 2009 about fifty-nine percent of the projected TB cases were attributed to the HIV/AIDS epidemic (GHS 2007).

to the Special Clinic (which is not close to the OPD), therefore avoiding being seen receiving ART by her visitors.

It was also observed that when people in the community are suspicious that a person is HIV positive, especially when there are overt bodily signs, they try to find proof in order to confirm these suspicions. This may include laying an ambush on the way to a known treatment centre to see whether the suspect will pass by. Some of the people I spoke with explained that they had to pretend every time that they are going to other units in the hospital, and then hang around (sometimes for very long periods) before they find their way to the ART clinic when the path is clear. Linda described how, at times, she hangs around for up to four hours in the hospital to be sure that the place is safe before going to the ART facility. She explained that on one occasion she had to leave for home without treatment because there were lots of people around she knew who she “didn’t want to know about me.” Others claimed that they stay outside when they see other community members at the hospital; some find ways to alert the nurses to their presence in order to make arrangements for them to see the doctor without going through the usual bureaucracies and the mainly long queues. Ellen, who is well known in the area because of the prominence of her late father, stated that she always had extreme difficulties going for her medicines:

The doctor and nurses even know about my situation, so when I get to the hospital, I call them and let them know I am around but monitoring the environment for a while. I only go there when all is clear. On one occasion, I had to wait the whole day because the place was never clear. I got there around 9:00am, and had to wait till it was 3:30pm when the nurse called to tell me all the patients were gone and the doctor was about to leave. They had to arrange for me to see the doctor at the theatre because my husband’s younger brother(*me kunu ketewa*) was at the hospital to meet with the Administrator.

The study also found that several of the clients who accessed ART treatment services at St. Patrick’s or Komfo Anokye came from very far away, including Accra, Tema, Obuasi, and Techiman, among others, ignoring the many other ART sites on the way to these facilities. Through links from my colleague in the hospital and also the people in charge of home visits, I managed to visit some of these clients (and talked to others on the phone) who had travelled all the way from the Greater Accra Region to access services in the Ashanti Region. Their reason for making such a long journey was mainly to remain anonymous. Ahoɔɛ, who was in her late twenties and not educated, ran a chain of stores in Kumasi, even though she lived about forty kilometres south of Kumasi. She explained that about eight months ago she thought she was pregnant and so reported to a private laboratory for a pregnancy test and later on decided to have an HIV test out of curiosity. She only proved positive for HIV. Later, she managed to locate an ART facility some fifteen kilometres north of Kumasi. She had not sold her sickness to anyone, not even her “serious boyfriend” who, she

said, intended to marry her very soon. In fact, she preferred to travel the long distance from her home (about fifty-five kilometres) or her business (about fifteen kilometres) to this facility so that no one would get a clue about what was happening to her. Her dilemma was not so much about how to disclose her status to her partner or another trusted person, but how to deal with the consequences of an open secret, because “a secret is only a secret as long as only one person knows about it.” For her upcoming marriage she said “I’m hesitating currently, but do not know what to do ... what excuse can I give for backing out?”

In Kakra’s case, she stopped going to the ART facility altogether, thereby stopping her treatment, because a friend who is a nurse in the same hospital had given the hint of her status to people in their community. These people, therefore, wanting proof, “go to the hospital on clinic days, as if they are also patients, just to see me get to the place. When I realized that, I decided to stop going there.” Plans to get Kakra transferred to another treatment centre, after I prompted the ART staff, were not successful; at least by the time I left the field.

The strategies used by HIV positive persons to prevent inquisitive people from finding out about their status are not limited to hiding from those who are not infected. Some people on treatment hide or avoid some of their fellows who they already know are infected and are accessing treatment at the same centre. This, the ART clients explained, happens when specific clients known to each other, or living in the same community, do not want to meet at the facility. They try not to be enrolled at the same facility or arrange with their doctors (and nurses) to give them different days for appointments. In addition, newer clients make arrangements in order not to meet these people who they knew are infected and yet do not want them to find out about their own status. The problem with this arrangement is that clients in both facilities are asked to report to the facility when they experience any form of ill health, even when their appointments are not due. There is therefore no certainty of always being able to avoid specific people at the facility. When they get a hint of their presence, they rely on the nurses to make special arrangements, such as being called in (on the phone or sent for in person) as and when these specific people had left. Mama Sɔfɔ mentioned that once, on her way for treatment, she did not get into the taxi as Ama Donkor (another PLHIV) was already on board. She had to call the nurses to make arrangements not to have appointments on the same day. She also refused to join the same PLHIV association as her. This is because Ama is already known to be infected in their community; Mama Sɔfɔ explained that because “she had lost all respect, even from children (*nkɔdaa mpo mfa no nnyehwee*), she would gladly reveal her new ‘partner’ if she found out.”

