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

Kwansa, B.K.

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## Friends and siblings: About trust and mistrust

*Dyɔnkoɔ bi sene nua*

Some friends are better than siblings

(Akan saying)

My experience when I went to Serwaa's house was the opposite of my expectations. Serwaa's demeanour was not inviting. She was unwelcoming, and frowned as if she was not ready to engage with anyone. She looked sad, morose, and visibly disconcerted. That was my first visit to her home after she had given me directions to her house at a PLHIV association meeting. At the meeting, though she did not talk much she was nevertheless friendly and full of smiles, interacting freely with a number of her fellows. Subsequent observations during encounters with Serwaa showed that, though not gregarious, she talked freely, laughed and shared jokes, and also engaged in serious conversations with a number of people at the association. She later explained that due to her current state of ill health, she had deliberately chosen which relations to activate and which to disengage from. The ones that might pose a threat to her well-being she denounced, accounting for the way she behaved at home. She explained:

My brother, you know we say that there is a friend who is closer than a brother. If I know my brother wants to kill me, I don't have to go and sleep under the same roof with him. I will rather lodge with a friend who will accept me just as I am.

The current predicament of PLHIV in Ghana makes them vulnerable to being stigmatized by friends, family, work colleagues, and others whom they relate to. As can be seen from Serwaa's case, they therefore develop new relationships,

while some of the old ones fade out or are severed completely. Due to the indifference that can arise in relationships with family and friends after PLHIV sell their sickness and/or the limitations imposed by non-disclosure, this chapter explores three other types of social encounters that the PLHIV experience: those with hospital staff, with other HIV positive people, and with home care professionals (including NGOs and PLHIV associations working in the field of treatment, care, and support). All of these three categories include people who are aware of the status of the HIV positive person and who should, for that reason, be trusted. These new relationships are, however, not without problems, and not all people can be trusted.<sup>1</sup>

### Care for the sick

In Ghana, all cultures have traditional ways of caring for the sick, though it is chiefly the responsibility of the family. Family members contribute their time and material resources in the care of the sick in order to re-harmonize the disruption in the family caused by sickness. Caring roles may be divided according to age and gender, however each member of the family contributes substantially. According to Nanbigne & Baataar (2009), among the Dagomba of northern Ghana, for instance, who use medicinal herbs and animal extracts, divination (*bagrebog*), or sacrifices to ancestral shrines (*yir nwimme/nwinwe*) in the treatment of certain illnesses, caring for the sick is a collective responsibility of the whole house (*yirdeme*). Adult males are expected to gather the required herbs, boil them (if so required by the herbalist), carry the sick person to the herbal centre or curer, visit and encourage the patient, and check (in fact, supervise) the activities of the women who basically care for the patient. The women are specifically expected to clean and wash the patient, prepare and administer the herbs, feed the patient, and sleep at his/her bedside. Children are generally expected to run errands for the men and women caring for the sick (Van der Geest 2002, Arhinful 2003).

Care for the sick by the family is seen as part of the healing process (Akrong 2009). In this sense, it provides both physical and psychological reassurance to the sick person that s/he has their care and support, which goes a long way in the treatment process. With regard to the search for therapy in the case of an HIV infection, it is not uncommon to find these forms of care being practiced complementarily with biomedical approaches, or old forms giving way to new ones, all with the convincing support of trusted friends and family (Kwansa 2010).

Though the primary responsibilities for care lie with the family, care givers may transcend kinship ties. Depending on a person's role in the community and

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<sup>1</sup> Similar developments are described in Chapter 7 in Dapaah (2012: 125-140).

his/her personal relations, the task of caring for someone who is seriously sick may be assumed by many other community members (Manuh & Quashigah 2009). Friends and other community members may provide food, shelter, and clothing, or with their visits keep the sick person company and give him/her reassurance. Janzen (1987) calls this the ‘therapy management group’. He notes that the family members of the sick person may also act as intermediaries and are involved as advocates between the sufferer and the various medical specialists. They lend assistance to the physicians and assume responsibility for both diagnosis and therapy, mainly in the home. On the whole, when it comes to serious disorders such as cancer, physicians in Africa share the diagnosis and other relevant information with family members, and may rely on them to ably care for the patient at home. These informal home care practices are mainly put in place in order to avert frequent and long hospital stays so as not to aggravate the declining health condition of the patient (Carter 2007, Van Dyk 2001). Family relationships thus play a significant role in ensuring that patients obtain humane care at home (Chimwaza & Watkins 2004) and also help the sick person to access medical treatment (Thomas *et al.* 2002).

