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

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## Sleeping or dying: The irony of the new hope

*Se yebewuo nti yenna?*

Should we not sleep because we will die?

(Akan proverb)

Sometime during fieldwork Nsiah called me for an urgent meeting to discuss an issue that had cropped up with his HIV positive uncle Kaakyire. Nsiah had agreed to Kaakyire's request to be his treatment monitor in order for him to receive treatment with ARVs as well as for his co-infection with tuberculosis. When Kaakyire had first fallen sick, he was so ill that all his family and friends thought that he was going to die. His wife, who did not know that he was infected with HIV, left him since she could not "continue living with someone who was going to eventually die." In view of the fact that Kaakyire could not care for them, his two children had also been sent out to relatives to be cared for, and therefore the family was scattered. His sister had decided to shelter and provide for him, at least until the worst happened. The decision to bring Kaakyire to her house reunited his relationship with her son Nsiah. Though they were not living together prior to his infection, Kaakyire had supported the schooling of his nephew and supplemented the provisions by his sister. They were thus very close, though living apart.

Nsiah was the only one who was aware of Kaakyire's HIV positive status (see full case in Chapter 4 under 'Selling willingly'). Nsiah had explained earlier that he agreed to the request because he "felt privileged that [his] uncle could confide such serious information" to him:

I understand why he [Kaakyire] trusts me among all his relatives and friends because we do everything together at home ... We eat together from the same plate, at times sleep on the same bed, and we bathe together ... You see, we are the only males left in the family [all the males had died, most mysteriously] so we are very close and therefore talk about everything. But, some of these things when someone is able to tell you, you know the person has so much faith in you.

When we met on the appointed day, Nsiah was visibly angry and disgusted. He narrated how Kaakyire had many ladies around him. He explained that when Kaakyire had originally confronted him with his predicament, he felt that he was the only person in the world who could assist his uncle and therefore did not waste time in accepting the request. However, he felt disappointed about what was happening now. He explained:

I respected him and knew that he would respect himself by taking good care of himself. However, just after about nine months on the medicines when everything seems normal in his life, look, he has started misbehaving. Every time, I see different women coming to him and the way they behave in the house, I suspect that there is something going on. There is one lady who has been sleeping overnight in his room and I presume they may be sleeping together [having sex]. I am very angry about the whole situation. Why does my uncle want to be so wicked ... ? To intentionally spread this deadly disease?

In another case, Sis Ellen had called me “to meet her urgently for an important discussion.” When we met, she mentioned that she was in a dilemma. She told me about how, before finding out about her seropositive status, she had led a very independent lifestyle and could choose with whom she had (sexual) relationships. She mentioned, however, that after finding out about her status she “did not have a sexual life” anymore, and fought hard to discourage all the men who came to her.

When I found out about it [the infection], it made me sick. I grew so lean because I felt bad that this had happened. But I decided to live. So I went for the medicines. When I came back fit and healthy, I decided to devote all my time and efforts to the work. Now, because the men know that I’m not going to die, they don’t stop asking me to marry them. I tell them that my mind is not on relationships but on my business, just to put them off.

But this was until Mr. Sam came into the picture, and that was Sis Ellen’s problem warranting the call for the meeting. Mr. Sam, according to her, had proposed to marry her even before she found out about the infection, “and he is still waiting for an answer.”

He would not leave even when I became unattractive (*meyee tantan*). He told me that I was sick because there was no man in my life. All this time, I put him off like I did to the rest, but he would not go. This time, he is serious. He has brought drinks to my family asking my hand in marriage. You know what, I love him too. I wish I could marry him. I cannot live like this forever. I don’t know what to do.

That same night, while lying on my bed reflecting on the day's trip to Sis Ellen's house, Maame Amponsah 'flashed'<sup>1</sup> me. I called her, and as if to add insult to injury, she lamented about how her husband Daniel was "misbehaving – he had taken to some bad habits," and when she complained, he asked her whether "he should not sleep because of death?" I return to this issue involving Maame Amponsah and Daniel later, but suffice it to note here that all these encounters – with Nsiah, Sis Ellen, Maame Amponsah, and Daniel – highlight some of the complexities in the lives of people taking antiretroviral medications, which is the focus of this chapter.

After between one and six months of being on ARVs, HIV positive people experience drastic changes in their health. A few experience deteriorating health, some of whom eventually die. Most, however, regain their lost weight, their appetite for food, and return to their normal routines prior to the infection. Some are even able to win back friends and loved ones who had rejected them because they suspected them of being HIV positive. They are able to win back their respect in society and its associated feelings of emotional and psychological satisfaction, as discussed in previous chapters. They feel human again since everything seems normal with them, thanks chiefly to the medicines. These improvements notwithstanding, being on antiretroviral medication brings about another phase of the complexities – physical, emotional, and social – associated with living with HIV/AIDS. First, these HIV positive people must battle with their bodies adjusting to the introduction of the medicines, and such difficulties may include side effects, treatment failure, and drug resistance. Secondly, some grapple with the numerous dos and don'ts associated with being on the medicines, for instance regarding their sexual lives, as seen in the cases above. Finally, people on ART can become involved in a series of contentions with members of their households and communities – with their associated accusations and counter-accusations – as shown in Nsiah's case.

This chapter discusses the HIV positive persons' intimate experiences while on antiretroviral medicines. Specifically, it explores their experiences of normality (responding well to treatment) and abnormality (being unable to do everything normal people do). One area that the chapter highlights is that of the sexual relationships and reproductive ambitions of people on the medicines, and their relationship with death. These concepts of feeling normal and yet abnormal, of sleeping and dying, are discussed using the local saying: Should we not sleep because we will die (*Se yebewuo nti yenna*)? The reactions of those in their environment that make HIV positive people feel normal, abnormal, or both are also examined in this chapter.

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<sup>1</sup> See footnote 3 in Chapter 5.

## Sleeping and dying

“*Sɛ yɛbɛwuo nti yenna?*” is a rhetorical question meaning that there is no point in worrying about the inevitable. The ‘question’ is usually asked when the speaker wants to defy norms or logical expectations in pursuit of individual gain or pleasure. For instance, if student A wants to party with friends when examinations are due instead of studying, he may use this question as an excuse to continue partying. In another instance, if a patient who has been prohibited from eating meat has found herself at a party with friends where everyone is eating meat, she may also question whether because of death she should not sleep, and will proceed to eat the meat.

In other cases, the one asking the question (*sɛ yɛbɛwuo nti yenna?*) may want to approve of or recommend a particular action to another that defies norms or logical expectations. For instance, other students who may not be writing the said examination may use this statement to encourage student A to act against what is logically required of him. In the patient’s case too, her friends may also use the saying to tempt her to eat the meat.