Some of the HIV positive persons also pretend to go to the market, visit friends, go for check-ups for previous sicknesses, and so forth, including dressing

appropriately for such trips or gatherings, in order to disguise the fact that they are going to the ART facility. This was particularly true for those who had not exactly sold their sickness. On one occasion, I met Serwaa in Kumasi in a black blouse and a matching pair of black trousers, on her way back from the facility in Offinso. Surprised, I asked why she was dressed this way – in black and also in trousers – since she had been suffering from shingles for about six months and it was not very healthy because of the heat of the sun at that time of the day (which averages about 38°C). She explained that there was a funeral in her family and she had to attend; this accounted for the black. That morning she also had to “dash to the hospital for her medicines,” and since she did not want anyone to know that she was that sick and was going to the hospital, she had to cover the shingles with the trousers. Others too claimed that they sometimes had to dress for the market or for work, since that was the only way they could disguise their visits to the facility.

### *Institutional factors*

The location of the ART facilities and the days on which they receive clients both contribute to the strategies that clients adopt to hide their status. In Kumasi, the VCT facility is positioned at the polyclinic where some of the administrative offices and other units of the hospital, including the unit for postnatal care, are located. The ART centre is at the chest clinic where all chest infections, including TB, are treated. The idea for having the facility at the chest clinic, which used to be solely for the treatment of TB cases, was to de-stigmatize the location of the ART centre and also to more easily treat clients' co-infections. In Ghana, approximately twenty-five to thirty percent of in-patient HIV cases have a co-infection with TB (GHS 2007). Since the percentage is much higher for cases in the sub-region (70%), HIV testing is mandatory for all TB patients.

During the period of fieldwork, a massive construction of new buildings to house the theatre, reconstructive surgery, and other departments of Komfo Anokye, including the mortuary, were being built just in front of the ART facility. The sheets demarcating the new site had therefore blocked off the activities of the facility from the curious eyes of the public. Previously, only a fenced wall with little openings (for fresh air, which also gave a view of the activities at the centre when watched closely) was the only demarcation from the public. Due to its positioning, PLHIV going for treatment usually want to escape the crowded places in Komfo Anokye, such as the polyclinic and the main wards. However, if using the D-block, the route to the ART facility requires passing the diabetes and hypertension units, which are right behind the facility and often very busy. The other option is to use the path for vehicles, which is right in front of the facility for hearing impairment and close to the public toilet. Those who

access the Komfo Anokye ART facility claimed to use both; the latter route was mainly used during peak hours at the hospital.

In Offinso, the VCT service is located beside the x-ray and injection rooms. As Dapaah (my colleague at the hospital) noted, it was therefore possible for other clients waiting for injection or x-ray services to see clients accessing counselling and testing services. ART is administered at the Special Clinic in St. Patrick's Hospital, which is the very first building on the extreme left when entering the hospital gates. On the extreme right is the mortuary (see chart of SPH on p. 96). Once, one HIV positive person joked that the position of the centre just across from the mortuary was "to make it faster for the infected people who do not survive to be sent to the mortuary, since mortality levels are definitely high at the ART centres." The name 'Special Clinic' was used for the unit, according to one of the nurses working there, to denote all the special cases, including hypertension, diabetes, TB, and HIV, with the main aim to destigmatize the latter group. "The public will therefore identify the facility with all the other cases which are deemed normal in society, therefore realizing that HIV is also normal," she explained. Before 2009, there was a shed just in front of the main entrance where cooked food (including *Kenkey* and fried fish, beans, and red plantain), and fruits (including oranges, bananas, and apples) were sold. This same nurse clarified that the building that currently inhabits the Special Clinic did earlier accommodate these food vendors, but they were eventually relocated to make room for the medical activities.

The HIV positive people attending ART services gave both negative and positive opinions about the location of these ART facilities. One person explained that the location of the units is a contributing factor to the difficulty people experience in keeping their status private. Sandra, who goes to the Special Clinic for her medicines, explained that the building is too conspicuous, and no matter how crafty you are you will be found out. She stated:

... some people even hide or pretend to buy some food from the shed and rather sit there looking out for people who will be going to and from the building. They brand you as positive if you frequent the building. It is worse for those of us who use the back door of the building and thus walk past the shed for the food vendors [through a footpath]. One day, as I sat there to eat my bananas I heard them [the sellers] even gossip about us [the PLHIV] explaining our reason for going there to the others sitting with them. I felt so bad about what they were doing but I couldn't say anything.