One would expect to observe these traditional care practices in HIV/AIDS cases (cf. Mupedziswa 1998, Van Dyk 2001), particularly since in order to receive ART in Ghana all HIV positive persons are required to have a treatment or adherence monitor, preferably a member of the family or the same household, who also takes part in the adherence counselling, reminds the HIV positive person to take their medicines, and helps at home when needed. However, in the case of HIV/AIDS, this issue becomes problematic. As the previous chapter has shown, in the majority of cases investigated it was not possible for the HIV positive persons to rely on family members, friends, and associates for care, because of the sick person’s decision not to sell their sickness, and due to the family’s stigmatizing attitude towards them. In the case of the monitors, for instance, it was found that the majority of PLHIV in this study use friends, fellow HIV positive persons, and even people they found on the streets whom they did not previously know, instead of relatives who would traditionally be the main active care givers of the sick.

This chapter discusses the shifting of care responsibilities from siblings (*anuanom*) – which is used here to also include other family members (as an inference from the saying ‘some friends are better than siblings’) – to friends (*ayɔnkofoɔ*) in the context of HIV/AIDS. The details and activities of these new relationships are discussed, bringing to the fore the concerns, agitations, reservations, and apprehensions of these HIV positive people, in terms of accessing therapy and in life in general. The chapter also discusses the HIV positive peoples’ relationships with the medical staff they encounter, which

sometimes transcend the hospital premises, and considers their relationships with their fellow PLHIV.

### The first encounter: The medical staff

After receiving a positive result from their HIV test and an onward referral to an ART centre, the HIV positive persons in this study explained their first encounter with the medical staff – a group of people whom they would have to “relate with for the rest of their lives, at least until a cure is found for their infection.” From conversations and observations, most seemed to have opened up to the medical staff – counsellors, laboratory technicians, nurses, doctors, and other workers, even the cleaners. It is worth noting that the medical personnel were generally good, as described by Dapaah (2012). However, the respondents mentioned that their first experiences in the ART centres were not always cordial and friendly. Much as the nurses and other medical staff welcomed them, these newly diagnosed HIV positive people seemed to be preoccupied with thoughts of coming to terms with their current situation – thoughts about “choosing to live or end it,” whether “to sell or not to sell the sickness,” and in some cases denying the positive test result or ignoring it by disassociating themselves from it.

#### *Befriending the staff*

With time, usually after two or three visits, the HIV positive persons tended to open up to the medical staff and respond to the usually friendly gestures. “By this time, the reality about the infection had sunk in, and we were ready to listen,” Linda remarked. They mentioned that the doctors, and especially the nurses, became concerned about their private lives and treated them well. As Seidu explained, they even asked about “our family, our work, and not just our health conditions, which is good because it shows they are concerned not just about your health but also about all aspects of your life.” Seidu continued:

When you get to the place for the first time, the nurses will open a file for you and ask you lots of questions; where you live, your spouse, children, and even parents. You feel obliged to give them all this information, because they need all that to take good care of you. They get to know more about you.

Through these interactions, the nurses get to know the HIV positive people. On several occasions, the nurses even realized that they were related somehow to the clients – through blood or through a mutual acquaintance, such as former schoolmates or other relations. These links usually begin the relationship, where these PLHIV risk their innermost secrets – which may not be known even by their close relations (including spouses, siblings, and parents) – to these medical staff whom they may hitherto not have known, talked to, or even associated with. They thereby develop a level of trust in these medical personnel and expect them

to be discreet as well as helpful in giving care and support; something which means the world to most of them. They also take the medical personnel by their word, not just regarding the fact that they (the staff) will keep their status secret, but also in terms of following their prescriptions and counsel without question.

Generally, these PLHIV saw the work of the medical staff towards their upkeep as a favour, referring to it as grace (*adom*). According to Eugene, one of my community informants who was not HIV positive, PLHIV in the communities of Kumasi and Offinso are seen as people who have brought the situation upon themselves through their past (sinful) behaviours. They therefore lose all previous status and respect in the community, which is reflected in the treatment some receive when their status is known (see also Last 2000). “They could have left us to die and no one would question them,” Linda said of the medical staff, “but God will bless them abundantly for all the efforts they are putting in to make sure we live.” Other medical staff were praised for the way in which they talk to the PLHIV, even when “we were obviously at fault.” Mama Sɔfo, for instance, described a situation at the hospital where she had shown her prescription to the nurses and later accused them of not giving it back to her:

I insisted that they did not give it to me not even after they kept telling me I had come for it earlier. I was ashamed when I found it later in my bag, but they were very cool with it. If it had been nurses somewhere else, they would have pounced on me. But these people, they are good. Even when you are at fault, they have patience for you.

The doctors were often referred to as ‘saviours’. Even though they gave the nurses all the credit for the explanations and counsel, probably because they spend more time with them, in the eyes of these HIV positive persons the doctors are like gods. “Seeing the doctor was enough to get me back on my feet again,” Miriam said. She explained that it is the doctors who prescribe the medications and can also put you on or take you off the medicines. Some specific workers were mentioned for their tact and skill in the care of PLHIV. One doctor in Offinso was specifically mentioned and credited by several people for being very quick in attending to them, so “if he is on duty and you are further away in the queue, you know you will leave in no time. And his medicines are very good too.”