*Sɛ yɛbɛwuo nti yenna?* may therefore be quoted under different circumstances. In the context of this chapter, to ‘sleep’ is used to refer to the ‘don’ts’ or prohibitions given to HIV positive people on ART. It is nonetheless used chiefly to refer to *ɛnna*<sup>2</sup> (sexual intercourse). Death, on the other hand, is used to refer to the process of dying as a result of the infection and/or non-adherence to the treatment principles, including “doing the don’ts.” Death, as it is used here, is a process and not necessarily a one-time event, and may include both physical and social death. This view is epitomized in Ayettey (2009: 14):

Life and death indeed co-exist ... Daily, and indeed every second, parts of us go through the process of death, ahead of the final event of death. Parts of us become ‘terminally ill’ and others ‘die.’ We lose our hair, teeth, and epithelial cells in a programmed cell death. This process continues throughout life with the rate of dying increasing and rate of living decreasing. We continually face decay and degeneration, obeying the second law of thermodynamics.

The case material suggests that some of the people on the antiretroviral medicines suffered severely from their side effects and felt that they were therefore “dying but not dying,” as formulated by Abranteɛ. For some of the others who responded fairly well to ART, they theorized that death (the final stage) would come when it should, so it should not prevent them from sleeping (i.e. enjoying themselves). This chapter discusses in detail these particular ramifications of being on antiretroviral medications.

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<sup>2</sup> *Da* in Akan is a verb which means to lie down or sleep. *Enna* (the noun form), just as it is used in English (‘to sleep with’) can also mean sexual intercourse.

## Dying but not dying

A few people in this study who took ARV treatment did not respond favourably to the medicines. For some people, these reactions to the ARVs lead to death. Others exhibited various signs of side effects and viral resistance, including symptoms ranging from dizziness, persistent headaches, abdominal pains, insomnia, anaemia, and diarrhoea, to hallucinations, nightmares, migraines, sexual dysfunction, and changes in taste perception. In a case in point, I was informed by a respondent that my “good friend Agyei is going mad since the past week. He has been taken to a prayer camp and been admitted.” I had met Agyei the week before and he had expressed his happiness about having finally been put on ARVs after about six months of undergoing therapy. He explained that he was “looking forward to ending the petty aches and pains, and sleepless nights” he suffered due to his ailing health. I went to his house a week later because we had made an appointment to discuss his experiences with the medicines. When I arrived I received the information about his having been taken to the prayer camp. When I enquired further, his mother (who knew about his appointments at the hospital but not about his infection) explained that:

It all began when he started talking to himself. You would find him talking but when you go to see whom he is talking to, you realize that he is alone. I am worried because he seems to be talking to strange people.<sup>3</sup> He picks petty quarrels and wants to fight everyone. He’s grown so aggressive within this short period. At night he gets bad dreams. He shouts a lot ... and sweats throughout. He has gone wild and no one has managed to tame him. So he was chained and sent to the prophet.

Another time, during a visit to St. Patrick’s Hospital, I encountered another person on ARVs behaving in a similar way. He was wild, agitated, sweating profusely, talking dirty, and looking visibly unkempt. He had to be held in order to sit still and arrangements were made for him to see the doctor before his appointment was due because he was causing pandemonium at the centre. Josephine, one of the nurses at the hospital, matter-of-factly stated that suffering from hallucinations was “a normal reaction to the change in the [body] system due to the medicines. It will stop after about a week. If it doesn’t we may have to change the drug combinations.”

Unfortunately for some, intake of ARVs did not correspond with any improvements in health. Some recounted that on the contrary it rather hastened their dying process. Asantewaa noted how she found herself not getting healthy, and

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<sup>3</sup> Agyei’s mother later told me in confidence that she feared that her son was dying, because it is believed that some people die before their physical death. During this liminal stage – of being neither fully alive nor fully dead – the person concerned is believed to have the ability to talk to “residents of the other world,” exhibited in the overt action of talking to oneself. This action, of talking to the spirits, immediately precedes death proper. This was therefore the concern and worry of the woman, that her son was almost dead.

yet not dying: “They [the health workers] say I will get better. I was hoping so but now I want to die. I don’t like the state I find myself. If I will die, let me die. And if I will live, let me live. Now, I am dying but not dying.” Asantewaa’s condition of health was poor when she started taking the medicines, but later she developed some “serious stomach and abdominal aches.” She could not eat because she vomited everything that “falls into the stomach.” She continued to grow thin and emaciated. Her hopes when she started taking the medicines – to get back on her feet again and live like she used to – were quashed, and she now prayed for death. For Asantewaa, and others like her, the medicines were keeping her alive though her condition was not improving. “It’s like slowing down your dying,” she noted. Various persons were found to have resigned themselves to their fate because of the effects of the medicines.

The symptoms of the HIV infection and of the ARVs, many of which were glaring, resulted in suspicions among family, close associates, and community members about HIV being the possible cause of the person’s suffering. These HIV positive people therefore suffered a degree of social death (as described in Chapter 3), including loss of status and respect, while they waited for the end-stage of death, the physical death.

### Between normalcy and abnormality

The majority of PLHIV who responded well to the medicines mentioned that they hovered between normalcy and abnormality, since through ART they had become “normal and yet were not quite normal.” Although in some ways their lives returned to normal, something had changed fundamentally due to the infection and the therapy, culminating in their inability to do everything that they used to do or wanted to do. Firstly, the prime reason they gave for this was the continuous physiological, psychological, and clinical discomfort, mainly brought about due to the effects of the medicines (as discussed above). They experienced feelings of uneasiness and reacted negatively to the medicines, especially during the very early periods. Within a week or up to eight weeks or longer the ill body gets used to the medicines, but not without associated feelings ranging from mood swings and headaches, to overt symptoms such as skin rashes, diarrhoea, and frequent nightmares, or in some cases death. Other serious sicknesses found in the field, such as asthenia, insomnia, and hallucinations, could be linked to the side effects of the medicines, though all could also be attributed to opportunistic infections as a result of the deficiencies of their immune systems.

Secondly, for the majority who were not displaying these overt symptoms of being HIV positive, this feeling of being “normal yet abnormal” came about because of some of the rules and regulations given to them as part of the therapy. They are normal because “the infection is not written all over [us] as it used to”

and they are “able to live without any [health] hindrances,” and yet abnormal because “[we] do not have the freedom to do all the [social] things [we] used to do.”

Thirdly, they also noted that societal antagonism against people suspected to be infected – looking down on them and in most cases shunning their company – also emphasized the fact that they were normal and yet abnormal. The following therefore discusses how HIV positive persons who were responding well to antiretroviral medicines experienced the treatment. It considers their experiences: with the side effects of the medicines; of being “normal but still fighting on;” of the rules and regulations, with special emphasis on ‘sleeping’; of normalcy as a sense of security; and finally of the negative responses from others to (i.e. the societal backlash against) asymptomatic HIV positive persons.