Kaakyire also confirmed such activities by the food vendors by saying that he "does not like them at all." If it were his decision, he believed that "they should be relocated since they not only tell others about the infected people, they also accommodate the punks who just come there to make others out."

It was observed that the hospital authorities at St. Patrick's, after noting these concerns (since major issues were raised by the clients about it), ejected these

sellers, cleared the area of the debris, and built a seven foot wall to prevent intruders. Some of the HIV positive persons, however, mentioned that since the area has been laid bare after the ejection, prying people can now stand across the street (which is some feet higher) to watch the PLHIV as they collect their antiretroviral medicines from the pharmacist.

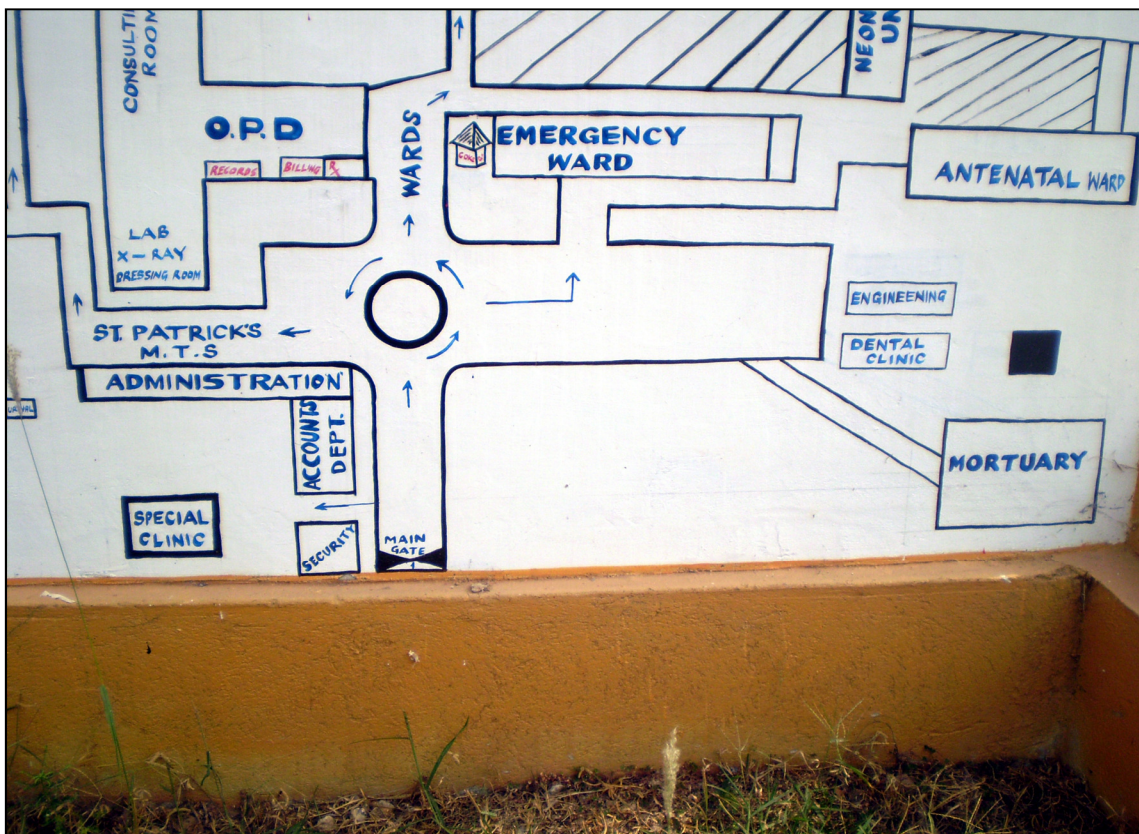
### *Home strategies*

Though the PLHIV in this study were more likely to trust people in their own household with their private affairs, it was found that they were not enthusiastic or motivated to voluntarily inform them or leave clues with regards to their infection. They thus kept all medical records in their possession – hospital cards, prescription forms, and even their medicines – away from all (prying) eyes. Usually, the hospital cards for ART treatment are different from the ‘normal’ ones used to access general services at the OPD. In St. Patrick’s Hospital, the card is labelled ‘Special Clinic’, while at Komfo Anokye Hospital the numbers on the cards reveal the difference. So HIV positive persons feel that their cards could give them away. Some also thought that the prescription forms for medicines, and the medicines themselves, were not safe to be left in the open. They therefore hid all of these things from others.

