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

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Blood and life: Money and the infection

Sika ye mogya
 Money is blood
 (Akan proverb)

Agyeiwaa lay moaning helplessly on the mat, her family clearly bemused as to the next course of action and feeling powerlessness to act. Her mother, Mama, told how the coffers of the family were empty and consequently their “precious jewel” was dying. Agyeiwaa had been relatively well-to-do prior to becoming sick. She had lived in Accra and looked after the family very well by regularly sending remittances to her parents and other siblings in the village, and also by taking care of the school fees of a number of her nephews and nieces. As a result of her sickness, however, she had sold everything she had – several pieces of cloth, clothes, jewellery, cooking utensils, and even the piece of land she had bought for the family to work on – in order to “get treatment for this inexplicable and strange illness” that no one in the family (but her mother) knew the exact details of. “All the sources of funds ran dry yet her condition kept deteriorating,” Mama explained.

... there’s no money to send her to the hospital when she has to go for a check-up [on appointment at the ART centre]. When she is not well, we don’t have any money to take her there [without an appointment]. Even as we talk, if she feels like eating something, we can’t get it for her. It hurts so much. She doesn’t eat but when she requests for something, at least, she eats a little. You see that she misses certain foods but we are not in a position to get her anything. See, just yesterday she asked for yams and *abomu*. I asked her brother to get some *kontomire* from our neighbours but they said they don’t have. I think they are tired of us begging all the time; today salt, tomorrow pepper! But what can we do. We don’t farm

anymore since all moneys have been channelled to help her. We even sold her land that was feeding us. Hmmn, *ohia ye yadee* [poverty is a disease].

Money played a central role in the lives of the HIV positive people in this study, as everything they did depended on it. One client termed it as *fa meko* (that which takes you along). This chapter contextualizes the role of money and its relationship with HIV/AIDS. This discussion will first make the case for the necessity of exploring the economic implications and financial needs of people living with HIV in general, and will subsequently discuss these issues in relation to the specific cases of the PLHIV in this study. The chapter concludes by looking at the ramifications of having or not having money and being infected with or affected by HIV.

HIV, blood, and money

For those who are sick or injured and who need a blood transfusion in order to survive, blood is life. Since HIV is known to be transmitted by blood – as well as through the transfer of semen, vaginal fluid, or breast milk – this fundamental life force becomes altered after infection. When a person is infected with HIV, their body responds by producing special proteins called antibodies that fight the infection. If the antibodies to HIV are detected in the blood through an HIV test, it means that the person is most likely to be infected with the virus.¹ Blood transfusions are therefore one way that people may infect others (although the risk of transmitting HIV through blood transfusion has been greatly reduced the world over, and in Ghana in particular). Blood, which is a source of life, can thus also be a source of illness. In effect, if you have altered blood, you have an altered life. This analogy is particularly true for HIV positive people, since most in this study had become incapacitated and unable to work, unlike prior to their infection, and thus their lives had been dramatically altered.² Being unable to work and earn a living meant that the majority relied on the benevolence of family and friends to meet their basic living expenses.

In general, lack of blood (both in terms of quantity and quality) has an effect on a person's life – *Se wonni mogya a, wonni hwee* [If you don't have blood, you don't have anything]. Blood donation can thus be seen as a valuable gift of life to

¹ Though the chances are high for the person to be infected, there are a few exceptions. For instance, babies born to HIV positive mothers retain their mother's antibodies for up to eighteen months, which means that they may test positive in an HIV antibody test, even if they are actually HIV negative. In addition, some people who have taken part in HIV vaccine trials may have HIV antibodies even if they are not infected with the virus.

² HIV infection does not necessarily incapacitate the infected. However, due to the fact that the majority of people in this study only got to the testing and treatment facilities at the end-stage of their HIV trajectory, by then most were suffering from several opportunistic infections, leading to their incapacitation.

save a dying person. However, for some people blood transfusion can be used to make money. Informal conversations with colleagues in Accra showed that some young men position themselves around the Korle Bu Teaching Hospital where they donate blood, for a fee, to desperate patients. For them, their blood is literally money; for the recipients, their blood is life (*sika ye mogya*). Speaking more generally, money is life.

In Ghana, there are unwritten moral requirements about how money is spent. Certain phrases and sayings highlight these societal expectations, and people play with the meanings of these proverbs and apply them to new situations: ‘No money, no friends’ (*Wonni sika a, wonni adamfo*) and ‘Money makes one a man’ or ‘Money be man’ (*Sika ye abrantee*) (see Senah 1997). In the case of the former – no money, no friends – this implies that when you have money many friends will help you to spend it, but when you lose the money they will run away. This idea is also expressed in the proverb ‘Money calls blood’ (*Sika fre mogya*) – if you have money, relatives will come to you, but if not, they won’t – and ‘Money is blood’ (*sika ye mogya*) – money, like blood, affects and determines the way people live. A poor man would be cautious in terms of what he spends his money on, but the moment he becomes rich this is reflected in changes in how (and about what) he speaks, reasons, walks, laughs, eats, drinks, dresses, etc. In effect, money is like blood, and one must have it in order to survive. For PLHIV, lack of money gradually but steadily sucks their blood, resulting in complications in therapy, ill health, and for many death. Indeed, money is blood, as the proverb goes, and if you have inadequate blood or if there is an alteration in your blood composition, you will get sick and eventually die. When you have money, you can live.

HIV is known to spread faster in regions where there is retarded economic growth and increasing levels of poverty (Farmer 2003). AIDS has been described as a disease of poverty, but it might be more accurate to describe it as a disease of inequality, which settles in the ever deepening chasm between rich and poor (Farmer 1999). The poor themselves know that money is at the root of their AIDS problem (Epstein 2007). Like Mama put it in the introduction to this chapter, “poverty is a disease.” In the eyes of the poor they thought that their problems would be solved with money; but among the relatively well-to-do many thought that money nevertheless does not guarantee everything. This chapter discusses the economic and financial situation of HIV positive people.

The economic situation

Available funding to support Ghana’s response to the HIV/AIDS epidemic includes about US\$ 6.7 million from the Global Fund to fight AIDS, Tuberculosis and Malaria (Global Fund); about US\$ 12 million from multilateral partners,

including the World Bank; about US\$ 8 million from bilateral donors; and fifteen percent of the Government of Ghana's annual health budget (UNAIDS 2005). The fact that these funds are being channelled towards HIV/AIDS interventions in Ghana notwithstanding, the economic situation of the majority of HIV positive persons in this study was dire and worrying. The majority were not working, and were thereby reliant on the benevolence of family, friends, and other support groups. A few still received wages and salaries from their labour, either by continuing with the same jobs as before they discovered their infection or in newer ones. This section is devoted to the economic situation of PLHIV, both the unemployed and the employed.³

Infected and unemployed

The majority of the clients said that prior to their infection they had been engaged in gainful employment and were very supportive of their dependents, as can be seen in Agyeiwaa's case and others to be shown in this chapter. A number, however, had used up their wealth in their search for treatment, which in most cases was not initially at the hospital (as discussed in Chapter 4). Many recounted how they had sold their belongings to finance such help seeking; mainly before finding out about their HIV positive status. Others had lost their employment because they did not have enough strength to continue as a result of their sicknesses brought about by the infection. Observations during the period of fieldwork showed that a significant majority of the HIV positive persons did not have any source of income. They were thus without means and relied wholly on the benevolence of others for their upkeep.