#### *Normal but still fighting on*

Even for those who responded very well to the medicines, it was not uncommon to see or hear them complain about one ailment or another. Muscle aches, skin rashes, and loss of appetite were most prominent in the complaints, though it was also observed amongst those who were relatively new to the antiretroviral regimen that they suffered from nausea, vomiting, and diarrhoea. A critical observation notes that all of these may be side effects of specific drugs or drug combinations, and rightly so some of the PLHIV were told that their ailments would subside over time. Those who had all manner of ailments felt disappointed since the medicines “lacked the ability to make them illness-free.” They reckoned, however, that their present condition was still better than prior to starting the medicines. Ruth explained:

I am feeling much better than I was four months ago. I am not fully fit as you can see, but I thank God for how far He has brought me. My major problem now is that I cannot eat well. One, I don't have appetite. And [two] when I force myself to eat, then I will vomit everything. When the food falls into my stomach then I will run [diarrhoea] till there is nothing more in my stomach. At times, I feel like I am shitting my intestines out. I have complained to them [at the hospital]. They keep giving me some medicines and telling me that it will be fine with time. In fact, it is much better, but I am still not as normal as I would want to (*me ho nto me sɛdea mepɛ no*).

The PLHIV did also express a level of hope for better health conditions. Musa, who had been taking the medicines for a little over a year and had had serious problems with skin rashes (shingles), also mentioned that “I hope things will get perfect very soon since I have come a long way up till this point and the journey left is but a little more. I never believed I can stand again on my feet so I will keep fighting on.”

For all the respondents followed extensively, the intake of the medicines was like a daily ritual. Even though they considered the daily intake of the medicines very arduous, most of them were motivated by the fact that they saw an im-

provement in their health situation, as Musa's case above illustrates. They therefore made every effort to continue taking the medicines. Kaakyire also noted that taking the medicines had made him more conscious about time, and he had bought a watch for the first time to adhere to the strict regime.

Because of the medicines, I bought a watch with an alarm so that it reminds me when it is 7am and 7pm. That is when I take my medicines. Even when I have to leave home before that time in the morning, I put my medicines in my pocket and when the alarm rings, I buy 'pure water' and swallow it. Now, when it is time to take the medicine, my body feels it and when I look at the watch, I will realize that it is two or three minutes to time.

Due to the exact times at which they have to take their medicines, as seen in Kaakyire's case above, the PLHIV claimed that their bodies had gotten used to taking the medicines, to the extent that some reported that when they did not take them on time they felt "uneasy" and "restless." Achiaa narrated her experiences:

I have to eat and take my medicines on time. If I have not eaten by 8am, I have to take my medicines before I will feel okay. Otherwise, when you see me, you will think that I am a little girl who cannot control her hunger. I sweat a lot, and I can neither sit nor stand. I just have to eat or take my medicine to be okay.

The major fight that all the HIV positive persons mentioned – and some complained about – was the fact that they must take the medicines for the rest of their lives. "So, will I be sick for the rest of my life?" "Won't there ever be a time that we will have to stop taking these medicines?" "Is that all the doctors can do for us?" were some of the nagging questions that the people on medicines kept asking. This problem was even more severe for the children taking the medicines. They cannot comprehend fully the situation they find themselves in, but nevertheless they will have to be on antiretroviral medications for the rest of their lives (as long as there is no cure). Linda, who had a five-year-old son who had been on the medicine for about a year, was always worried about him:

At times, he protests that he will not take the medicines again, and I wonder what he will do when he grows a little older. I feel sorry for him that he must take all these medicines, unlike the other children he plays with, but what can I do?

#### *Normalcy: Sense of security?*

Interestingly, some of the PLHIV expressed the thought that being on the medicines and getting back on their feet also secured them from infecting others. These feelings were based mainly on rationalizing the information they heard during the sessions at the ART centres. Abiba noted that she was told that:

HIV was more potent during the early stages of the infection and therefore an infected person has to be careful even when practicing safer sex. However, being on medicines reduce the viral load to a minimum depending on how positively one reacts to the medicines, and also the person's nutritional intake. ... if you want to get pregnant, then there is a particular level your viral load has to drop to, and as you continue taking your medicines, the probability of transmitting the infection [both to the partner and the baby] would be minimal. If all these are true, then I can confidently say that the medicines, though they do not wholly cure

you, secure you from infecting others. Why is it then that they say we cannot have unprotected sex?

Egya also explained that:

After being on the medicines for some time, everything feels normal. You can do whatever you wish to do because you are again very healthy. It is at this point that you tend to doubt whether you were really infected in the first place. For me, I don't stop taking my medicines. Because I don't get sick anymore and I am able to do everything again, I feel it is very unlikely that I can transmit this thing. I may still have them [the virus] in me, but it is not that much and [not] powerful enough to be able to get into others.

The implication of these ideas, as expressed by the HIV positive people, is that after becoming well again due to ART they may not need to 'sell their sickness', since they no longer feel sick and may even doubt the continued presence of the virus in their system. Several scholars have shown the link between early use of ARVs and a decline in transmission rates. For instance, Granich *et al.* (2009) used a mathematical model to show how once receiving antiretroviral medicines, the infectiousness of HIV positive persons falls to one percent of their value before treatment.<sup>4</sup> As a result of such information and ideas, HIV positive persons may knowingly engage in unsafe sexual practices, although not with the specific intention of spreading the virus, and such ideas may have implications for adherence to treatment and in terms of drug resistance.

During an informal discussion on the side effects of the medicines and associated ailments, some nurses in Offinso mentioned that most of the people taking ARVs were not adhering strictly to the rules. Clients at the facilities are advised about 'healthy practices' including hygiene (personal and domestic cleanliness), diet (encouraging certain dietary habits while prohibiting the intake of certain foods), social behaviour (such as not engaging in quarrels and not worrying about their condition), spiritual life (joining a religious group and praying), and medical advice (such as regularly taking the medicines, and abstaining from alcohol intake and unprotected sex). Non-adherence to any or all of these prescriptions, according to the nurses, comes about when the PLHIV regain their health through ART after battling with various opportunistic infections. Nurse Rose explained:

This [state of feeling normal] makes them complacent. It makes them forget all the toils and distress they endured. Indeed, good living brings forgetfulness (*Eye ampa, asetena pa ma awerefire*). If you had seen them on their dying bed, you wouldn't believe what you see now ... that they don't want to listen to common instructions.

Specifically, the nurses also mentioned that some of the PLHIV drink alcohol, take the medicines on an empty stomach, and most especially miss doses.

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<sup>4</sup> This calculation was made on the basis of the relationship between plasma viral load and antiretroviral medicines, and estimated decreases in viral load for people receiving the medicines.

When you do these things, the medicines do not work well. They rather cripple you. The viruses behave in extremely different ways and the effects are what you see in the clients. When they come here we advise them, but they go home and do other things. It's unfortunate but a lot of them are dying just because they don't listen.

These behaviours, that may result from the false sense of security brought about by improved health as a result of the ARVs, were so widespread that Nurse Josephine once retorted that she was no longer interested in working with these clients, because "they end up bringing all our toils to Cos 90 [zero]. It just becomes a waste of time." A visibly frustrated and angry Josephine explained:

In this work, you are encouraged when you see that, through your efforts and the grace of God, someone who came in almost dead is now back to his [or her] feet. You know how most of these people came in. You put in all efforts. You spend extra time and money. You try to let them feel like living again. You talk to them. You visit them at home. Some do not welcome you and chase you away. You do all these to let them live. And then, they choose to die. They don't listen to you anymore. It's very sad and unfortunate. The more it happens, the more you ask yourself whether this whole work is worth it.