Serwaa explained that she hid her medicines in her suitcase, under a number lock, to be sure that she was the only one who could access them. Kaakyire hid his under the family’s sofa and claimed that he was sure that nobody would consider looking for them there. According to Linda, she previously kept her prescriptions and medicines, including those for Adu-Poku, her five-year-old son, together in a polythene bag and placed it on top of their television set in her living room. This was because, since they were “alone in the house with her younger sister, who is not troublesome and inquisitive, there was nothing to be afraid of.” She had to relocate these materials, however, when she realized that her neighbours had grown suspicious about Adu-Poku’s problem since he, unlike his older brother, was always sick and had to be sent to the hospital. They had repeatedly asked him (and his older brother) to get them his medications so that they could find out what was wrong with him. Linda therefore put the medicines under a lock in her wardrobe and asked her sons to refer anybody who asked them about the medicines to speak to her directly. “That ended the story since they cannot talk to me directly about their suspicions,” she stated.

During visits to both hospitals (and the accounts of my colleague in the hospitals corroborated this), it was clear that some of the PLHIV disposed of their ARV packages and leaflets even before they left the hospital premises. The main place for disposing of them in Komfo Anokye, for instance, was along the

Picture 7-8 Directional signs/chart of the St. Patrick's Hospital



footpath that linked the medical students' hostel with the major road to the treatment centre. This path was used often by clients who went to the main bus station, *Kejetia*, after treatment. Another strategy was to scratch off the writings on the containers of the ARVs or pour the contents into a different container altogether. The main motivation for all these activities was to do away with any indication – be it on the container or in the leaflet – that would show that the person was taking 'AIDS medicines'. Serwaa had scratched off all the writings on one of the containers, and for the other medicines she poured them into a polythene sack which she hid among her clothes. She explained:

... they [her family] know that I take medicines every day, but what exactly I take no one knows. My small sister is the reason why I hide the medicines. She is the only one who has attained higher education. She is inquisitive. She reads everything. I know she will read everything about my medicines if she gets them. That's why I try not to make them available to her.

Interestingly, Aba gives some of her medicines (mainly co-trimoxazole, an antibiotic used mainly as a secondary prophylaxis) to other people in the household when they are not well:

Often when someone [in the compound house] is not well, they come to me because they know I take lots of medicines, and also know much about how to get relief from pains because of what I have been through. Usually, I give them two tablets of septrin [co-trimoxazole] and it always helps. They therefore come to me every time someone is not well for advice and also for the 'magic' pills.

Due to her previous experiences with battling several illnesses, the others in her housing compound felt that she was the best person to ask for help during their sicknesses. She also made use of the situation to normalize her status by offering them some of the medicines she was taking. Aba explained that they probably do not know that the medicine she gives them is septrin; rather, they may take it for "a different or more potent type of paracetamol," which is more common for relieving pains. "Amazingly, they all reported improvements in their health after taking the medicines, so they keep on coming. I had to plead with them not to abuse the medicine or else it will cease to perform the magic," she explained.

This practice of giving one's medicine to others in order to normalize the situation or to keep one's HIV status private was found amongst a number of the clients visited. This is in line with the usual pattern of most people first resorting to self-medication in times of ill health. The ill person or an aide may go to a chemist or drug store to explain the symptoms and get advice for the right medicine, or they may simply buy the medicines known to be good for the condition. It is also not unusual to ask a neighbour for a pill or two. These HIV positive persons thus capitalized on this existing practice to normalize their infection.