An occurrence during a visit to Konama's house highlights the economic situation of the majority of the PLHIV in this study. It was around 15:00 when I decided to leave for the next town to honour another appointment, after spending most of the day with Konama. Midway to the bus station we paused for a rather long talk, as I could not come to terms with her seemingly limitless show of appreciation – "Thank you very much!" (*Oh! Yeda w'ase paa*), "May God bless you abundantly!" (*Nyame nhyira wo, Ei!*), etc. Konama had earlier told me that for the past two years a young teenage girl had been helping her with her domestic chores – fetching water from a stand-pipe some hundreds of metres away, and also firewood a further distance away. I therefore gave Konama the equivalent of US\$ 2 to give to the girl in fulfilment of an earlier promise to reward her for her

³ Employed and unemployed are used here to refer to the person being engaged (or not) in a venture that provides an income. Thus it does not refer only to formal employment. People working on their farms, or in the informal sector such as in the quarries or selling along the streets, for instance, were all classified as employed. In fact, the majority of the employed persons discussed in this study were earning their money in the informal sector. Being unemployed meant that the person did not do anything to earn money.

continuous assistance. I had visited several of my respondents and I knew how hard pressed they were financially, but never imagined that US\$ 2 deserved all this praise – after all, it was not even meant for her – until I heard the whole story.

I usually keep lots of *gari*⁴ and sugar in my room since it is very handy to have and to mix for eating. It is also not expensive so with a little money you can have lots of it and eat over several days. The first day she [the girl] came to help, I gave her a little *gari* and some sugar, and since she hadn't eaten the whole day, she was so happy. She comes along every time she is free to help and I try to compensate her with the *gari* as and when I have it, because that is all I can afford.

For the past weeks, however, I don't have any money to buy food for myself. The *gari* stock has depleted and I cannot replenish it. You wouldn't believe that the last meal I had was yesternight when one of my mothers' cooked some yams and stew (*ampesi* and *abomu*) and gave me part.

So how do you manage with your medicines? I queried.

Oh! I still take them regularly. You see, the body is used to it now and does not really depend on food again in order to work. This morning I took them at 8:00, and in the evening at 8:00 I will take them again, whether I eat or not.

I suspended my other plans for the day in order to sit down with Konama under the *odum* tree that had been shading us from the scorching sun to share my snack for the day, and also to probe further. I gathered later that Konama had been what people in the community termed *premanni baa* (a sleek young woman). She had been young, beautiful, had had her own trade (travelling to Lagos to buy cloth for sale), was always dressed up, independent, and very supportive of her children and other family members.

I ate what I wanted to, went where I wanted to, and was really enjoying life. I had enough to give my family and so they respected me. Usually, I spent about a month in Kumasi where I was living after my trip from Lagos. Within this period I supply goods to my customers, collect my accrued debts, and then leave for Lagos where I spent most of the time. I however made sure that I am home during Easter, Christmas, other festivities, funerals and other family occasions. When I am unable to be here, I contribute substantially.

It was during one of such festivals that I had what was later diagnosed as Buruli Ulcer⁵. Uneducated as I am, I thought it was an attack [i.e. spiritual], so I went from one healer to

⁴ *Gari* is made from fresh cassava, which is grated and the excess liquid is squeezed out. The cassava is then fried over an open fire in a broad metal pan that has been greased with a little oil. The resulting product – *Gari* – is crisp and crunchy to taste, and is stored easily. It can be eaten with stew or soup or *shito* and fish. As used mainly in high schools, it can be soaked with water, sugar, and milk. It can also be used as a side dish at parties under the name *Gari fɔtɔ*.

⁵ Buruli Ulcer is an infectious disease caused by mycobacterium ulcerans. The early stage of infection is characterized by a painless nodule, with non-pyogenic necrotizing lesions developing in the skin and occasionally in the adjacent bone as the disease progresses. Buruli Ulcer is currently endemic in Benin, Cote d'Ivoire, Ghana, Guinea, Liberia, Nigeria, Sierra Leone, and Togo. In Ghana, Buruli Ulcer is more prevalent in the northern parts of the country. Data from 1999 put the prevalence rate of the disease in the Ga West District (in southern Ghana) as 87.7 per 100,000, higher than the estimated national prevalence rate of 20.7 per 100,000, though lower than in the most disease-endemic districts, where it can be as high as 150.8 per 100,000.

the other looking for a cure. By the time I got to the hospital, it was so serious my arm was amputated. In fact, it was a battle for my life, which I only won because God was on my part.

After about eight months to about a year, after the surgery, I started feeling unwell again and I haven't recovered since. It was during that period that I found out my status. I was told that I might have had it from the blood transfusion during the surgery since I wasn't positive prior to the surgery. That made me believe more that this whole thing was an attack. Foolishly, I started another sojourn from one healer to the other. I don't know where I haven't been to here in the Ashanti Region – prayer camps, shrines, *mallams*, etc.

I sold all I had because what is money at all; we came to meet it and we will leave it behind (*Sika ye den, yebeto ye, na yebewu agya ho*). I have gone several places searching for life, but it eluded me. When I finally got to the hospital, I had no source of income, I had no savings, I had sold all my properties including even my cooking utensils and mattress ... you won't believe it. Now I think in this situation, the lack of money will lead you to your grave. Now I have nothing. At times my daughter sends me some money and some few clothes. But look at me, I look like an old woman ... I don't even need the clothes, its money I need.

Later on I had the opportunity to see some of Konama's pictures (taken between five to seven years prior to my fieldwork) and the change was striking, particularly her weight loss. Once, we went together to the funeral of a late PLHIV in the next community, and looking at her dance in tune energetically to the current *hiplife*⁶ songs, not being overwhelmed at all by the vigorous body movements, I realized that she was more in tune with current trends than her looks portrayed. Konama was gradually losing the battle for fitness, however, and by the end of the first phase of fieldwork she was very sick. She could not buy any of the medicines that were not covered by the National Health Insurance Scheme (NHIS). She expired before the next phase of fieldwork, obviously because she could not eat well, buy her medicines, and also cater for the other needs of her family and community.

The cases of Konama and Agyeiwaa – who moved from grace to grass due to the loss of their jobs and earnings, the selling of property and belongings, and becoming financially dependent – present a common theme running through the life stories of many of the HIV positive people in this study, including the men.⁷ I observed several cases where people had sold their personal belongings or those of their care givers in order to meet some of their pressing needs, such as going to the treatment centres. A few months after the above described encounter with Konama, for instance, I saw her during one of my visits to the ART centre. She appeared unusually worried and her facial demeanour was uninviting. I could hear her disagreeing with one of the nurses as I eavesdropped. I became more

⁶ Hiplife is a Ghanaian musical style which fuses highlife and hip hop. Recorded predominantly in Akan, hiplife is rapidly gaining popularity across West Africa and abroad, especially among black communities in the United Kingdom, United States, Canada, Germany, and the Netherlands.