In the homes of these HIV positive people, these problems mentioned by the nurses were very obvious. Especially among the men, when they became 'normal' again it was not uncommon to see that they resumed their drinking sessions with friends. It was found that they did so as a means to debunk earlier suspicions of their infection, to show that whatever people thought about them earlier when they were sick was not true, and that they were still "normal as they used to be." Maame Amponsah, in the same conversation as cited in the introduction, narrated how her husband Daniel (who was also taking antiretroviral medicines) had changed all of a sudden and was now "misbehaving" and "taking to his old habits of drinking and chasing women."

He gets so drunk that he at times forgets to take his medicines. When I confront him, he gets angry and at times violent, so I am scared to do that again. He is killing himself because he wants his friends to think that everything is well with him ... but that is killing him.

Maame Amponsah further explained that she could not discuss the issue with anyone since neither family nor friends knew anything about Daniel's (and also her) infection, and she did not want to talk to the medical personnel as Daniel might think that she had reported him. Armed with this information, I asked Daniel about his behaviour and its relationship to his compounding ill health, but he avoided all attempts to delve into these habits. Even at a later stage of the research when I often found him tipsy, he only confided to me that "I go out with friends and also drink a little." He knew that "the alcohol may be contributing to my random ill health," though he still maintained that he did "not miss taking his medicines." Others were found to have missed their appointments at the ART centres due to drunkenness. Their concern was mainly to live without the societal or health constraints linked to HIV, just like other (HIV negative) persons.

Although, together with their families and friends, the PLHIV were extremely delighted about their improved health as a result of ARVs, they still wished that things would improve further. They desired to be like they used to be. They hoped for a time when they could enjoy life without any limitations and that their activities and behaviours would not be scrutinized by family, friends, and the general public. Being normal as a result of the ART, however, can be said to give some PLHIV a false sense of security that all is well, leading to non-adherence to the advice of the medical personnel. This eventually caused some of the people on medicines to die.

### *Sleeping in spite of death*

Another area of concern for those who were responding fairly well to the therapy was their sex life. A significant percentage of the men were very concerned about their apparent loss of sexual drive after they had begun taking the antiretroviral medicines. They expressed worry about how they had lost all feelings for engaging in sex, particularly during the early periods of being on the medicines. Once, a worried HIV positive man asked whether it was a deliberate attempt by the whites (i.e. the producers of the medicines) to stop them from having sex. Observations, information from gossip, and other complaints received from close associates of HIV positive people, however, showed that those who had been on the medicines for some time (at least six months) and had regained their health did engage in sex like they use to.

In contrast to the earlier periods, where those on medicines felt that they had lost their sex drive, this return of their sex drive and the desire to have children was linked not only to their intention to continue their lives as they used to, but probably to test their newly achieved ‘normality’ when the opportunity arose. A number of those on antiretroviral medicines were found to have made their partners pregnant, without any serious pressure from those in their environment to do so. For instance, Anokyewaa (a mother of five and on antiretroviral medicines) became pregnant to Opoku’s eighth child after “he was able to have sex again even though [they] had agreed they would not have children again.” I did not obtain Opoku’s opinion on this matter since he could not honour the several appointments we had made. However, his wife Anokyewaa indicated that:

Ever since he was able to do it [have sex] again, he wouldn’t let go. He demands it more than before. Even when I tell him I am not safe, he does it. He thought I was using it as an excuse because we had decided not to have any more children. And he is not worried that I am pregnant. In fact, he is rather happy (*Sé me mmoa, meka se n’anigye mom*).

As discussed in the following sections, the reasons given for ‘doing the don’ts’ were mainly the desire to fit (back) into society, to feel human again, to achieve personal aspirations for life, and to a lesser extent to test their normality. Signifi-

cantly, the case material also suggests that HIV positive persons taking ARVs do these things, including having (unsafe) sex, as a coping mechanism to withstand societal pressure.

It is often reiterated to clients during pre- and post-test counselling sessions how they should practice safe sex, mainly by way of abstinence and condom use, in order not to infect others and/or re-infect themselves. To the clients, however, it was a huge challenge to abstain when people in society expect otherwise. Similarly, condom use is also difficult because of its association with promiscuity and spoilt morals (Bosompra 2001, Anarfi 2003). Kaakyire, for instance, had to live at variance with his sister's wishes, who felt that he was "recuperating and so must re-live [his] life to the fullest, including getting married and possibly having more children." Since his sister was not aware of what was actually wrong with Kaakyire – because he had not disclosed his HIV status to her – she and some other family members mounted incredible pressure on him to get a woman to live with.

She started inviting some of her friends to our house and [virtually] forcing them to come to my room and get to know me ... you know what I mean? Initially, I would just sack them by telling them I was busy or sleeping or something else, but they wouldn't stop coming. Later they started coming home when I was alone but I tried to put them off. Can you believe they misinterpreted my actions to the extent that one day my sister told me they were asking whether the sickness I had and the medicines I was taking had made me lose my manhood?

To Kaakyire – and this epitomizes the possible reactions of many men – challenging his manhood "was the worst thing any woman, whether your friend or relation, could ever think of for a man." He could not stand it. To prove his manhood he started living with one of the ladies, "with the hope of eventually marrying her." Kaakyire's case is not an isolated one, and many other cases corroborate his story; it shows how people have to navigate between social norms and expectations and their own conditions. Oftentimes, they do not have much success in having their own way and follow societal expectations instead, even though these actions may consequently affect both the individual and society as a whole.

At the time of fieldwork, Kaakyire had a farm and was growing assorted vegetables, including carrots, spring onions, lettuce, and cauliflower. As a result, he was thought to be capable of catering for the needs of a partner and children. It was therefore not surprising that a lot of women, especially the unmarried ones, wanted him after his recovery from his serious ailment and "delivery from the hands of death" (they had all seen him go to the hospital having been paralysed by the HIV infection). For young men like Kaakyire, living with a woman was meaningful to them. It meant that they were responsible, which came with a higher status and respect in society. For the young women living with HIV,

getting a stable partner showed even more that they were decent and good for marriage, since being single was usually associated with prostitution.

From the communities studied, it was found that societal norms and expectations had a way of putting pressure on individuals – who were good looking, or who had stable jobs and were therefore independent – to take on a partner. From Kaakyire’s case, for instance, three ways come to the fore: family and friends constantly echoed the idea of him getting married; he received recommendations of women who were deemed good for marriage; and the women themselves took the initiative to let him know that they were available.