### *Spiritual strategies*

Several of the PLHIV in the study resorted to spiritual therapy, partly as a strategy to conceal their sickness. Since the HIV infection conforms to people's perceptions about spiritual attack, including the work of witches, curses, and other malicious powers, HIV positive people can get the sympathy of friends and relations and also draw attention away from themselves when they consult for spiritual help (see Kwansa 2010). A variety of health care-related practices occur within the medical set-up of Ghanaian society. These include the activities of herbalists, bonesetters, traditional midwives, Moslem scholar-healers such as *mallams* and *marabouts*, possession priests (such as *trɔnua* among the Ewe, *akɔmfɔɔ* among the Akan), *Tigare* and *Mami Wata* shrines, and a variety of Christian healers and prophets. However, use of these different methods is not mutually exclusive, and people may combine a variety in their quest for health and healing (Krause 2006). For HIV positive persons, four main options are used for this strategy: *akɔmfɔɔ* (traditional priests; *ɔkɔmfɔɔ*singular), *asɔfoɔ* (mainly pastors from Pentecostal and Charismatic Churches [PCC]; *ɔsɔfoɔ*singular), *adunsifoɔ*(traditional healers known to use spiritual therapy for diagnosis, treatment, and protection; *odunsini* singular), and *mallams* (Islamic healers; *mallam* singular). A cursory stroll through communities in the Ashanti Region leads one to the various locations of the shrines, cults, traditional healers, mosques, and churches, via meticulous directions posted on decorated signposts of different sizes.

Depending on the extent to which some PLHIV had sold their sickness, they would embark on the search for spiritual therapy alone or accompanied by a friend or kin, similar to what was described long ago by Field (1960) in her study among the Ashanti concerning visits to shrines by the sick. Where sick persons depend wholly on family, it was found that the PLHIV were more likely to reluctantly agree to their proposal to visit a healer. They went to particular healers and churches, either because they had met other people who had been there personally or because of the recommendation of others, who sometimes based their testimonies on hearsay. The usual pattern followed was to discuss various options (traditional healers, spiritual churches, *mallams*, etc.) until the PLHIV or their accomplice arrived at one or more that they hoped would ensure the betterment of the sick person.<sup>6</sup> Most whom I met had gone (or were going) through several regimens, although they were also on ART (see Kwansa 2010). Due to the many options in terms of spiritual therapy, and the relatively religious

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<sup>6</sup> For more on how the HIV positive people's behaviours of negotiating between denominations and religions are guided more by proximate, seemingly pragmatic decisions, rather than by decisions guided by the principles of a pluralistic medical system, see Kwansa (2010).

nature of most persons in Ghana<sup>7</sup> (and in the study area in particular), many people negotiated between the various systems. However, these negotiations oftentimes resulted in the PLHIV compromising strict religious doctrines or practices, and at times led them to partake in altogether new doctrines. Accordingly, there is a frequent crossing of religious and denominational boundaries in people's search for therapy (Kwansa 2010); all these negotiations being primarily strategies to hide the infection.

### To sell or not to sell? Cost-benefit analysis

In their quest to keep their status to themselves, HIV positive people often miss out on opportunities that could ensure a comparatively better life. In the first place, several positive persons refuse either to start ART or to continue treatment because it could lead to others finding out about their status. Obaayaa, for instance, was diagnosed as HIV positive at St. Patrick's Hospital about a year before fieldwork commenced, but she had refused all attempts by the hospital staff to get her to the ART facility to access treatment and care. Although all attempts to have her talk to me failed, Sis Akua, another HIV positive person and a close neighbour of Obaayaa, explained that Obaayaa refused to go for treatment because she felt that it would expose her. She had been feeling unwell intermittently but preferred to go to the Quality Care Clinic (QCC), a private hospital in Offinso, where the opportunistic infections were being treated, rather than to St. Patrick's, because she "felt safer there," probably because of the anonymity. However, a few months into the study Sis Akua told me that Obaayaa had begun attending a private hospital in Kumasi to continue treatment for her prevailing ill health, since she suspected that the doctor at the QCC "may also be suspecting that" (that she may be infected with HIV).

Obaayaa's case epitomizes that of several others, who would keep looking for alternatives for help – biomedical, folk and spiritual, self-therapy, and also substitutes within these alternatives – because they either did not want to know their HIV status, or did not want to accept the reality of their positive status and start ART, for fear of being discovered. In the process, some had to spend substantial costs in terms of money, time, and deteriorating health, which could all have been avoided if they had chosen to confront the possible consequences of selling their sickness.

Some of the clients also failed or were unwilling to join support groups for PLHIV, which would offer them collegial, financial, and emotional support to fight off the socio-economic concerns surrounding being infected.<sup>8</sup> Most of the

<sup>7</sup> According to the 2000 government census, approximately 69% of the population of Ghana is Christian, 15.6% is Moslem, and 15.4% adheres to traditional indigenous religions or other faiths.

<sup>8</sup> In-depth discussion of the activities of PLHIV associations follows in Chapter 6.