⁷ Though no rigorous efforts were made to establish the validity of these grace-to-grass claims, some substantial evidence was found to support them; for instance, Konama's pictures, and the respect shown by family members to Agyeiwaa, among others.

curious since that too was very unusual for her – generally she had a calm disposition and did not argue. I gathered from one of the nurses later that Konama had brought some pieces of cloth to sell to the nurse, who had offered a rather ridiculously low price, which set off the argument. Konama explained later that she preferred to sell to the nurses because they offer better prices compared to others in her community and they also offered ready cash. However, on this particular day she needed some money to buy food and medicines,

... but she [the nurse] refused to give me even half the market price. I felt it was not fair since I had budgeted for a bit more. In the end, I had to take what she could give me because I don't know who will buy it at a higher price.

Though in some cases the children and siblings of the PLHIV had taken the clothes that were not useful to them anymore, especially when they became sick and thin, a few of the PLHIV mentioned that they were lucky enough to get something for their belongings when they sold them, albeit in most cases at very low prices. Mama (Agyeiwaa's mother) explained how they had sold her land, including some yet to be harvested plants, for about half its value since they were in dire need to “find a cure for our jewel.”

In addition, some of the PLHIV lost their jobs during the course of their infection. Though other scholars have noted that stigmatization leads to loss of jobs where PLHIV are fired out of fear of possible infection of colleagues and financial loss to employers (see for instance Howley *et al.* 2010), none of the cases studied supported this. In this study, the PLHIV who lost their jobs were mainly those who could not continue working because of their ill health or their continuous excuses covering their visits to the health facility. Whether they would have been fired if their employers knew that they had HIV was not found out; however, informal conversations with members in the communities showed that many people would stop buying from a seller known to have HIV. Anecdotal evidence also attests to this fact: that people who are suspected of having HIV and those whose status has been made public – for instance Maakua, whose status was announced by her in-laws after the death of her husband – lose all their clients. Maakua sold various farm products – plantain, cassava, palm oil, pepper, onion, etc. – and explained that “... even after we moved to this community, nobody was buying my products.” Things changed for her, however, when the rumours were not accompanied by a drastic deterioration in her health:

Now they don't believe it anymore that I have HIV. It's been more than six years now since my husband died. They think that if I had it I wouldn't have survived up till now, so now they buy from me. Initially, it wasn't easy ...

Due to the fact that many had sold their properties and belongings – for some this included the tools for their vocation, lands for farming, and other implements – some of the HIV positive persons in this study were not able to return to work

again even after getting better. They did not have the money to buy back the tools they needed for work. Others were found to be too weak to engage in the usually labour-intensive vocations of the majority of people in the communities. They were thus rendered financially dependent on friends and family for sustenance and survival. However, some families found it extremely difficult to cope (as seen in the case of Agyeiwaa) since the HIV positive person had hitherto been their main source of income.

Infected and working

Another group, mainly those who had started treatment when they were not seriously sick, were still managing with their labour-intensive jobs and were relatively well off. They explained, however, that their current condition was not as it had been before they found out about their infection, “since they get tired easily nowadays” or “fall sick intermittently,” as Daniel and Ellen indicated. These problems notwithstanding, they were still very productive, and able to meet most of their financial needs. Ellen, who had a large palm and cocoa plantation, as well as several acres of other food crops and many farm hands, explained:

I was relatively healthy before I found out about my infection. I can't remember the last time I was at the hospital preceding that. Now, I go to the hospital, at least, once a month for my medicines. Once in a while I feel sick, with fever, headaches, and general body pains being the common symptom. However, I still haven't had any serious sickness to warrant admission at a hospital.

I still work very hard. I leave for the farms, as usual, very early and as you know we don't come home on time. Even for the Wednesdays that I go to the hospital [for ART] I still manage to go and supervise my boys. The crops are doing very well and I hope to expand the cocoa plantation next season.

For most of those in this group of employed PLHIV, their health had not affected their work much. “I break down here and there although just for a while, but I get back to business and work normally with time,” Abiba recalled. Even though in Ellen's case she was not involved every day in the strenuous farm work because of the many farm hands she employed, others, such as Daniel who worked in a quarry and for a building contractor, performed strenuous activities most of the time. As Daniel described:

My brother, how can I cater for all these children [he has five biological children and one step-child] if I refuse to do all these. I can't afford to be lazy. It is difficult but I have to do it. Every night, as I go to bed, I feel drained, as if I have had a severe beating, but I manage it sometimes with some painkillers [he takes ibuprofen very often] and I wake up refreshed for the next day.

They all mentioned, however, that the frequency with which they go to the hospital these days is much greater than before the infection. The fact that they

are able to earn money to buy food, medicines, and cater for other necessities could be said to motivate them greatly.

The majority of the HIV positive people in this group were involved in some form of trade, ranging from table top sellers to those who travel to neighbouring countries outside of Ghana to bring in goods for sale. A number of them, whose status was not known or suspected in the communities, were into processed food. Mapanyin, for instance, sold ‘red-red’⁸ beside the main Offinso–Akomadan road. She also used to sell ice water until her refrigerator broke down. During the construction of the main Kumasi–Offinso stretch in the first phase of the fieldwork, a number of these HIV positive people were also seen selling items such as boiled eggs and plantain chips. For these, the infection “may just have slowed them down for a while but they were still moving on,” as Ahoɔfe put it.

Those with a vocation, such as Massa (a teacher) and Abraham (a photographer), were still involved in it. Abraham, for instance, was contracted by St. Patrick’s Hospital to cover the activities of the World AIDS Day celebration organized in Offinso district. On the day he went there with his workers and covered all the activities, including the two-hour float parade through the streets of Offinso New Town and the three-hour durbar. He was also seen covering a wedding ceremony in Kumasi during the course of fieldwork, where I met him coincidentally. He later explained:

People like the quality of my work so I am oftentimes busy, especially on weekends where I cover funerals, weddings, naming ceremonies, and other occasions like parties. I have had to get more workers to help me out, but it is only due to the increase in demand; it has nothing to do with my health.

The relatively healthy conditions that some of the PLHIV were able to maintain ensured that they could continue to work to earn an income, without the necessity of selling their sickness.

Remarkably, some PLHIV were found to be using their HIV positive status as a way to make a living. These were mainly those who had been among the first to start therapy at Komfo Anokye Hospital and who had trained as peer educators to assist in the treatment facilities. In the hospital they answer all questions that are otherwise not attended to by the health workers.⁹ These peer educators are also used for HIV/AIDS campaigns to testify about their lived experiences of being on ART. They receive invitations for conferences and other workshops where they are given very good compensation for their efforts. Some of the PLHIV had set up their own associations, and when their proposals are successful they

⁸ Red-red is a popular Ghanaian dish consisting of boiled black-eye beans in red palm oil and tomato sauce, served with fried ripe plantains, so named probably because of the combination of the fried red plantains and the red palm oil.

⁹ The activities of the peer educators in the hospital are discussed extensively in Chapter 6 in Dapaah (2012).

receive large sums of money that they use for the associations' activities and their remuneration as officers. At times, the invitations for workshops and conferences are extended to these associations; the leaders of these groups, who have sold their sickness, often grab these opportunities to attend and to receive the remuneration.