The fact that the majority of the PLHIV in this study were in the prime of their lives, combined with the expectations from society, could explain why these currently healthy persons chose to remain normal by hanging out with friends, having (sexual) partners, and having (more) children. According to Ghanaian tradition, marriage is a sacred duty and every adult is expected to marry in order to extend the lineage. Anarfi (2006: 170) notes that in Ashanti communities, marriage is “accorded much respect, mainly because it confers respect upon the people who enter into it.” Gyekye (1996: 76), in his essay on African (in fact Ghanaian) cultural values, and writing on the subject of marriage, also observed that:

... an unmarried woman [in African societies] is almost an anomaly. Marriage is a requirement of the society, an obligation every man and woman must fulfil, a drama of life in which every man and woman must participate. Traditionally in many African societies, a young man who has a gainful employment of any kind and earns some income is expected, in fact, to marry. Any undue delay on the part of the young man to marry will cause his parents or the elders in the lineage to worry and even interfere in his private life in order to advise and encourage him to marry.

Gyekye further notes that among the Akan, if a man has reached the age at which he is expected to marry but does not do so, or is not seen as making attempts to do so, he will be regarded as *ɔkwasea*<sup>5</sup> (a fool). One of my informants, Eugene (not HIV positive), even said that among people in the communities in the Ashanti Region, such a person would be regarded as highly irresponsible (*ɔkwaseampanin* – ‘elder of fools’). This expectation puts pressure on the youth to get married when they are of age, although it is observed that increasingly many women and men do not marry until later and there is evidence of an increase in single mothers because of the absence of men, since the latter may not be financially ready to settle with the women.

These pressures to marry notwithstanding, it was evident from the lives of the PLHIV in the study that although they wanted to abide by the counsel of the

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<sup>5</sup> According to Gyekye, the term *ɔkwasea* has a moral rather than an intellectual connotation. It means one who is irresponsible, worthless, good-for-nothing, and contemptible, rather than one who is simply unwise.

medical personnel (to abstain from unsafe sex, for instance), it was difficult for their families to understand – why would a ‘normal’ person decide not to get married and have babies? These conflicts between norms and realities are rooted in traditions. Societal expectations force some HIV positive men and women to navigate between these traditions and the counsel from the medical staff, which oftentimes are in opposition. For example, as described above, people in society expect every young person to get married and have children, and if they do not they will be classified as irresponsible or a fool, while the medical staff’s advice is that they should abstain from sexual relations or at least use a condom (thus seriously curtailing the possibilities for marriage and children). Making the decision to not get married and have children is often considered highly unacceptable by a person’s family and members of the community. Like Kaakyire, the majority of PLHIV had to consider what was ‘safe’ under the circumstances. Some went ahead and followed the medical counsel, while many engaged in sexual activities and made babies.

Especially for the youthful, unmarried or recently married, and industrious HIV positive persons, being unable to disclose their sickness brought untold pressure from family and friends for them to live normal lives by having partners and/or children. They were therefore caught in a dilemma: whether to live normally while being abnormal, or to be normal through and through. Oftentimes, they were found to have succumbed to external pressures and to have opted for the latter. On one occasion, Ahoɔfe (as mentioned in the introduction of this dissertation) confessed to me while conversing on the phone that she would not mind having a baby, even if it meant that the baby would also be infected. She explained that “If I give birth today and the baby dies tomorrow, I don’t mind. I’d be very happy. After all, everyone will know that I also gave birth but s/he died (*Anyɛ koraa no, obiara behunu se menso mewoo ba ma no wui*).”

The HIV positive people were under a great deal of pressure to live up to societal expectations, and often this pressure posed a great challenge to them. During my visits to PLHIV, and at PLHIV association meetings, many women were found to be pregnant or carrying babies. Most had not disclosed their positive status to their husbands. Some did not even know about their pregnancy until it was quite late in its term. Dapaah (2012), who was my colleague researcher in the hospital, reported for instance that Patricia only realized that she was pregnant during the early period of her last trimester. She had frequently complained about problems in her abdomen and a distended stomach, but brushed away all suggestions by the medical staff to have a pregnancy test. One of the side effects reported with HAART<sup>6</sup> combinations, especially the protease

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<sup>6</sup> When several antiretroviral medicines, typically three or four, are taken in combination, the approach is known as Highly Active Antiretroviral Therapy, or HAART. HAART decreases the amount of the

inhibitors, is the uneven absorption of body fat and other nutrients, known as lipodystrophy. The symptoms may include high levels of cholesterol and other fats known as triglycerides, which may make the HIV positive person feel very tired and generally ill. Other symptoms are a swollen belly, enlarged breasts, loss of weight in the face and loss of muscle in the arms and legs (so that the person looks very thin). Most of the HIV positive people in Offinso had distended tummies as a consequence of the medicines, and Patricia felt that hers was also the same. She was only proven wrong after a pregnancy test was finally conducted.

The affairs of the female PLHIV were more glaring because of the visibility of carrying a pregnancy, though the men were also found to be engaging in (unprotected) sexual relationships. From listening to gossip among the PLHIV, some of the men taking ARVs were said to have impregnated their spouses. During the latter stages of fieldwork, for instance, Ahmed's wife was found to be pregnant. I later came to understand that because Ahmed had not disclosed his status to his wife, he was hoping that when she went for antenatal care "she would be found out" (through the PMTCT programme). He explained that "since there are medicines to manage the situation, when they catch her too [diagnose her as HIV positive], she will also be put on the medicines, and they [mother and baby] will both be okay." In Ahmed's case, he was not found to be under any (societal) pressure to have more children since he and his wife already had four (three sons and a daughter). From the above quote, however, it may be interpreted that the action of getting his wife pregnant may have been his way of disclosing to her. A significant number of the HIV positive persons were also found to be engaging in such 'normal' behaviours, but with little social pressure.

This desire to be normal in society – just like everyone else – ensured that most HIV positive people chose not to reveal their sickness to others (see Chapter 4). Oftentimes, I came to understand that the partners of the PLHIV in the study did not know about the latter's HIV status. It was therefore unsurprising that many of the HIV positive people who were relatively healthy became pregnant or made their partners pregnant. Most of the clients were bewildered as to why they could be 'normal' again in most areas of life, but when it came to their sexual relations they "would have to always think twice" and "use condoms when having sex with even your spouse," as Mr. Nkansah put it. As seen in this section too, some of these HIV positive persons succumbed to societal expectations and resorted to 'sleeping' in order to be found 'normal' again by society at large. The case material also suggests that some of them were 'sleeping' in order

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active virus and rebuilds the immune system. If an HIV infection becomes resistant to standard HAART, there are limited options. One option is to take larger combinations of antiretroviral drugs, an approach known as *mega-HAART*.

to experience the ‘normal’ human feelings and emotions of being a man or a woman – being in relationships, having (unprotected) sexual relationships, getting (someone) pregnant, and having babies (as seen in the case of Ahoofe above, who wanted to have a child even if the child would die the next day). Sis Ellen (whose case is outlined in the introduction) also displayed these feelings when she lamented that “if all is well with me, at least overtly, why can’t I get a partner, and have my own family?” Remarkably, the material further suggests that some of the PLHIV used their current status as ‘normal’ to resist society’s pressure. The following sections are dedicated to the HIV positive persons’ encounters with society at large.