The small details in their relationships with the medical personnel mean so much to the PLHIV, probably because they lack similar attention from the people who would traditionally be expected to care for them. Being identified by name, and also being asked about relatives by name (based on previous communications, even where the medical staff have never met these relatives), is, for instance, very much appreciated by the PLHIV. Maame Amponsah noted:

The nurses are very good since they remember everything you tell them about yourself. On every visit, as they take your details [vital signs – blood pressure, weight, temperature, and

height], they make time to talk to you. You see, we are many, but you could see that they know everybody and talk to us all. It means they really care about you. That is very good.

During this time for the taking of vital signs, the nurses also check the clients' medicines to be sure that they are adhering to the regimen. The PLHIV also remarked that they get to talk about their general health condition, including the side effects they are encountering, and other things such as appetite and hormonal swings. Furthermore, as some explained, they usually arrive at the hospital premises on clinic days much earlier than the staff, in order to be at the front of the usually very long queues, and thus receive treatment on time in order to leave for their other chores. As Egya noted, the staff are very dedicated in caring for them, since "They arrive on time, and are very earnest to get ready to attend to us. May God richly bless them."

#### *Reassurance and assistance*

In addition, the PLHIV stated that the medical staff understand their plight and do not judge them. This ensures that "there are no fingers pointed at us and no accusations of wrongdoing and immorality. They feel for us and are always keen to be of help," Aisha noted. Musa also explained that the medical staff always reassure them that all is not lost: "As we wait for the doctor to come and see us, some of the nurses lead us out in praises and worship. We also pray for our health and their work. Such periods for me are very comforting." It is worth noting that to most of the HIV positive people, the medical staff, especially the nurses, go out of their way to ensure that they are physically fit and emotionally stable. As noted by Musa above, they encourage them a lot, and oftentimes sing and pray with them when they go to the hospital on their appointed day.

From the interactions and bodily gestures of the respondents, it was clear that, due to the fact that the doctors examine them to understand their problems and give medical explanations, they are seen as the main persons in their treatment process. As Miriam outlined the care she was receiving from the ART centre, the smile she revealed as she mentioned the name of the doctor treating her was enough to explain how grateful and content she was with him. Miriam, like most of the clients at the ART centre in Offinso, had a distended stomach from being on ARVs. Hers was, however, unique and abnormal, according to her account of what the doctors had told her. Her stomach was not only bloated but also hard, and she felt extreme pains during the night. She told me that each time the doctor touched her stomach, and gave explanations for her problem and prescribed medicines, she instantly became well. She went home very okay, only for the condition to recur after a few days. Although the problem grew worse and Miriam eventually died, she never stopped talking about her encounters with the doctors.

Some of the clients, especially those who were illiterate, also mentioned that the nurses were kind and helpful in telling them how to take their medications and when to come back for their next appointment. For these clients, the nurses wrote the dosage diagrammatically on pieces of paper or on the boxes containing the ARVs. Sandra described the process that led to use of this strategy by the nurses in Offinso.

When we started [taking ARVs], the medicines were given to us and the doctor [pharmacist] told us how to take them. But when we leave the doctor's room, the nurse will ask us to repeat what the doctor told us about how to take the medicines. They realize that most of us who haven't been to school get confused because there are different medicines and all are taken differently. This one [showing the medicines to me] I take at 7:00am every day. These two, I take at 7:00am and 7:00pm. So you see I keep them in different bags so that I don't get confused. Because of these differences and the confusion, the nurses started drawing the dosage on the containers or the boxes or on pieces of papers depending on what we want. When you see only '0', then you know you take it only in the morning. If it is '0 - 0', then you know it is both in the morning and in the evening.

It must be noted, however, that confusion with the dosage is not limited to those who are illiterate. Many of the PLHIV explained that they had, at one time or another, confused the dosage of the different medicines they were taking. This was because most of them were taking more than two different combinations of medicines and therefore it is not surprising that they became confused along the way. Ellen noted that after being on the medicines for some weeks she felt all the more sick and weak by the day, so she called one of the nurses who explained that it may be her body's reaction to the medicines and therefore may be normal. She was, however, asked to report on the next clinic day if the condition persisted. It was there that the nurse realized that she was taking the wrong dosage, which had caused the mood swings. The majority of the HIV positive people thus welcomed the idea of the nurses writing the dosage or showing it in the form of a drawing on the box.

To show their appreciation, some PLHIV sent gifts to the staff, including jewellery, money, and farm produce. They wrapped these gifts and clandestinely gave them to the staff they admired. Some left the gifts with other people in the vicinity and prompted the staff to pick them up later. Although these PLHIV felt that the gifts were "nothing compared to the services they were receiving," as Abiba explained, the act of giving them was very dear to them. The staff's reactions were varied, according to them. One group, exemplified by Opokuwaa's statement, thought that "they know we don't have much, so the little we give them we know they appreciate very much," while others felt that their reaction to the gifts was one of resistance (*akwansie*), either because "they did not appreciate the gift" or because "they did not want to encourage such behaviours from us who were poorer," as Esther and Kaakyire said respectively. Several situations like this, where the staff acted contrary to the expectations of



the PLHIV, were found in this relationship. I discuss these in the following sections.