Chief Appiah, a peer educator, founder and leader of one of the PLHIV associations, and an executive of the Ghana Network of Persons Living with HIV and AIDS (NAP+) in the Ashanti Region, explained that due to the HIV infection he has had the opportunity to travel to several countries outside of Ghana and even outside Africa.

This time I travel a lot. Last year I was in Uganda for a conference. This year too, we will have one outside [the country]. As for internal workshops and conference, they are too much. Most of the time I am unable to attend. I have slept in some of the best hotels in Africa. As I talk to you, I am currently on the payroll of one of the international NGOs in the country. I offer consultancy services for them, and I always go and present myself as a PLHIV in most of their programs. I think I am getting more money now than before [the infection].

Some of the HIV positive people, like Chief Appiah, have turned peer education into a career. Indeed, their activities as peer educators support them greatly, providing not only for their own sustenance but for their dependants too.

In addition, during the visits to the ART centres, it was observed that some of these HIV positive people were engaged in both buying and selling at the centre. One notable case is that of Maame Kay, who sells snacks at the ART centre in Kumasi. As clients wait in the long queues, Maame Kay, who may be counselling fellow HIV positive persons, especially the newer ones, and also serving generally as a link between the clients and the health workers, will also be selling her products. She might not have been allowed to sell at the centre but for the fact that she is living with HIV and also involved in the activities at the centre.

The financial needs

After enrolling on ART, the HIV positive persons are mandated to go to the treatment centre at least once a month. During these monthly appointments they generally have a physical check-up and receive their monthly stock of medicines. For those who have been on ART for around three years or longer, they have longer periods between appointments. In Komfo Anokye, for instance, some have six-month intervals between appointments. Due to the resources available to the PLHIV to purchase medicines, however, it was observed that some clients have to go to the hospital (the pharmacy and not necessarily for treatment) in order to collect their medicines more than once within this six-month period. They are also advised by the facility to come to the centre whenever they feel unwell, even if this falls in between appointments. In these cases, some people

may get to the hospital more than once a month, depending on their health condition. Since the majority of PLHIV in this study had financial difficulties, every trip to the hospital required a lot of strategizing in order to balance the cost of accessing therapy with their other pressing needs, all of which must compete for their limited resources. The sections below discuss the financial needs of HIV positive people, focusing mainly on transportation, hospital expenses, food, and other costs including family care and various life expenses, and how they manage the situation.

Transportation

Transportation is another cost that has to be borne by HIV positive persons. Those who accessed treatment at the ART centres comprised of people who came from near and far, though in most cases travelling to the centres involved the use of *trotros* and/or taxis. For those living very near to the facility, a few who had been on treatment for some time and were therefore relatively healthy managed to walk, while the others, because of their ill health, took taxis. Those who lived close to the facilities where they accessed ART were, nonetheless, in the minority because of the high levels of stigmatization, as discussed earlier; the majority preferred to travel to distant locations where they were less likely to be known.

Those who were fairly weak and/or did not want to be traced going to the ART centre (see discussions in Chapter 5) used either the public *trotros*/taxis or chartered taxis. In Offinso, taxis are the most common and convenient way of travelling within the town, since *trotros* do not run within the Offinso municipality. Transport costs to and from the facility ranged between GHS 0.60 and GHS 3 (US\$ 0.60 and US\$ 3) depending on the distance and whether it was chartered. In Kumasi, though *trotros* are a more common means of transport for middle-lower class people because they are relatively cheap, taxis were found to be more convenient and comfortable for people going to and from the hospital. In *trotros* it is not uncommon to see passengers getting off occasionally in order for others sitting behind them to alight, so for people who are sick, such experiences may be draining. Transport costs in Kumasi were found to be slightly higher than those in Offinso, depending on the distance and the choice of transport means. In both Kumasi and Offinso, however, when going to the hospital for treatment most of the HIV positive people were compelled to evaluate how they could get there, depending on the amount of money they had to spend on transportation, meaning that sometimes they would either have to walk or miss their appointment altogether.

Picture 9-10 Trotros and taxis at the Kejetia main station



For the significant numbers that travelled several kilometres to the treatment centres, their transportation costs were comparatively high. Some used either *trotros* or taxis for the journey, while most often people had to use both. They would therefore spend between GHS 2 and 8 on transport to and from the ART centre for each visit.

Coupled with the fact that the majority of the PLHIV were not earning an income, going for their monthly appointments at the facility and also to the monthly PLHIV association meetings required some savings and assistance from care givers. In some cases they did not succeed in getting the required amount for transportation. Not being able to raise the money for transportation to the ART centre was found to be one of the main reasons for missed appointments and absences from PLHIV association meetings. Consequently, they were unable to replenish their stock of medicines, leading to missed dosages. Several people living in the same neighbourhood and who used similar combinations of antiretroviral medicines told me how they often shared their stock at times when one person may not have had the money to travel to the clinic to top up their own medicines.

The inability to pick up the medicines when needed due to financial challenges went hand in hand with non-adherence to the medicines, which over time led to ill health and the compounding of existing health problems. When medicines are not taken regularly over extensive periods, PLHIV may also develop resistance to the medicines and therefore need a more potent line of treatment, which are oftentimes more expensive. If they cannot access these drugs, they do not recover and die. Ruth told me:

Sometimes the nurses and doctors do not understand us. Who will consciously love the idea of dying? Nobody wants to die. But at times when you don't go to the hospital when you are supposed to, they talk to you as if you don't know the consequences. When the *fa me ko* ['that which takes you', usually a phrase for money] is not there, what can you do? The last time I walked half the distance to the hospital [ART facility] because I only had GHS 1 for transport. Look, do you think I'm healthy enough to do that every day? But I did, just because I really want to get to the hospital for my medicines. I know what they [the medicines] have made me. I know I owe my life to the coming of these medicines [showing me the couple she had in her polythene bag],¹⁰ so I do everything to get it when I'm running out of stock. But when I don't have the money what can I do?

Like Ruth above, a number of the PLHIV did manage to get to the facilities, motivated by their belief in the therapy and its ability to sustain them. However, money for transportation seemed to be one of the major obstacles in terms of honouring appointments. As mentioned in the case above, sometimes after managing to get to the facility after having missed a previous appointment the

¹⁰ Ruth is one of the many people who routinely carried their daily stock of antiretroviral medicines in order not to miss the time to take the medicines.

health workers did not take it kindly. A number of the clients complained about such maltreatment, mainly from the nurses, when they missed appointments, ranging from insults to making them wait longer for treatment. In some situations, the PLHIV mentioned that they had seen their peers being turned away.

Hospital expenditure and medicines

In addition to the transportation costs to the facilities, after enrolling on ART HIV positive persons encounter medical-related expenditures – including buying their patient folders and hospital cards, laboratory tests, the antiretroviral medicines themselves, and other prescribed medicines – which need to be paid in order to get the full effect of the treatment. As Egya put it, citing an Akan saying, “To get the full effect of a medicine, you need a spoonful” (*aduro begye wo a, eye atere ma*). One needs to satisfy all of these expenditures (i.e. take a whole spoonful) and not just some (anything less than a spoonful) in order to get the full effect of the treatment. Antiretroviral medicines and some other prescribed medicines are not covered by the NHIS, so one needs money to get this spoonful of treatment.