PLHIV associations provided financial support of GHS 8 (about US\$ 8) monthly to their members to help defray the cost of ARVs and also transportation to meetings and to the hospital. Members also received food support, in the form of cooking oil, *Tom Brown*<sup>9</sup>, yellow corn flour, and occasionally rice, which went a long way to augmenting the family's diet in most of the poverty stricken homes of these HIV positive people. Because of their attempts to hide their sero positive identity, the HIV positive persons who did not make it to the PLHIV associations or other meetings where these supports could be obtained missed out on these potentially lifesaving opportunities.

Others joined these associations but chose at will which programs to commit to and which to stay away from. Kaakyire, for instance, lived close to an animal farm project run by one of the PLHIV associations – the Christ our Hope Foundation. He was therefore frequently unable to participate in the project's activities. When the group launched the project, for instance, I observed that he was unusually quiet and stayed very much in the background. In fact, at a certain point I realized that he had vanished from sight. I later found that he had gone into hiding behind the caretaker's single room apartment on the site. He explained that one of the guests at the launch was a very good friend of his brother-in-law who he was currently living with. Since only his nephew knew that he was positive, he was sure that the man would be extremely surprised to see him there, and would eventually inform his sister and the family, since the launch was being done for PLHIV.

In addition, those who had not sold their sickness at all or who had sold it by proxy were inhibited from taking an active role in the work of these associations, as well as other, mainly public, advocacy responsibilities. These public campaigns – which include PLHIV giving speeches and talks during HIV/AIDS sensitization events, discussing their experiences at public gatherings or with the media, and attending workshops and training programs – were all found not only to be a very significant way for those who had sold their sickness to gain invaluable knowledge about their current situation and also psycho-social support, but they also received (sometimes) huge financial compensation. This is because of the limited number of people ready to defy the consequences of publicly and openly revealing their HIV status, even amongst those who had sold their sickness. During the 2007 World AIDS Day celebration in Offinso, for instance, I identified only one of the HIV positive people in attendance during the whole programme; he was the video cameraman and was therefore not recognized as a PLHIV.

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<sup>9</sup> *Tom Brown* is ground lightly toasted corn flour, used for several Ghanaian delicacies including porridge (also called Tom Brown) and *aprapransa* (a palm soup dish with toasted corn flour).

When invitations to such programmes and other financially rewarding trainings and conferences become available, many a time the leaders of these associations go through the routine of trying to convince their members of their importance, not only to the individual but also to the group. This notwithstanding, only a few people were ready to take up these invitations. Though illiteracy and the associated lack of confidence were found to be the reasons for the reluctance of many, the primary reason was the positive persons' attempt to hide their identity. Frequently, Chief Appiah<sup>10</sup>, head of the Christ our Hope Foundation, would talk about how he wished he had members who were ready to defy the public shame, like he had done, to take up these challenges, since he was fed up of being the main focus of the group and having so much on his hands. On one occasion, probably because I was a regular attendee at the meetings, Chief Appiah was bent on nothing else but convincing me to represent their association at a conference.

It wouldn't cost you anything ... all expenses are fully paid. They will cover your accommodation and meals for the whole one-week period and in addition you will pocket not less than GHS 200 [about US\$ 200] in per diem by the time all is over.

His decision to convince me may have been based on the thought that I was better able to represent the association, and give them a voice at the conference. He was obviously disappointed when I could not take on that responsibility. But the fact that he could not get anyone to attend explains how very daunting a task it was for members to go out with the "HIV infected person tag" hanging on them, as Esther phrased it. For the majority of PLHIV, who struggle to have at most two square meals a day, who literally rush at the end of the month to these meetings to get the GHS 8<sup>11</sup> and some few grains, and who almost always have outstanding medical bills to settle, the fact that they allow around GHS 250 to slip through their fingers explains the enormous cost they bear for not wanting to publicly sell their sickness.

Esther, a very astute young lady who said that she had found out about her infection after she had worked at St. Patrick's Hospital, and thus was "very careful to come out since she was relatively known," explained how she always counted the cost of not taking such responsibilities.

My brother! Those who go there do not know anything and when they come, they mess up in the reportage (*na wototo paapa so*). Hence, we don't get anything substantial and beneficial from those meetings. What hurts me most is that they have pocketed these huge sums of money for virtually doing no work. No work, my brother. No work. I can't explain to you how much time I spend in bed thinking about these. I could be so much wealthier if I can get

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<sup>10</sup> Chief Appiah is not a chief, but his personality commanded the title given to him by his peers.