### *Complaints about treatment*

Many of the PLHIV felt hesitant about indicating some of their apprehensions in their relationships with the medical staff at the ART centre. Generally, they thought that they had no reason to demand better treatment or voice their reservations about the services received. They felt that in saying anything negative about the people “keeping them alive,” or about the services they received, it would seem as if they were either ungrateful or not content. Only a few were convinced that telling me would help develop the relationship between medical staff and clients; something which was, after all, part of my research goals.

Massa (a teacher) cited an Akan saying to underline the helplessness that PLHIV feel in demanding more than they are receiving: “If your chin is falling off and someone offers to help you hold on, do you retort that if s/he doesn’t come faster you will let it fall off?” (*Se w’abɔdwe rewae, na obi mmeboa wo a, wokase se wɔamma ntem a meregyae mu?*) Like in the saying, the health staff help the HIV positive people to hold on to their falling chins, and thus the PLHIV feel that they cannot make complaints or demands, since, as Massa put it, “if they [the HIV positive persons] complain about the services they receive, the health staff can decide to let go of their falling chin. Who suffers?” This hesitation notwithstanding, from observations and informal comments made by the PLHIV during extensive home visits and conversations, I noted that all was not well with them regarding the services received, yet they did not seem to have a choice but to accept it that way. Even when they discussed their complaints among themselves they seemed to sympathize with the medical staff, and blame themselves for causing the problems. They also found ways of discussing their problems with me and some of the workers at the NGOs, since they felt that we could channel these grievances to the authorities without giving them away.

Some of the PLHIV mentioned that the workload at the ART centres seemed to overwhelm the few medical staff assigned there, to the extent that they often became irritated over very trivial matters. Some complained that their first experiences at the facility were not pleasant, but that once they got used to the procedures and regulations things improved. Mama Sɔfɔ, for instance, narrated her first encounter at the hospital, where she felt that the nurses were rude to her for no reason.

After the nurse took my BP and temperature [and other vital signs], she asked me to sit at a particular place. I misunderstood her, so I joined the queue because I didn’t know that my treatment [for a first timer] was going to be different. After some few minutes, another nurse came angrily shouting my name and I might have responded after about the third or fourth shout, to which she started raining insults on me. She kept saying that I was not the only person there to take all their time. She even asked me to go home if I wasn’t prepared for

treatment. She wouldn't listen to any explanation. I had to keep quiet and listen to them insulting me ... as if I am foolish. If I had given birth early, my child would be of their age, but they reduced me to nothing.

This attitude of the nurses, as described in Mama Soffo's account, is not unique to those working in the ART facility. Such perceptions of nurses are widespread and complaints are made against the nurses in the majority of public hospitals and clinics. Though workload is often cited as the main reason for the nurses' attitude, it was also realized, including in Mama Soffo's particular case, that there is a general assumption on the part of nurses that every patient that comes to access the service knows all the right procedures to be followed. Probably because the medical staff are so used to the procedures, they (especially the nurses) therefore provide little or inadequate information, and this means that clients fail to follow the procedures correctly. In the specific case of PLHIV, their confusion regarding the nurses' procedures is not too surprising, especially during their first visit to the ART facility, since at the time they may be going through possibly traumatic psychological struggles in terms of accepting their HIV status and dealing with the ramifications of the test result.

Some of the PLHIV also complained that some of the nurses are stern and unfriendly. They are said not to interact with them, probably because they do not want to get close to someone who is HIV positive. Asked why she did not initiate such interaction, Serwaa noted that "they [the medical staff] are big/prominent people (*mpaninfo*), and a child does not initiate such a relationship with an older person." It must be noted that this relationship (doctor-patient, superior-subordinate) that Serwaa is speaking of is not necessarily based on age, since most of the doctors and nurses in the ART clinics are in fact younger than the majority of the clients. It is more about power and authority, where the client feels subordinate to the medical staff. Abiba also stated that even where they (the clients) felt like opening up, the countenance and attitudes of the medical staff prevented them from initiating such interactions. This was corroborated by most of those whom I visited at home, who said that they often had questions about their treatment, though they had to rely on me (or the PLHIV associations) for answers. When asked why they did not ask the medical staff, they explained that "they didn't want to disturb them," they "felt the doctor would think they were stupid to ask such a question," "they cannot just ask them," and "they didn't know how to talk to them."