At the ART centres in this study, the patient folders and hospital cards were free for all HIV positive persons. This was not the case for the general OPD, however, where some of the PLHIV with other problematic health conditions went, and they therefore had to pay for these additional services. Furthermore, although the antiretroviral medicines were highly subsidized, the PLHIV were supposed to pay an equivalent of US\$ 5 per month, no matter what combination they were taking (this is instead of the roughly US\$ 500¹¹ market value of the antiretrovirals). In addition, all the HIV positive persons took co-trimoxazole, and depending on their health condition were given other medicines including painkillers, blood tonics, nutritional supplements, etc. The minimum amount an HIV positive person might spend monthly in the hospital was thus GHS 5 (for the antiretroviral medicines), though this figure could rise to about GHS 20 for some. For those with specific problems – for instance Nana Adjoa, who had an eye problem – they could spend up to GHS 100 weekly. Nana Adjoa explained:

As you can see I have lost my left eye, but the problem is affecting the other eye too. The doctor prescribed some medicines – eye drops – which I only bought to be used for two weeks. I could only buy for three days and that costs more than GHS 90. When I used it too, I realized that the eye was getting better but where can I get the money for the rest of the days? I asked him [the doctor] to give me a cheaper medicine but he tells me that this is the only one that can help me. Now, I don't know what to do to be better. Unfortunately, the little improvement that came has become worse.

¹¹ Prior to the use of antiretroviral medicines in Offinso, Martha reported that HIV positive persons were given a magnesium dietary supplement product – V-1 – costing an equivalent of US\$ 150, which was available through donor support to her NGO.

Nana Adjoa had become temporarily blind in one eye, and as she explained she was “losing the other eye too.” Temporary blindness is not a known side effect of any antiretroviral drug. Blindness, however, can occur among PLHIV as a result of opportunistic infections¹² (Epstein 2007). Nana Adjoa was relatively well-to-do; she had a large provision store and a ready market for her products, since it was strategically located close to a public facility. Unfortunately, however, since the NHIS does not cover the medicine for her ailment – even though the package is said to cover about ninety-five percent of diseases in Ghana, including malaria, diarrhoea, hypertension, diabetes, and asthma¹³ – the amount needed “just for the eye” was more than she could support. She was therefore resigned to her fate and only “hoping for a miracle” to save her sight – and life. Since, unlike Nana Adjoa, most of the PLHIV were not working, had no income, and lived on the benevolence of friends and/or family, they had to go through the monthly ordeal of ‘begging’ for money and support in order to meet these hospital expenses and thus to live.

The introduction of the NHIS in 2005 brought a little relief to people living with HIV, since some of their medications are now covered under the scheme; however, the antiretroviral medicines and many medicines used for other opportunistic infections are not covered. The PLHIV in this study who were enrolled on the NHIS paid between GHS 18 and 25 annually to benefit from the insurance package. As of the time of fieldwork, only about half had managed to sign on to the scheme, mainly through the initiative of the PLHIV associations. All the PLHIV associations had made arrangements to register their members on the NHIS, but some associations still could not do so because of inadequate funds. Apart from the plan to insure all members, the associations also paid the GHS 5 needed by their members to get their monthly dosage of antiretroviral medicines. They also gave all registered members of the association an additional GHS 3 every month to help them meet other expenditures, such as transportation

¹² There have been reported cases of blindness among people taking antiretroviral medicines worldwide, but this is mainly caused by cytomegalovirus (CMV), a member of the herpes virus family, which leads to absolute and total blindness in those with compromised immune systems. Blindness this way is, therefore, not a result of the antiretroviral medicines.

¹³ The excluded services must be paid for by the recipient, if required. These include appliances and prostheses (including optical aids, heart aids, orthopaedic aids, dentures), cosmetic surgeries and aesthetic treatment, antiretroviral medicines, assisted reproduction (e.g. artificial insemination), gynaecological hormone replacement therapy, echocardiography, photography, angiography, dialysis for chronic renal (kidney) failure, organ transplants, all drugs that are not on the health insurance list, heart and brain surgery other than those resulting from accidents, cancer treatment other than breast and cervical cancer, mortuary services, diagnosis and treatment abroad, medical examinations for purposes other than treatment in accredited health facilities (e.g. visa applications, education, institutional requirements, driving licenses, etc.), and VIP wards (accommodation). For a brief note on Ghana’s NHIS, see:

http://www.ghanaweb.com/GhanaHomePage/health/national_health_insurance_scheme.php

to the facilities. Members who had not registered in a PLHIV association or the NHIS had to find other ways to fund their medicines and other hospital expenses.

The HIV positive people noted that the two ART centres in the study had made provisions for those who did not have the money for the antiretroviral medicines to collect their prescriptions on credit. Although a very welcome initiative, some felt that getting their medicines on credit “made them lose face” before the medical staff, which, according to them, was clear in how the medical staff related and reacted to those in debt. An angry female client was once heard complaining to a fellow PLHIV outside of the ART facility during a visit to St. Patrick’s Hospital:

Indeed the elders said that the poor man has no honour – *ohiani nni animuoyam*. Do you think if I don’t owe them they would have made me wait all the time for so many hours before they attend to me? The last time, I was one of those who got there [to the facility] on time but when it gets to my turn the nurse asks me to wait and call on the others who came after me. She [the nurse] later said that my case is different so I should wait. What is my case that is different? Am I the only person who owes? Aren’t they the same people who said if we don’t have the money we can come [for the medicines] and pay later? Or because I haven’t paid for the past three months they think I won’t pay so they treat me anyhow?

The nurse in question disclosed that she could not remember this incident when she was asked to explain the circumstances later that day. She did say, however, that some of the clients needed to do some laboratory tests in order for their reports to be ready by the next visit, and that may have been the reason for the long wait. This explanation notwithstanding, it was observed that some people indeed stayed in the facilities much longer than others. Those who stayed longer were observed to be those who interacted least with the nurses during the course of receiving treatment, probably because they were less sociable. The link to debt was not found during this observation. The reaction of HIV positive persons in relation to their alleged maltreatment due to their debt could also show how extra sensitive many were in handling issues as a result of their infection. As noted in previous chapters, this general suspicion was not limited to accessing services at the treatment facilities. In their homes, communities, and even at PLHIV association meetings, they were quick to attribute any negative word or deed, sometimes not even related to them, to be the result of their infection. They may have internalized the stigma associated with being infected and therefore easily mistrusted other people’s behaviours.

Food

After managing to get their antiretroviral medicines, and taking them for some time, HIV positive people face another challenge: meeting the pressing need for food as a result of taking the medicines. Food is an important element in the therapy for HIV positive persons. Mr. Nkansah, an auto mechanic, equated the role of food in the human body to that of oil in a car:

... as food is like oil in the human body so is blood like petrol in a car. Your system can be very okay, having everything intact, but you need enough lubrication, which is performed in the body by the food you eat, to go about your daily tasks. Without it, the whole system will be weakened.