### The cost of being ‘normal’: A struggle within society

A significant number of the HIV positive persons in this study claimed that they refused sexual interactions, marriage, and other promising opportunities because they did not want to infect others. Although some succeeded, a number did not. Maame Mensah, for instance, had just lost her pregnancy after some complications when she got to know that she was HIV positive. During my first conversation with her some weeks after she had received the news, she blamed her predicament on a curse, since a friend during a feud had told her “You will see (*wobehunu*)!” About six months later, however, she reckoned that her husband might have infected her. “He is a public figure with much power and authority, and many women want to have him,” she said. Although she trusts him very much she claimed that sometimes she “just knows that he is sleeping around.”

Maame Mensah had not told her husband about her HIV positive status because she claimed that if he found out “he will kill me, and then kill himself too.” She had therefore rejected all attempts by the professionals at the ART centre to get him to come in and also take an HIV test. Initially, she told her husband that she could not have sex because of the effects of her health condition – she was visibly ill, looked extremely pale and wasted, and was bed ridden. Her husband had therefore allowed her time to recover without any sexual intercourse. After taking the antiretroviral medicines for a while, Maame Mensah had become healthy again but did not want to infect him or re-infect herself, and thus she did not agree to have sex. But her husband could not wait any longer: “He raped me over and over.” Maame Mensah had on two different occasions called me after midnight to sobbingly tell me what had happened.

Several accusations were heard from the HIV positive people and from some members of the community about people they suspected or knew to have the infection, who were having sex with unsuspecting others. As noted in earlier chapters of this dissertation, the majority of the HIV positive persons in the study who were accessing therapy had not informed their sexual partners about their

infection, yet continued to have sexual intercourse with them. In some cases, however, the partners were found to be unwillingly stuck in the relationship, even though they knew their spouses to be HIV positive. They were thus very conscious of the importance of practicing safe sex. An example of this is the husband of Memunatu, who had wanted to divorce her after she told him about her infection. But because they owned a large cocoa plantation together on her family's land, the divorce never took place. Memunatu's husband felt that he would lose the property and go broke if he separated from her, so he reluctantly stuck to the marriage. Although Memunatu knew that he had grown indifferent about their relationship and had other sex partners, she was content with the current situation as he was satisfying her sexually and keeping her status secret.

There were other incidences of members of society who may not necessarily have gone for the test, but about whom people had ample evidence to suspect that they were infected (see 'Other ways of getting to know' in Chapter 3). Some clients at the ART facilities were also found to be careless and to knowingly have unprotected sex, which gave support for the commonly held perception that HIV positive people "do not want to die alone" and thus indiscriminately infect others. The following discussion is about those who were perceived to be consciously spreading the infection.

Mama Sofu had lost her husband from a previous marriage and as a result was finding it difficult to cope with the demands of raising five children single-handedly. Though she received infrequent support from both her own and her late husband's family, it was still not enough to make ends meet. She explained:

That was when Bonku came into the picture. Because he was an old man I didn't think he was *basabasa* [one who messes about] so we didn't do enough checks on him. He comes from my mother's village so when my mother okayed it, it was just a matter of time and he would marry me. In fact, I thought he was too old to hurt a fly.

After undergoing a fibroid operation in the hospital in Offinso, however, Mama Sofu realized that her husband<sup>7</sup>, Bonku, had knowingly infected her with HIV. It was also after she was diagnosed as HIV positive that she realized that Bonku had already infected his first wife, who was sick and on the verge of dying.

It was then I realized that he needed a sexual companion at the time he met me because she [his wife] was dying. I later understood that he had refused all attempts by the hospital [that was treating his wife] to go for a test, and because he is a slim old man, nobody suspected that he would be positive.

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<sup>7</sup> Although Mama Sofu referred to Bonku as her 'husband', they were not formally married. However, because he was financially meeting her needs and those of her children, she was obliged to satisfy him sexually. This system is known as *asmpenatwe*, a publicly known relationship that is not formally ratified.

Mama Sɔfo explained that Bonku was not shocked when she told him that she had been diagnosed HIV positive.

It was like he expected it. He just sat there for some time; about thirty minutes. He didn't say anything. Then, he got up and went away. He didn't come back to me again. I sent for him after about a week. I asked them to tell him I was very sick and I needed money to go back to the hospital. He came the following day with some money. And then he left, and didn't come back again.

Since not every sexual encounter leads to an HIV infection, many people may lead a risky sexual lifestyle and still not be infected with the virus. However, if someone has had sex with a person who is later found to be HIV positive, they may no longer care to protect themselves, such as in Bonku's case with his first wife. They may become careless, not wanting to protect themselves, and will just continue to live a normal life. Even though at this point they may unknowingly not be HIV positive, there is the possibility that they may acquire the infection if they continue to engage in risky sexual behaviours in the belief that they could already be infected. The study found that some people engaged in risky sexual behaviours in the belief that they may already be infected. Many others also failed to inform their sexual partners about their HIV positive status. These behaviours pose serious questions about both individual and public health issues.

In addition, some of the HIV positive people were noted as being intent on locating others with whom they planned to have unprotected sex and thus transmit the infection to. From observations and listening to gossip, some of these HIV positive people seemed to have knowingly engaged in unprotected sex with others. During a PLHIV association meeting, for instance, an interaction between two members revealed this:

Member 1: So how did it go?

Member 2: Everything went well only that I feel a little bad about it now. Just after I got there, he got the news and he came. He was all over me; he just wouldn't give me any breathing space. So I gave it to him. I thought he would be surprised how I gave in willingly to him this time round, but I told you he is a fool ... he thought he was enjoying himself.

Member 1: It serves him right; he thought he has got it cheap ... little did he know that he was scooping it [the infection] (*ɔtwea, na ɔdwen se wanya no fo, na ɔnnim se ɔretete*).

Later, Member 1 explained that Member 2 had been living in her hometown until about two years ago when she moved to Kumasi. This was because the man at the centre of the conversation above had been harassing her sexually. After persistent refusal from Member 2, he arranged for a meeting and forcibly raped her. After the incident, the two families had agreed for him to marry her, but she loved another man who had promised to marry her prior to the incident. Her true love (the second man) refused to marry her, however, as a result of her humiliation from the rape. She felt disgraced and therefore left for the big city. She went home to the village about six months before the incident described in the conver-

sation above to find the man still pestering her, which made her leave again unannounced. She knew her HIV positive status and had been trying to avoid sex, as she had been counselled. It was when she came back to the city, and upon reminiscing, that she decided that she would teach this man a lesson the next time he pestered her.

According to Member 1, when Member 2 went home for her late uncle's (mother's brother) funeral, she expected the man to hassle her again and so she set out to "give it to him so that he gets what he deserves [the virus] since she blamed him for making her move out of her village and exposing her to conditions that culminated in her infection." The conversation I eavesdropped on during the meeting was therefore a report of the proceedings at the funeral. She went for the funeral and, as she expected, the man came to her and she gave in.