The PLHIV noted that very few of their fellow HIV positive persons managed to talk about their reservations when they felt bad about the services provided, and usually they were only able to voice them when they were very angry. In their bid to express their misgivings, they often had to face the displeasure of the medical staff, mainly the nurses, who then tended to be very critical when attending to them. They often felt upset by this. Furthermore, some people felt

that due to their HIV positive status they were treated less cordially by medical staff, and this was a source of anguish and displeasure. Abiba, who said that she had many a time incurred the displeasure of the nurses because she speaks out, argued that “anybody can get sick so sickness does not make you less of a human being. It must not give people the leeway to just behave anyhow to you.” She alleged that once she confronted a nurse at the ART centre who was showing disrespect and sheer arrogance towards another client:

She [the other client] was seriously sick when she was brought to the clinic. She was so weak and was therefore asked to be given some food/drink before being attended to. When she could not eat the food brought to her, the nurse just descended on her, telling her how she was going to die soon because she wouldn't eat. She even insulted her family for not making her eat her food. I thought that was not fair since other people who are sick and cannot eat are given [intravenous] drip. Why didn't they choose that option for her? Is it because of this disease? Well, I didn't say anything. However, after some time, when she had been forced to eat something, and was waiting to see the doctor, she spat on the floor, which her family immediately wiped clean. But that was when they really descended on her. They insulted her, and even threatened to sack her from the place. And that was when I came in. I also reacted and told them my piece of mind. I told them that what they were doing was too much and that they couldn't see that the poor girl is so sick that whatever she was doing was not intended. We exchanged words and she blacklisted me. Anytime I go there, she [that nurse] doesn't want to attend to me. But I reported her to a senior nurse and she was talked to. I know she wants me dead but it wouldn't come to pass.

In Ghana it is common that patients and family simply look on while the medical personnel diagnose and treat. The authority of the medical staff is seldom questioned, no matter how sick one is (cf., Andersen 2004). Their words are commands. Some of the HIV positive persons felt that though nurses can be rude and arrogant in general, some of their actions (such as those described by Abiba above) are specifically related to their HIV positive status. Martha also explained that there were situations where the care givers (who accompany the PLHIV to the centre) had to make a case on their behalf.

The PLHIV further noted that some of the health workers fail to understand what they go through in order to get to the centre for treatment. “If they know, they will be glad that we manage to be present every time we are asked to,” Serwaa remarked. Many explained that the nurses in particular insulted and maltreated them when they were late or missed an appointment. Serwaa: “Can you believe that they tell us if we don't come on time, we will not be attended to?” Massa also mentioned several cases where people had come late for treatment and the nurses refused to attend to them so they had to come back another time. “That's inhuman, insensitivity at its best,” he noted. Since the majority of the PLHIV in this study had not sold their sickness, it was noted that they must adopt several schemes in order to prevent others from knowing that they are going for ART (as described in the previous chapter), and this often makes them arrive at the facility late or at times miss their appointments entirely.

Another point of friction between medical staff and the HIV positive clients is over correct ARV adherence. As Aisha stated, “when they count your medicines and realize that you have more medicines than you are supposed to, meaning that you didn’t take the medicines correctly, they don’t spare you.” A number of the PLHIV confirmed this. To prevent these reactions and avoid the fury of the medical staff, especially the nurses, most counted their available medicines before attending the clinic and removed the excess. Ephraim explained, however, that on one occasion the plan backfired when he removed too many of the pills. He was found out, but the nurse rather joked about it:

Instead of insulting me ... she asked whether I thought she was stupid, to let me know she is smart, and I agreed, and we laughed it off. I think it was a good day; otherwise I would have been dead [in great trouble].

As explained in the previous chapter, some of the HIV positive people, because of the problems they face in getting to the facility, make arrangements with the nurses in order to facilitate their treatment at the ART clinic. Those who were involved in these arrangements were very thankful for the assistance and understanding of the medical staff. However, others explained that such preferential treatment was not limited to these special cases; they accused the nurses especially of granting preferential treatment to people whom they knew and shared something in common with, including fellow church members, people from their hometown, old schoolmates, or family relations, as well as those who give small tips such as money, food items, jewellery, and farm produce. Memunatu:

There is so much *whom-you-know* here in Kumasi. It doesn’t matter how early you come to join the queue, when they come, the nurses will just put their file on top and there they go. This is especially the case for the northerners. We will come here at dawn. Sometimes we sleep here for more than two hours before the nurses come. And they [those who receive the preferential treatment] will come later, and they will jump the queue.

In Komfo Anokye, some of the PLHIV alleged that since the nurses are mainly from the north of Ghana, they tend to support people from their region more than others. In Offinso, the PLHIV felt that preferential treatment is given not only to those who are related to the nurses (or the main nurse on duty in particular) but also to those who give gifts. Mr. Nkansah, for instance, mentioned that he had realized that:

Those who give foodstuffs, money, and other gifts to the nurses and the doctors are usually on very good terms with them. So when they come for treatment, they are called in separately for attention, without joining the queue.

Maakua also observed that professional people, who are still active in their profession while on ART, are also given preferential treatment.

From observations, it was clear that some of the accusations of preferential and ill treatment were true, though some of the HIV positive people seemed overly sensitive and critical when it came to finding faults in the system. Mama

Sofa admitted that there were sometimes cases when it is rather they, the HIV positive clients, who misplaced their aggression onto the medical staff by getting angry over little or at times no provocation from the medical staff.