Enough quality food can help reduce the side effects of the antiretroviral medicines and increase the immunity of PLHIV, making it easier to adhere to the therapy regimen. Poor nutrition generally weakens a person's immunity, more so in the case of HIV, hastening the progress from HIV to AIDS. In such cases, antiretroviral medicines become ineffective since there is no equivalent satisfaction for the increasing appetite as a consequence of the medicines. Regarding food availability and intake by the HIV positive people in this study, three groups were identified: those PLHIV who had lost their appetite and consequently could not eat; the few who had the resources to satisfy their food demands and also had the appetite to eat; and the significant majority who did not have regular food provisions but had an avid appetite.

Those who had lost their appetite and could not eat, though only a few, were mainly those who were in the early stages of ART, though they also included those who had gone to the facility at the end-stage of their HIV trajectory and were thus very sick. Money and food availability was not necessarily the problem at this stage. It was more about having the appetite to eat. Like Agyeiwaa cited in the introduction, those who had problems with resources for daily upkeep were not in a position to eat, but even when food was made available to them they still might not be able to eat it. Serwaa, who had earlier gone through this process, explained:

At that stage you do not feel like eating. You are in so much pain that eating itself is an arduous undertaking. My brother [referring to me], you feel like eating but when the meal is prepared and set before you, you lose appetite the next second. Other times too, after managing to eat a little, you vomit it all. Since you do not have enough food in your stomach, it is as if you are vomiting your intestines out. So you want to eat, it is painful, and when you eat, it is more painful. You do not want to experience that. It is something you wouldn't even wish for your worst enemy.

The majority of respondents indicated that this "horrible" stage could last for several months, after which, when they successfully recovered, the majority developed an insatiable appetite, which also brought another challenge: finding enough food.

The second group, the few who had the resources to satisfy their food demands and also had an appetite, were mainly those who were HIV positive but still employed. Regular access to money through their work engagements ensured that they were more likely to get food and eat well. This accounted for their lack of overt symptoms and the seemingly normal lives they lived.

The third and final group, who were in the majority, were those HIV positive persons who did not have regular food provisions to match their strong appetite.

Many of the respondents in this category – like those in the first – had lost weight and looked malnourished, probably due to not getting adequate food for their ever-demanding appetites. Although the desire to eat more was earlier welcomed by the HIV positive people and their families, since “it helped in no small way to improve their health and physical appearance,” it was found to have brought untold pressures, especially to the care givers, since they were unable to meet the demands. Ephraim noted that at this stage:

... you eat and eat and eat to the extent that your family members do not appreciate that any more. The case is different if you are seen not to be in a position to also contribute something for the home. I understand their worries very much. If they have any chance of getting back their investment in you, I'm sure they wouldn't worry much. As it is, it is as if you are not contributing anything yet eating more than those who are contributing. Everybody in their shoes would also not be happy. As the saying goes, no contribution, no *chop* [enjoyment].

In addition, they expressed their desire for food in a rather unpleasant way. For instance, Patience, narrating her bizarre yet worrying experience, said “... when I am hungry, I am unable to control myself. It is as if I am possessed. I feel dizzy, irritated, and you will find my muscles shaking. It only relaxes after a good intake of food. It makes me behave like a child.”

One significant thing worth noting is that the HIV positive people mentioned that during adherence counselling they were counselled to “eat well balanced meals” and “taught about which food combinations they should take,” all of which are necessary to support a healthy life. Cheaper alternatives that are easily accessible in their communities were also relayed to them. Mama Sɔfo explained that prior to her infection she thought that the only way HIV positive people could live was to “take their expensive medicines and eat their expensive foods.”

Initially I thought I needed to buy chicken, milk, tea (cocoa, chocolate, etc.) and meat and eat *check-check*, apples and the other rich foods before I can get the things my body needs to get me better. However, the nurses showed us that I can get *kotomire*, beans, garden eggs, or *nkwaasusua* with a little fish (*amane nketewa*) or eggs, which are all not only easy to find around but also affordable.

These cheaper alternatives notwithstanding, the situation on the ground – lack of funds and the consequent inadequate food supplies – ensured that getting a balanced meal every day was a luxury. In the homes of most of the HIV positive people in this study, it was observed that when it comes to what to eat, it was more about finding something to eat to survive rather than having a balanced diet, a somewhat ‘survival first’ issue. Most of them therefore took their medications on an empty stomach while strategizing how to get the day’s meal. On one occasion when I arrived at the home of Memunatu in a distant suburb in Kumasi at around 11am, she and her three-and-a-half year old daughter were visibly hungry but were waiting to take the day’s only meal at 3pm, drinking water all morning in order to survive the day. Some of the employed HIV positive persons

who were not in a position to afford meals throughout the day were also found to work on an empty stomach for long hours and to ration their limited stocks. Earlier cases in the chapter, such as that of Konama resorting to the cheaper alternative of eating *gari* to survive, show some extra dimensions to these strategies.

The dire situation of most PLHIV with regards to their lack of food was most evident at the PLHIV associations, where they wait patiently for the meetings to end and for food to be shared. Petty murmurings were observed when these meetings were delayed for whatever reason. These murmurings would graduate into quarrels during the sharing of the food, where parties who felt that they were receiving less than the expected amount vented their frustration towards the others. As discussed in Chapter 5, the receipt of food donations could expose the PLHIV to the inquisitiveness and attentions of others. However, since the nature of the PLHIV association meetings are disguised, receipt of food aid from the associations did not pose the risk of exposing their status, and thus they were not discouraged from taking their food rations home, at times in full view of the public. These food rations were, however, still inadequate to meet their dietary needs, since they were insufficient for the one person they were intended for, and yet were often used to feed entire families.

A direct relationship was observed between money and food: those who had money were more likely to have food. Since money was a major challenge for most of the HIV positive people in the study, they ended up relying on the benevolence of PLHIV associations, families, and friends, and at times begging. In fact, some of the deaths recorded during fieldwork, such as those of Konama and Abranteε, could to a large extent have been related to a lack of adequate food and money to survive. Just like blood, people needed money to make it in life.

Kin and communal responsibilities

The descent group-based kinship system that still prevails in most Ghanaian societies ensures that relatives are tied together both in times of joy and sorrow. Apart from fixing lineage affiliations and the citizenship of members of kin (Fortes 1950, Nukunya 1992), it also redistributes resources and ensures communal solidarity among members of the community. This system therefore allows both human and material resources to be redistributed to all members of the kin group. These responsibilities are most pronounced during rites of passage – birth, marriage, and funeral ceremonies – and other ceremonial and leisure activities such as festivals, parties, etc. By custom, in most societies in Ghana, such as the Ashanti, Ewe, and Ga, during child naming, marriage, and funeral ceremonies both families and friends alike are expected to grace the occasion with their presence and presents. In addition, for mothers, since combining the care of a

young child with their own income generating activities or other unpaid services can be daunting, friends and kin members, particularly the females, often go to the home of a new-born to help out. This assistance also extends to meeting household expenditures, as well as possibly accommodating and paying or helping to pay for the education of a member of kin and affines and some community members too. This was the norm in the respondents' communities. Most of these HIV positive persons (the majority of whom had not disclosed their sickness) had benefited significantly by receiving help (including financial support) from kinfolk, friends, and other members of the community.