<sup>11</sup> By the middle of 2008, many of the associations did not have their proposals accepted and thus their funding was not renewed. They therefore could not sustain the monthly money given to their members. Read more about this in Chapter 6.

the confidence to come out. And the group will benefit too. Ei! But I can't imagine the consequences ... my mother will die when she hears about it ... she will die. And for my little girl, I don't want to think about it. I can't do it ... no, I can't.

Others also missed out on very promising favours from friends and relatives since accepting them could expose their secret. These opportunities would obviously be beneficial, not only to them but to their families in general. They would not have thought twice about grabbing these opportunities with both hands prior to their discovery of their HIV positive status. For instance, Serwaa, who has several siblings living in Europe and the United States, refused to travel abroad to see them even though she was staying at home "doing nothing." Her siblings had earlier promised to resettle her abroad when things went well for them, only for Serwaa to constantly refuse when the time came. She feared that she would be found out, because "technology is so high abroad and I cannot hide it." Esther also explained that she missed the opportunity to get married to a very rich and noble professional because of her current predicament, and because she did not want to infect him.

He is innocent, and does not know anything. It is not right to do that. Previously, I was taking a lot of money and presents from him but I have stopped that. I don't want to further disappoint him. I have told him on countless occasions that it can't happen, not because I don't love him but it just can't happen. He doesn't want to back out. You know, he is flooding my mother with gifts here and there, thinking that she can make a case for him [to me]. She [the mother] is therefore putting so much pressure. 'You don't work,' meaning I don't earn much, and 'you are always in debt. Your child will have a father and the man will take good care of you,' she always says. In fact, I know it is true. And that is why I can't tell her the whole truth [about the infection]. She will die.

People living with HIV take into account not only the costs to themselves, but also those of others, including care givers and dependants, such as Esther's mother in the above case. One drastic cost of either selling your sickness or not selling at all is death. Some of the HIV positive people died because their families did not know exactly what was wrong with them, so they were taking them for treatment – often to several different places and healers – but not of course to the ART facility. Abranteɛ, for instance, whom I met at a PLHIV association in Kumasi, became terribly sick close to the end of the fieldwork period. After I had not seen him at two consecutive meetings, I went to his house only to find him bed ridden. He had not been at the ART facility since he ran short of ARVs because the sickness had started and he felt too weak to make the journey. At that point, his treatment monitor, who was also HIV positive, had travelled with his six months' supply of medication to a neighbouring country, so Abranteɛ could only hope to get better and go there himself or get lucky to have a visit from someone who knew about his condition. Neither had happened until I arrived. He could not sit, talk, eat, or even turn around as he lay on his mat. His family members had taken him from one traditional healer to another, and as he

lay down pitifully he still had some concoctions beside him that he was intermittently forced to take. But “he will vomit them all few minutes after taking them,” his older sister explained. I made arrangements for some peer educators in the hospital to visit Abranteε at his home, and he was later taken to the hospital.

A week after fieldwork, when I had left the country, I was told that Abranteε had passed away. The peer educator who gave me this information said that he was sure that Abranteε would still be around if he had heeded their advice and confided in at least one family member, or had called any one of them during the critical period. I also think that his physical and mental condition might have contributed to his indecision, although the extent of his fear of being stigmatized, culminating in his preference for silently taking concoctions rather than divulging his secret, cannot be ruled out. In order to be safe from the stigma of living with HIV, Abranteε refused to disclose even to the point of death. On the other extreme, however, is the situation of HIV positive persons who did confide in some trusted family members, only to be rejected, quarantined, and discriminated against, also to the point of death, as discussed above.

## Conclusion

Studies have shown that many people in sub-Saharan Africa are reluctant to disclose their HIV positive status; moreover, those who do disclose are selective in choosing their audience (Greeff *et al.* 2008, Campbell *et al.* 2007, Miller & Rubin 2007). This study has shown that the majority of people in the Ashanti communities living with HIV continue to keep their status secret, even when the disease progresses and the symptoms become obvious. They also continue to remain silent up until the point when they are extremely ill and weak and are taken to hospital by relatives, where the staff sell their sickness to their relatives instead of directly to them. This disclosure route is contrary to the disease progression argument. Their incapacitation warrants the sale of the sickness to others. Regarding disclosure to sexual partners, the study did not find any significant link between the progression of the disease and its sale. Rather, it corroborates the argument of the consequence model of HIV disclosure, where PLHIV anticipate the reactions of those in their environment. When there is an anticipated positive reaction, the sale is transacted. In a situation where a person anticipates a negative reaction, s/he chooses not to sell, or to sell by proxy.