## The home visits

The relationship between the medical staff and the PLHIV is not limited to interactions at the hospital on appointed clinic days. Both Komfo Anokye and St. Patrick's Hospitals had programmes to follow up PLHIV in the community in order to continue assisting with their treatment, and to offer care and support in times of sickness. The care and support provided to HIV positive people in their homes, known as home-based care, was originally based upon the coping and caring capacity of families (as described above; see also Jackson & Mhambi 1992: 14). However, in the Ashanti Region home-based care has for some time now been initiated by hospitals and implemented by health workers (cf. Radstake 2000: 30), as well as by some NGOs working in the field of care and support of HIV positive people and by the HIV positive people themselves through PLHIV associations.

The main objectives of these follow-up programmes are to check whether PLHIV are following treatment regimens, and also to attend to any problems associated with the treatment before their next (usually monthly) appointment is due. In addition, the home-based care team hopes to offer love and support in times of need to those who may not enjoy such things from family and friends, due to the stigma and secrecy surrounding HIV/AIDS. The home-based care team also visits those who have missed their appointments, for one reason or another, to check on their concerns. These visits last between twenty minutes to an hour, depending on the condition of the client and also the relationship between the client and home visitor (where the more cordial the relationship is, the longer the stay).

Skilled personnel – peer educators<sup>2</sup> in Komfo Anokye and nurses and/or counsellors at St. Patrick's – visit HIV positive people at their homes (or any other agreed location) in order to provide them with various forms of medical, psychological, and/or material care. In particular, those who are weak and cannot make it to the hospital are taken care of by this team, who even bathe and feed them when necessary. One unique factor about the home visits in Kumasi was that they were undertaken by just one peer educator. He seemed to know all the

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<sup>2</sup> Several peer educators were working in the ART centre in Kumasi. Peer educators are HIV positive people who have been trained extensively in counselling and care for their fellow HIV positive persons. Some are also responsible for the home visits. In-depth discussion on the role of peer educators in Komfo Anokye Hospital can be found in Dapaah (2012). Other aspects of their role in treatment, care, and support of PLHIV are discussed in Chapter 7 of this monograph.

clients and their various problems. The clients in turn had introduced him to their families as someone who worked at the Komfo Anokye Hospital and who was responsible for following up on all the people who had been to the hospital in that area/neighbourhood. Since he was very active and looked professional, no one suspected that he was HIV positive, which made it easier for the clients to welcome him into their homes. Another peer educator whom I identified later on during the fieldwork had undergone special training on providing care for HIV positive people who were bed ridden; he was sponsored to go round and support this specific group. In Offinso, however, the main nurse in charge of the home visits – Nurse Rose – was a native to the area, and because of its comparatively rural nature, members of the community seemed to know her and the work she did at the ART centre. According to Nurse Rose, St. Patrick’s Hospital had received funds from the National AIDS Control Programme (NACP) in 2007 to provide money and especially food aid to its clients on ART through the home-based care programme. Within this period the food was distributed to the people in their homes using the hospital van. The team that was responsible for these visits also used the van to provide food to other community members in need.

According to the HIV positive respondents, during the collection of their vital signs and other personal particulars on their first visit to the ART centre, they were informed that plans would be made for them to be visited at home by the medical staff or another person appointed by the centre. Depending on their state of physical health, which determined the urgency of the visit, arrangements were made. Due to the secrecy adopted by PLHIV to prevent others from getting to know their HIV status, however, many did not want to be visited at home at all, while some agreed to the request for a visit, albeit reluctantly, and others arranged with the team for ways to disguise the visits.

#### *Unwanted visits*

Most of the PLHIV who had not sold their sickness to other members of their household were very hesitant about allowing the home-based care team to visit. This came to light when I was arranging with the nurse-on-duty in Offinso and the peer educators in Kumasi to find out the homes of those receiving the services from the two centres. In Kumasi, it was not uncommon at all to pass by a house and hear a comment from the peer educator to the effect that “there is one gentleman/lady here ... but s/he doesn’t want to be visited, so we cannot go there.” The nurse-on-duty in Offinso also told of a case where a man, Daniel, had threatened to chase the team that had gone to visit him without his permission with a machete. “They were lucky not to have met me at home when they came,” Daniel later told me. He explained that no one apart from his wife, who also receives treatment in Offinso, knows about his HIV status, so he did not want to

“loosen [his] guard. What do they want in my house? If they have anything to do or tell me, can’t it wait till we come on our next appointment?” Daniel had accepted to host me in his house “anytime I wanted to come,” so I was curious to find out why he would want to host me but not those from the hospital. He explained:

No one knows you and you don’t come in a white gown or in a hospital car, so between us it is just a *boys-boys* relationship. I can explain to everyone you are my friend from Kumasi who has come to visit, but what do I tell them about these hospital people? My friend, I don’t want any trouble.