To ensure solidarity and collectivity amongst the various members, there is an expectation for all members of kin and community members to be of help to one another in times of need. This implies that, as members of kin and the community, PLHIV also have responsibilities, aside from those for their own (conjugal) families, to care and provide for the needs of others, including their own relatives, their spouse's relatives, and other community members. The fact that relatives tend to be dispersed and not living in the same neighbourhood is no excuse, as the expectation is that if one is not able to be present, a delegate and/or gifts can still be sent. Where these resources are found to be scarce or not forthcoming, as was the case for most of the PLHIV in this study, lack of fulfilment of these norms becomes a potential tension breeder. Since many of the PLHIV were not working at all and had no income, or worked but at a slower pace, they were no longer able to shoulder these responsibilities. They lamented their inability to meet these responsibilities because of their current situation, especially because of the feeling that not being able to support others portrayed their lower status in society. The case material suggests that their inability to continue in these roles meant that they no longer commanded the respect that comes with it. Sarfo showed how providing for the needs of others ensures that you have their respect.

Up till the time when I got sick and had to spend much of my money on my health, I was paying for the school fees of my nephews [two of them] and nieces [three of them]. Now, two of them [one nephew and one niece] have completed high school, while the others are all in high school [two in senior high, and the last one in junior high]. They all came to me in Accra during the holidays in order to get some provisions and also their fees. They do anything I ask of them. Even my sisters [the mothers of the children] respected me very much. Unfortunately, since I cannot do it anymore, I have been reduced to nothing.

Sarfo was now living in the family house in his village with one of his sisters, whose children he had supported. He showed that it was now very difficult to send the children on errands since they knew that they would not get any tip or reward for it. The norms and ideals, described earlier, which demand that children respect adults and that good deeds are reciprocated may not always relate to actual practice. Sarfo explained that "Yesterday, I had to go and fetch

water with a bucket from the next house because none of the children I asked wanted to go.” Subsequent explanation by Sarfo’s sister brought to the fore the fact that PLHIV often do not have their expectations met because of these norms. She explained that although Sarfo had asked for the children to be with him, even prior to his illness he was stingy and did not treat the children well. “He deserves no sympathy from anyone,” his sister indicated. There is therefore a thin line when it comes to cultural norms and practices.

The majority of the PLHIV who did not have the means were left to *care about* those who they were responsible for rather than being able to *care for* them as they may have done prior to their infection. Konama, who used to command the respect of members of her community because of the support she offered, mainly cash, during ceremonies, had decided to no longer go to these gatherings in order to protect her hard won reputation. She narrated:

What is the use in going for these gatherings [marriages and funerals] if you are just going to eat and drink and not contribute anything? They will say you are irresponsible – that you don’t give but you eat. They’ll forget that you used to do it for others. It’s shameful! So these days, I pretend to be sick and don’t go for such gatherings. Then, I don’t get to hear these insults.

There is an association between people who offer assistance, mainly granting financial requests, and the domestic help they receive in times of need (Kwansa 2005). That is, the help given or received under these circumstances is more likely to be reciprocal, as can be seen in the case of Sarfo. This issue of reciprocity is likened to a person’s two hands – the right hand washes the left, and vice versa. This means that when others are in need and you are unable to help them, they will also be unable to help you when you are in need. Although in reality these norms may be different from actual practice, the PLHIV in this study were nevertheless likely to miss out on the benefits of these support structures since they were not in a position to demand such assistance.

Sources of funds for people on ART

As the majority of the people on ART in this study either did not have the strength or lacked the capital to engage in income generating activities, lack of money was one of the main challenges they battled with. They were unanimous in the belief that having money goes a long way in terms of positively impacting on one’s life before, during, and after becoming infected, as the case materials discussed above have also proven. With money, too, it is easier to maintain one’s social position and be independent, as evident in the life stories of those HIV positive persons who were still working. The stories of the peer educators and other PLHIV who were engaged in income generating activities, such as selling at the treatment facilities, running the activities of the PLHIV associations,

farming, stone quarrying, and petty trading, are examples of those who maintained their social esteem and position through money (see also Dapaah 2012). It was also rumoured that some of the HIV positive people, especially the females, maintained sexual relationships with richer partners as a survival strategy in order to get regular financial assistance (see in-depth discussion in Chapter 7).

Due to the fact that it is a serious and chronic illness, HIV ensures that an infected person has to be on medicines and have a good diet for the rest of her/his life. There is also the possibility that the PLHIV may not be able to work fully, and therefore will not be able to earn enough to offset the rather high expenses brought about by the sickness. They thus have to rely on the support of others. Furthermore, it was found in this study that the hospital was, in most cases, the last resort for clients, after they had tried several other sources of treatment that had drained their material resources.

Family and friends were the primary source of funds for the basic living necessities and sustenance for these HIV positive persons. It was evident that families had sold various properties (including land, farms, houses) and personal belongings as they searched for a cure for their ill member. For those who were bed ridden, or those who were too sick to work, their daily sustenance was at the mercy of family and friends alike. Some of the families, as a result, had drained their coffers and were living on begging as they continued to support their ill member. However, resentment over the situation of drawing (unendingly) from the family or community's resource pool without any expectation of payback probably accounts for the bad treatment given to the HIV positive people by their families and friends, especially in the situation where they were blamed for causing their own sickness (such as the case of Mary, discussed under 'Selling reluctantly' in Chapter 4, who was kept isolated in a room and denied any visitors, even those from the hospital). There were several cases where I had to intervene financially, providing money for food, medicines, and even to start an income generating venture, or else they would slowly die.

Another source of income for some of the HIV positive persons was assistance from working relations, mainly abroad. Serwaa, for instance, mentioned that she receives a substantial amount of help not only in cash but also medicines (nutritional supplements) from her siblings in Europe. As with all help from relatives, it decreased when they either suspected or found out about the real cause of the ailment.

Others had to live on money they received monthly from participating in the activities of the PLHIV associations (outlined above). Occasionally, they received food and medical aid from other donors, mainly foreign philanthropists, who sometimes visit the associations and participate in their activities. On one such occasion, an American philanthropist visited the Life Assurance association

and donated quantities of assorted food supplements and immunity boosters. Martha, the leader of the association, indicated that they receive these donations occasionally, though she thought that the majority of the donated goods were very close to their expiration date when they are delivered. “We are therefore forced to use all of them immediately we receive them since we do not know the consequences of giving it to them after they expire. It may worsen their condition.” She hoped that one day they “will receive a lot of these medicines that [they] can use continuously for at least six months in order to benefit fully from it.” Indeed, a look at the expiration date of the items brought by this American showed that the majority had to be used within one month.

The PLHIV associations also engaged in income generating ventures, which they hoped would help augment the financial assistance given to the members. However, during the course of fieldwork, none of these ventures had made substantial profits that the members had benefited from. Rather, they had generated heated arguments and fracas amongst members of some of the associations, bringing the activities to a halt in two of the groups (Christ our Hope Foundation and Preach the Word association).