This anticipation of a positive reaction is the main consideration for disclosure, and is not limited to spouses. HIV positive persons disclose their status when they are convinced that it will not jeopardize their safety. They therefore weigh the benefits against the costs of selling the sickness. Though some PLHIV expected great rewards for selling their sickness, the majority feared that the reactions from the sale would be negative. They therefore resorted to decisions

that may seem illogical, such as rejecting testing and treatment, resorting to alternative healers, refusing to attend workshops and seminars, and thus either waiting for death or actively hastening it through suicide. Others who were 'lucky' to have a co-infection (with TB, for example) disclosed by proxy, selling their unstigmatized sickness. The majority did not disclose at all, however, even to their spouses, for fear of repercussions such as social exclusion.

Selling or not selling one's sickness is tied to the experience of shame or respect, coming not only from individuals but in the broader context of one's kinship relations. To uphold their good name and restrict the shame of HIV as much as possible, families go to the extent of hiding HIV positive members. The material also shows cases where some families broadcast the news of an infected member as a way of distancing themselves from the individual's predicament. In all these cases, the family's respect was deemed paramount and the individual's stained identity was not allowed to affect the whole family. This must be understood within the context that some sicknesses can take on a family dimension, as the status and respect of a family can be jeopardized by an individual's problems; an entire family can be categorized as having a particular disease. Such sicknesses – mainly leprosy and epilepsy – can be taboo in terms of social mixing, so that members of a family where this sickness is present may have difficulty in marrying persons from other families. In the case of HIV/AIDS, this taboo is exacerbated because of the shame brought about as a result of 'courtesy stigma'. Sick people may be quarantined, or families may disown members for having such sicknesses. Another study carried out in Ghana has also shown that even though people living with HIV may regain their strength with ART and that the physically devastating effects of HIV/AIDS is tempered, they still face psychological isolation and condemnation from their family, friends, and society because people around them are aware of their HIV status (Blackstock 2005).

In exercising their agency not to disclose, or to disclose either partially or fully, the majority of PLHIV do not necessarily toe the line when it comes to the Akan proverb "It is only when you sell your sickness that you get medicine." When HIV is concerned, selling the sickness does not necessarily get you medicine, and you can get medicine without necessarily selling your sickness. As the case material suggests, the majority of those who sold their sickness were instead isolated, lost their status, and lived in fear, while the majority of those who got help were those who either did not sell their sickness or sold it by proxy. For each selling strategy, amidst the high levels of fear of stigma, people developed several coping strategies, which included schemes to deal with the infection in their homes, households, communities, and even for trips to the ART facilities for treatment. These involved disposing of the boxes and leaflets of the antiretroviral medications before getting home, keeping medicines away from others in

their homes, giving some of their medicines to other ill people in their homes, disguising their trips to the hospitals, and resorting to alternative – mainly spiritual – therapy.<sup>12</sup>

Also related to the issue of disclosure is consideration of the extent to which a PLHIV may be treated differently after s/he discloses. Disclosure could, for instance, lead others to be more careful in relating to the infected person, for example by refraining from having unprotected sex with them, while in other cases the infected person may face the possibility of others avoiding all contact with them, from avoiding touching to shunning even causal interaction.

For those who test positive for HIV, in deciding to sell or not to sell their HIV status, they must adjust to the shock of their diagnosis, consider the possibility of living in total secrecy while still getting the support of family and friends, consider the probable recipients of the sale, consider what aspects of the sickness can be sold, and anticipate the reactions of the recipients of the sale. After these considerations, and weighing the rewards and costs of selling the sickness, the infected person will decide to sell or not to sell.

Interestingly, the benefits of selling were often found among other people with HIV, who became quasi relatives bearing one another's secrets. Their associations and activities became avenues to de-stress and to get the social, physical, psychological, familial, and emotional dividends that would otherwise be the motivation to disclose to family and friends. HIV positive persons are likely to disclose only to persons they trust. Nurses and other medical personnel play a central role in this new 'family' of trusted people. As discussed in this chapter, several infected people used them as accomplices in the hospitals and at times in their homes. These networks and the activities of the PLHIV associations are discussed in the next chapter.

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<sup>12</sup> Even though the healing of an HIV positive person through spiritual therapy never occurred during the course of this research, its significance as a coping mechanism and way of escaping stigma should not be underestimated (Kwansa 2010).