He also explained that his threat to chase them away with a machete was real and that he would have denied knowing them and taken them for thieves if they had met him at home that day. True to his word, he never allowed the home-based care team to visit him.

As seen in Daniel’s case, the home-based care team at times defied the request of the PLHIV not to be visited, which also then became a problematic aspect of their relationship. Since the clients did not want to incur the displeasure of the medical staff, on most occasions they could not directly communicate their feelings to them. Indirectly, however, a number of the PLHIV informed me about their problems, and though some were not bothered if those responsible were informed of the complaint, the majority did not want this. Maakua, for instance, called me one day to make an urgent appointment with me because she “had something on her heart she wanted to let go.” On the appointed day, she narrated how one particular nurse was harassing her because she wanted to visit her at home, and wanted her only daughter to be present. She explained:

... everybody in the community suspects I am positive because of the circumstances that led to the death of my husband about six years ago. After his death, I also became severely sick and was at the point of death. That led to the suspicion and rumours in the community that I was also infected, just like my husband. However, after being on ART all these years I have regained my health and the people now doubt whether I was really infected. Previously, I could sit out here [selling foodstuffs and vegetables] and not even one person will come and buy from me. Now, as you can see, people come to me and buy, and I am happy. My daughter [about fourteen years and in high school] is also on ART. Nobody knows about it. You know that I have arranged to take her medicines since she is always in school. However, the new nurse at the hospital claims she is coming to visit us and wants to see my daughter. She doesn’t understand why she is on ART and does not come to the centre and is not monitored by anybody. I tried explaining to her but she will have nothing of it. She insists she will come home this week to see her, and I am very worried. I don’t want her to spoil all the gains I have made all these years.

I managed to explain the situation to the nurse, who for her part said that she did not know all this about the client and that there could be a way for her to arrange to meet Maakua’s daughter and still disguise it. She felt, however, that Maakua “was too defensive of her child to the extent that she was being too aggressive. It was because of her attitude that I threatened to go there. She is not

doing her child any good.” Luckily, several of the PLHIV did mention that when they had informed the home-based care officers that their presence in their homes would wreak havoc, they had managed to plan together ways to disguise the visits.

### *Disguised visits*

Some PLHIV arranged to meet the nurses outside of their homes at places they deemed convenient and safe, such as the market, school grounds, and even churches. These places served as a cover-up so that they would not be suspected. Kakra, for instance, described how she arranged a visit to the market to coincide with the nurse.

The nurse will call me in the morning to let me know she will be there at this particular time. I will then do everything I need to do for the day in order to meet her at that time. She will ‘flash’<sup>3</sup> my phone to alert me when she is around and then I will walk the few metres to the market. We will stop and talk for some time, continue walking, talk, shop, until we are done. I will then leave for home without anyone suspecting anything.

The idea here is that it is normal to bump into a friend or acquaintance at a public place, so it seldom raises any suspicion. It was considered by the ART clients to be very important that for the home visits it was possible for special arrangements to be made, minimal though they may be. They explained that as long as those coming for the visits alerted them of their coming, they could make the necessary arrangements to ensure that their HIV status is protected from those who they do not want to know.

Making arrangements for a disguised visit was one way of avoiding home visits. Unfortunately for the home-based care team, however, some of the PLHIV – rather than asking to make special arrangements away from the home – instead hid and asked other household members to tell them that they were not available, or simply walked out of their homes around the time of the visit so that they did not meet them. In such cases, they were not convinced that their safety could be guaranteed in the presence of the visitor, and yet they did not have the courage to turn down the invitation. In addition, running away from the visits happened when the PLHIV “were not ready to meet visitors,” or when they felt that they could not meet their obligations for the visit. In the latter case, Maapanyin clarified:

... although they see the visits as part of the duties of the visitors, they are obliged to find something, even if it is small, for them. You realize that they [the home visitors] take transport and come to you. At times, they walk a long distance to come to you, so you just cannot leave them to go like that. It is fine if you get them some money, foodstuffs, or anything you have, to show that you appreciate their coming.

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<sup>3</sup> To ‘flash’ is a popular term used in Ghana to indicate when a person calls (or is called on) a mobile phone but the call is cut after only a few seconds of ringing. This is a popular way of alerting others, since it comes at no cost because the receiver does not pick up the call.



In effect, though the PLHIV said that they understood the importance of the home visits, their inability to offer something to the home visitor in return, an act which they explained as a necessity, led to them rather escaping from the visit and thus avoiding the obligation altogether.

### *Agreed visits*

Another group of PLHIV agreed – either straight away or reluctantly – to be visited by the home-based care team when the request was made at the ART centre. Those who agreed straight away had sold their sickness, one way or another, to their family and household members (as discussed in the preceding chapter), and were therefore not too worried that the home visits would expose them further. They explained, however, that they must inform the home visitors about to whom – and what details about their sickness – they have disclosed, so that together they can devise strategies to keep their secret life hidden from those who they do not want to know it. This ensures that the home-based care team are circumspect in their interactions in the HIV positive person's household.