Conclusion

HIV/AIDS brings tremendous costs to the individuals and families living with and affected by it. In the case of most of the HIV positive people in the study, they were no longer contributing anything to the family coffers, yet they were the biggest spenders of the family income. Apart from the costs mentioned – transport, food, medical expenses, other kin and communal responsibilities – colossal sums of money in the form of potential income are lost due to illness or death, as well as the significant rechanneling of labour to the task of caring for sick members. In addition, the time spent accessing and undergoing treatment by the PLHIV, and in some cases the care giver(s), would otherwise have been time that could have been spent in an income generating activity. Some families too had the unenviable task of looking after children orphaned by relatives who had died of the infection. HIV/AIDS therefore has the negative effect of increasing both individual and household poverty. Finally, there were the emotional costs of having to care for people who are continuously suffering and yet being unable to arrest the progress of the disease.

Money impacts on every aspect of the lives of a person infected with HIV. It is like blood. If you do not have it, you have no life. Epstein (2007: 27) captures this impact among people in Uganda when she notes there are two types of AIDS – one that affects the poor, making “them slimmer and slimmer and slimmer until they finally disappear, and one that afflicts doctors, bureaucrats, and foreign-aid consultants with enormous grants and salaries; they fly around the world to

exotic places and get fatter and fatter and fatter.” The majority of the respondents in this study were poor and they got slimmer and slimmer and slimmer until they finally disappeared (as in the case of Konama); though a lucky few were still engaged in occupations that ensured that they managed to meet their treatment expenses and therefore maintained a normal weight and could live normal lives.

One of the most devastating observations was that the majority of the HIV positive people, both women and men, were in their productive years, in terms of both economic and social activity. Their sickness and incapacitation thereby deprived their families, communities, and the nation as a whole of their productivity. Individuals who would otherwise have provided their household with an income were prevented from working – either because they were ill with HIV/AIDS themselves or because they were caring for another sick family member (see also FAO 1995, Guest 2003). The families in which a parent (or both parents) have been incapacitated by HIV or have died found themselves experiencing additional social and economic burdens.

Although no part of the Ghanaian population is unaffected by HIV/AIDS, it is often the poorest sectors of society that are most vulnerable to the epidemic and for whom the consequences are most severe. Farmer (2005: 181), based on their experiences with PLHIV in both the global north and the south, ask:

Why is it impolitic in the groves of academe to argue that dying of never-treated AIDS in a dirt-floored hut in Africa is worse than dying of AIDS in a comfortable hospice in Boston after having failed a decade of therapy? I've been present for both kinds of death – at matside and at bedside. No death of a young person can reasonably be called good. But I've seen almost nothing worse than dying of AIDS and poverty, incontinent and dirty and hungry and thirsty and in pain.

The toll of HIV/AIDS on households is very severe, as AIDS strips families of both their assets and their income earners, further impoverishing the poor.

All contributors to the Social Security and National Insurance Trust (SSNIT) are automatically registered for the NHIS; however, these are mainly people working in the formal sector. The poor therefore have to pay in order to benefit from the NHIS, which even then excludes antiretroviral medicines from coverage. Since the majority of the HIV positive people in the nation's workforce are employed in the informal sector of the economy, and consequently they have little or no access to health services and social protection, the impact of the infection has been more severe, leading to even greater impoverishment and earlier death.

AIDS has been described as a disease of poverty, but it might be more accurate to describe it as a disease of inequality, which settles in the ever deepening chasm between rich and poor (Farmer 1999). In Ghana this inequality between the rich and the poor is further reproduced within families in terms of personal wealth and attitudes towards sick members, gender roles, and most especially

occupational status. These factors show that the poor suffer more. As mentioned earlier, it was a common sight to see some of the HIV positive people take their medications on an empty stomach, which to some extent had an effect on their health. Others skipped their ART appointments because they did not have money for transport costs to the facility, or had not eaten so did not have enough strength to walk the distance, while others may have resorted to cheaper alternatives including local medicines (see for instance Kwansa 2010). Like Agyeiwaa, some of the clients died during the course of the study, when it was obvious that if they had had sufficient food and money to buy medicines they would not have expired.

Having money is linked to respect, honour, and the level of care one receives in times of need (Van der Geest 1997). As long as HIV positive persons continue to be financially independent, and also able to take on their kin and communal responsibilities, they are highly esteemed by society. The ramifications of constantly relying on others for their basic necessities are that they lose the respect of their family and other care givers. The poor suffering as a result of their HIV positive status consequently become additionally frustrated about their loss of independence.

Those in this study who were well-to-do, though HIV positive, were not 'sick'. In fact, they refused to get sick, and some even managed to circumvent the system in order to get their treatment, as found in the previous chapter, by giving gifts (bribes) to the medical staff. They ate well, were fitter, and therefore could keep their friends and loved ones close because they did not suspect anything, thereby enjoying their warmth, which the majority of the PLHIV lacked. They therefore did not suffer from the stigma and discrimination that the others went through. The majority of the PLHIV were sicker, and suffered from emotional and psychological instability, which might have contributed to some of their deaths. "Poverty therefore is not only sickness, but also death" (*Ohia nnye yadee nko ara, eye owuo nso*), as Abiba put it. The poor thus made attempts to lift themselves out of poverty.

On a rather positive note, the activities of the HIV positive peer educators in Komfo Anokye Hospital and representatives of the PLHIV associations showed that some PLHIV were finding ways to use their status to make up for their otherwise gloomy life. Others also used their positive status to find work, presenting themselves as PLHIV during sensitization campaigns in exchange for financial compensation, which they could spend to help their families, their communities, and at the medical institution where they received ART.

The study proposes – and this was unanimously agreed upon at the follow-up workshop in Kumasi (see Appendix 4) – that since HIV positive persons provide a unique perspective on living with HIV, they should be incorporated more

formally into the medical system, where they can act as resource persons for the various forms of counselling – especially adherence counselling. This process was started but was not continued at the Komfo Anokye Hospital (see also Dapaah 2012). Such a move will achieve two main goals – provide a badly needed income to some HIV positive persons while also giving them a life, and it would allow them to put their hands-on expertise at the disposal of their fellow HIV positive people in need. Extra training could be given to them in this regard. It must be noted that although Dapaah indicates that such an initiative was not supported enthusiastically by the medical personnel of the hospitals and ART facilities, because the few PLHIV who were involved in peer education were thought of by the medical staff to have abused the opportunity, such initiatives have been tried and proven successful in other countries (see Salomon *et al.* 2005).

In summary, the HIV positive people in this study who had money were living better lives. They were more likely to eat well, buy their medicines, renew their health insurance, honour their appointments at the facilities, and therefore fared better on ART. Most importantly, they looked happier because they could continue to maintain their familial relationships (and, as will be seen in the next chapter, their sexual relationships), and continue to enjoy the respect of society since they were not suspected to be infected. These wealthier PLHIV nonetheless posed a greater risk of the further spread of HIV within society, since some hid under the cloak of being ‘normal’ and engaged in unprotected sexual activities and other risky behaviours, which in the long run pose a significant threat to others. The next chapter discusses the irony of the ‘new hope’ provided by antiretroviral medicines; issues of being normal on the one hand and abnormal on the other.