Informally, some of the clients also narrated how they suspected one person or another to have been the cause of their infection. Some vowed to make sure to pay them back by infecting other people close to them, mainly friends. Some of the HIV positive women in this study, however, noted that when men find them attractive and still unmarried, they "pester" them. When they cannot withstand the harassment anymore, they give in. Some of those who knew that they were HIV positive made all attempts to avoid sexual relationships with others in order not to infect them; giving in only occurred when they felt that they had no choice. Opokuwaa, for instance, said that she avoided all sexual relations with men until she could not handle her landlord any longer, as he threatened to evict her if she did not give in to his advances. She narrated:

When my rent advance ended, he [the landlord] said that he was going to double the monthly payments. He also said that he was no more taking a year's advance but for three years. I knew he was up to something, because he had been worrying me a lot. I had resisted up till this point. But I didn't have the money to move away from the house. I couldn't also pay the increment. So I gave in. It was difficult in the beginning. Now, I don't only live in the room for free, he even gives me money occasionally.

Further conversations also showed that Opokuwaa had given in to other people who had pressured to have sex with her. In one case, she said that she had lied to the man, telling him that she "was pregnant and collected GHS 70 to 'wash it out [abort]'. I tricked him (*Meyee no "azaa"*)."

This behaviour of some of the HIV positive people is not as contradictory as it might at first appear. The cases of Bonku, Opokuwaa, Kaakyire, Daniel, and Sis Ellen (who eventually married Mr. Sam without telling him about her HIV status) show that there may be more to it than malicious slander that some HIV positive people continue to have unprotected sex without their partner's knowledge. Indeed, these examples explicate the impossible situations and experiences of ambiguity that many people encounter after finding out about their HIV infection and taking ARVs, exemplified by the complaint of being

normal and yet not normal – looking normal enough to be pressured to have relationships and even marry, for instance, yet only doing so against their will. It needs to be stressed that in the majority of cases, while these HIV positive persons behaved in ways that may seem deleterious to societal cohesion, they only did so as a means of feeling safe in a highly unsafe environment, due to the repercussions of being found to be HIV positive.

These safety mechanisms notwithstanding, some PLHIV nevertheless experience antagonism from some people in their communities. HIV/AIDS causes tensions in society because of the perception of ‘intentional’ transmission on the part of infected people. This perception is aired via rumours in the media, which perpetuate the antagonism against PLHIV. During the course of fieldwork, for instance, a news report by the Ghana News Agency (GNA) from the Volta Regional capital Ho referred to some PLHIV deliberately spreading the disease.<sup>8</sup> The report alleged that they were taking advantage of their good looks to “wilfully engage in unprotected sex in the Ho Municipality.” According to the report, the target for the HIV positive males were Senior High School girls in town, while their “fashionable looking” female counterparts went in for middle-aged men with whom they had babies. This allegation supported a dominant perception held among the people in the communities in which I conducted fieldwork that HIV positive people “do not want to die alone” and thus deliberately infect others. Several people in the communities were suspected of having HIV, and their sexual behaviours were questioned and criticized in the communities. Women who were seen to be promiscuous were accused of having contracted HIV and of deliberately wanting to spread it by snatching people’s husbands. Men too were subjected to these accusations (see for instance Odotei 2006). Like Nsiah in the introduction, the majority of people who had reasons to suspect that a person was wilfully spreading the infection became infuriated.

Informal conversations with people in the communities – families and friends of HIV positive people, focus group discussion members, and other informants – showed that many of them (several of whom had not personally undergone counselling and testing) felt that HIV positive people subscribed to this fatalistic attitude and deliberately went about infecting others. Awo, for instance, mentioned that when these people find out that they are infected, no matter whether they are religious or not, “evil enters into their head(*adwenbone ba won tiri mu*). They then think that because someone had infected them they also have to do the same.” It is important to note here that this and all other negative perceptions of PLHIV are based on gossip and assumptions.

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<sup>8</sup> Story online at <http://www.modernghana.com/news/175841/1/danger-people-wilfully-spread-hiv-aids-in-ho.html>. Accessed on 24 July 2008.

These community members thought that current legislation was not enough to protect the general public. With this frustration looming, they often decide to fight back, as Awo shows:

You just have to protect yourself by keeping them away from you. When you do that, they say you are withdrawing from [stigmatizing] them. But how can you keep them close to you when it is obvious that they will give it [the infection] to you, and there is nothing you can do to cause them to be held responsible.

For those respondents who were HIV positive, they felt that legislation may not be enough to deter people from having unprotected sex indiscriminately, since any reporting of such activities by the victim would lead to loss of their privacy, disclosure of their own HIV positive status, and consequent stigmatization. Mama Sɔfo, for instance, lamented:

Later, after about a month, after things had gotten better, Bonku [whom she suspects to have infected her] came back again wanting to sleep with me. I refused. He doesn't come back very often these days. Now, when I ask him for money, he tells me how can he give me money and not sleep with me?

I have asked him to go for a test. He said even if the doctors come to his house he wouldn't do any test. I told him I would report him to the police, but he doesn't care. I hear he is now going after another small girl in the next village. This man is wicked. He knows I cannot talk about this, since if I come out and say it, everyone will know I also have AIDS. He is really wicked.

Speaking about those PLHIV perceived to be deliberately infecting others, the members of the focus group discussion in Offinso were also agitated at the fact that “the government is wasting so much money and resources to keep these evil people alive.” Although Awo had earlier lost a son to HIV and had firsthand experience of caring for an HIV positive person, she shared this opinion since she felt that “if all those who are found to be positive are quarantined ... it will go a long way to protect the rest of society from being intentionally infected.”

In a study by Adjei, Owusu & Ablordey (1993), which was based in the Ashanti and Northern Regions of Ghana, a large number of the focus groups participants held a similar view, that persons diagnosed as HIV positive should be surreptitiously injected with poison by the doctors so that they would not be able to spread the disease. For my carpenter informant, he found nothing good about the ARV medicines, since previously people who had AIDS were easily found out, making people more careful when relating to them. “Now they look normal like all other human beings and because of that they lure unsuspecting members in the communities and infect them.” Awo added:

Why are you [pointing at me while referring to the hospital staff] keeping these [HIV positive] people alive for them to come and worry us? Look at all these young girls around. They are walking here as if all is well. They are all carriers. Yet they won't stop chasing people's husbands. The medicines you give them are contributing to the spread of this virus. If people don't die anymore and yet they keep spreading it because they are chasing people's hus-

bands, won't the disease spread? Who will go in for someone who has a pitiable sight and is in excruciating pains? But you give them medicines, and no one gets to know that they are sick, and then they infect others. So whom are you helping? Which is better – to keep more people alive living with the infection, or let the few who have it die?

To Awo, and the other worried members of the community, quarantine would be one way of preventing HIV positive people from sleeping with unsuspecting members of the community and infecting them. Quarantine as a way of reducing the incidence of HIV has, however, been contested.<sup>9</sup> The reactions and seemingly antagonistic stance of the people in the communities, which may be classified as stigmatization, must be seen in the context of a society struggling to cope with the perception of the deliberate infection of others by HIV positive persons.

Others were accused of actually using the tag of being HIV positive to dupe unsuspecting members of society. One day as I travelled from Kumasi to Accra, for instance, I encountered a self-proclaimed HIV positive person who was soliciting money<sup>10</sup> to buy his medication. The man mentioned that he had been diagnosed HIV positive six months prior to our encounter and had lost all his life chances – his job and his family, while his landlord had evicted him. He mentioned that he needed GHS 7 to buy some food and medicines. He sounded convincing when using the medical terms – CD4 count, antiretroviral medicines, and drug resistance – though no one on the bus offered to help. He left a few seconds after his unsuccessful appeal, at which point a few people commented:

Passenger 1: Why would someone want to dupe others by pretending to be HIV positive?

Passenger 2: Say it again my brother! Couldn't he have found another disease, other than this scourge? Who in the right sense would, if indeed he is HIV positive, go about broadcasting it?

Passenger 3: And he is not ashamed ...

Passenger 1: That is what he is been doing. Today is the third time I am meeting him with this tale. The storyline is the same. He should pray that he gets unsuspecting people to part with their monies, not people like us.

The Public Agenda newspaper also reported the case of Charles Gardiner, a trickster who “duped many people using false pretences as an HIV/AIDS victim,” including the editor of the paper. Charles Gardiner was reported as

<sup>9</sup> For instance, Mensa-Bonsu (1995) questions the use of quarantine for people living with HIV when there are other infected but healthy looking persons who are equally or perhaps even more dangerous to the uninfected population. How can all HIV positive persons be found out without compulsory testing of all citizens? With what frequency would such mass testing be done in order to isolate those who become infected after mass testing? Can any country afford the expense of such testing with the frequency that would make the policy effective? These and other such questions, none of which have obvious or easy answers, render the prospect of quarantine an exercise in futility.

<sup>10</sup> In Ghana, it is not unusual for people to stand in buses as they load passengers or to ply the bus routes to sell goods (including books and medicines – traditional, herbal, Chinese, and biomedicine), solicit funds to treat a disability or ill health, or simply to preach from the Bible and pray with the passengers for a safe journey.

narrating stories about being “abandoned by his family” and being “sacked” as an engineer with Top Industries “after he contracted HIV/AIDS,” and therefore relied on the benevolence of strangers to assist him to buy his medicines from the Pantang Psychiatry Hospital. Such people exploit society’s negative attitude towards HIV positive people to try to make money.

## Conclusion

The expectation for a normal life course is that a child is born, reaches adolescence, marries and brings forth children, grows old living with the grandchildren, and dies peacefully. Even for the very old, death in Ghanaian society is considered abnormal and unnatural when it occurs due to sickness or other external causes (Owusu 2009: 43). People therefore refuse to prepare for abnormal death (Oppong *et al.* 2009). A very sick (and terminally ill) person would prefer to think positively about life, and pursue all forms of healing and cure, rather than plan for an organized afterlife after their demise. The logic that a dying person would “put her/his house in order” before the fatal day does not apply to such people.

For an HIV positive person, whose death warrant is perceived as signed when s/he becomes infected, death – as inevitable as it is to all mankind – seems to loom especially close. However, the extent of the housekeeping that occurs before the final event varies when it comes to PLHIV. This is especially true since the arrival of antiretroviral medicines, which to a large extent are effective at postponing the HIV positive person’s funeral. For the PLHIV, therefore, they have another chance at life. However, several people expressed fear that the use of ARV medicines will decrease transmission concerns among HIV positive people (Greeff *et al.* 2008) and will increase risky behaviours (see for instance Holstad *et al.* 2006). It is assumed by these people that death will come when it will, but until then there is a life to live – “Should we not sleep because we will die?” Some of the HIV positive people were therefore “sleeping in spite of death.”

The primary reason given for wanting to “sleep in spite of death” was because the PLHIV found themselves in an awkward position between normalcy and abnormality. The continuous physiological, psychological, and clinical discomfort brought about as a result of the medicines, and especially the many dos and don’ts regarding food, alcohol, and particularly sex and having children, made them feel abnormal. Yet for many the medicines had delayed their death and restored their health, and in the eyes of the public they were cured and therefore normal (again). Plummer *et al.* (2006) and Holstad *et al.* (2006) have noted that HIV positive persons and their partners may themselves believe that because their viral loads are undetectable and they feel so much better, the virus is absent

or dead and they are incapable of transmitting HIV to others. This was also found to be true for some of the PLHIV in this study, the ramifications of which were that some experienced their 'normalcy' as a sense of security and therefore did not bother to adhere to the rules and regulations. They did most of what they were not supposed to do, and did not do most of what they should do. Others used their seeming 'normalcy' to get money (for food, clothing, shelter, education, medicines, etc.) and gave in to pressure from society (to get married, have sexual partners, have children). Since most had not disclosed their sickness to others, they were compelled to live these normal lives, sometimes against their own volition. To them, the dishonour resulting from people finding out about their infection would be more bitter than keeping their status secret and "sleeping in spite of the death before them." To some others, this "extra time" bestowed upon them by ARVs was a way of avenging wrong deeds, for example through knowingly having unprotected sexual relations. Other HIV positive persons were suspected of intentionally spreading the infection to unknowing individuals, especially in the case of sexual and marriage partners who had not disclosed their positive status to their partners.

In all these cases, most people in the communities felt that people who are HIV positive do not want to die alone and would thus want to intentionally spread the disease. Some of the HIV positive people linked their infection to others who did not want to have the test. These attitudes of the PLHIV – to sleep in spite of death – because of pressure from society and also in some cases as retaliation to being infected, also contributed to the communities' ambivalence and hatred in most situations towards HIV positive people. This ambivalence was also observed among leaders of PLHIV associations and among some of the health workers, who observed that good living, a by-product of antiretroviral therapy, seemed to have brought about forgetfulness (*asetena pa ma awarefre*). The HIV positive people who were redeemed by the medicines were seen to have forgotten about their former state when they were dying from the infection, and were thus being less careful.

Some members of the community, out of fear of becoming victims of those HIV positive people who do not want to die alone, withdraw from all contact with them. This raises the obvious question of whether this act of 'withdrawing' from all interaction with HIV positive people is an act of self-protection or stigmatization. The answer obviously depends on the side one finds oneself on; the HIV positive persons feel it as stigmatization, while for the general public it is considered self-protection. This demonstrates the many complexities – especially the contradictions regarding the lives of the infected *vis-à-vis* the uninfected or untested – in the management of HIV where treatment is available. This chapter has shown how HIV positive people in particular navigate these

difficulties by making decisions in ostensibly impossible situations. Although in a few cases the PLHIV in this study were found to knowingly engage in unprotected sexual relations with the intention of infecting others, many were rather constrained and pressured by the expectations of living normal lives in society, and for this reason ended up engaging in unsafe activities.