In the case of those who had accepted the visits reluctantly, they explained that since they had not agreed to any specific visitation day while at the hospital, they had assumed that it was just one of those things the nurses did “to make you feel fine.” Fosuhemaa explained that occasionally a nurse (or some nurses) visited her without prior arrangements, to see how she was coping with life in general. She said that if they had told her earlier about their intention to visit on a specific day, she might have told them that she would not be at home, because if she had her own way she would not want them to come to her house at all. She commented:

In fact, they told me at the hospital that they will be coming to my house, and asked whether I had any problems with it. In fact, the way they asked it, I couldn't say no. Initially, I didn't like the idea because I was not sure what to say when my husband [who is not aware of her positive status] confronts me. However, on the first visit, the nurse met him [the husband] and explained to him that I had met her [the nurse] in the market and have been of help when I returned money she had earlier dropped on her way. She explained that she had come to thank me because I did the unthinkable in this age where no one can be trusted. They [the husband and the nurse] instantly became friends and that has helped. They [the home-based care team] don't visit very often, but my husband calls her a lot when I am not very well. Usually, it is when she is leaving and I'm going to see her off that we discuss things. I was worried about how to let my husband know the situation before it becomes obvious but I am happy how things are now. With time, he will know.

It was during the home visits that the PLHIV mentioned that they saw the human side of the medical staff and therefore felt more at ease sharing their problems with them. Ellen indicated:

You hear them talk about their own difficulties, at home and even at the hospital. You then ask yourself whether they are the same people you meet at the hospital. They also have family problems and problems with their relationships. If you get to know all these, then you know you have someone to talk to. One who will truly understand you and offer you help.

During these home visits, they reveal their problems to the visitors, who do their best to offer help. Ruth described a situation when the peer educator who visited her found her very hungry:

When you are on medicines, you eat a lot. When I told them [the nurses and the peer educator] how I am unable to get that much food, they thought I was not serious because I am staying with my brother who is taking care of me. When he [the peer educator] came to my home, he realized that I was eating once a day because that was all he [her brother] could provide. That day, he came without prior notice to find out that I was so weak. I had taken my medicines on an empty stomach. Usually, I sleep the whole day, because I don't have enough strength to do anything. He [the peer educator] decided to register me for his association so I can get something small to add up to what my brother provides.

The problems of the PLHIV that are dealt with during home visits are largely medical – related to reactions to the medicines or issues that have arisen since their last visit. But very crucial to them is the opportunity they get to talk about other problems, which may not necessarily be related to the medication. These include issues of disclosure to spouses and other family members, financial difficulties, and especially inadequate food intake and sexual issues with partners.

### “Meeting with one’s kind”: Fellow positive persons

An important aspect of HIV positive people’s experiences at the hospitals was meeting fellow PLHIV. Massa described how different it is to meet someone who understands your situation, in contrast to experiences outside of the hospital premises where it could lead to one “being looked down on.” He used the expression “I meet my brother/kind (*m’ahyia me nua*) when I go to the centre.” New relationships are formed and developed between HIV positive persons that otherwise may not have been possible. Esther described the situation where people with a lower social status get to associate with others with a comparatively higher status, as “everybody is not everybody” (*obiara nnye obiara*), meaning ‘we are all equal’. She referred to the fact that HIV/AIDS does not respect people’s social status and can infect anyone: “Since we share the same fate, it was normal to see an educated teacher sharing the same seat with a common mason talking heartily and discussing their plight together.”

More often, these relationships were found to develop through mutual characteristics such as age, sex, place of residence, common illness experiences, and sociability, as well as having the same days for appointments. Daniel, describing how he made some friends at the ART centre, said:

When you get to the hospital on the same day [every month] with a particular group, you meet them often during subsequent visits. If on a particular occasion you don't see one, you ask about them. The next time you see them, you ask why they missed their appointment. If they tell you of any problem and you can help, you offer your help since it is difficult to

discuss this sickness with just anybody. Through that you develop some friendship. In fact, you just miss people if you don't see them around.

Such relationships also served as a tool in motivating them both directly and indirectly to continue therapy. When they see new faces or those who are not yet responding to the treatment, they share their experiences and strategies that have sustained them up to now. Most recounted that these interactions and friendships really motivated them to keep on fighting. Abiba explained:

If you see someone who is looking very fit and healthy, and s/he tells you that s/he had been in worse conditions than you are now, then when s/he advises you, you take it serious. We work very hard not to make the same mistakes they did and to a large extent it has helped.

Indirectly, some noted that they are motivated by the mere fact of seeing someone, who was at first so weak and sick, now being very fit. "S/he doesn't have to speak to you. You know you will make it too," Linda explained. Chief Appiah, the leader of one of the PLHIV associations, also affirmed this by noting:

We are always happy to meet each other and know how we are doing. If you are not well and you see everybody looking well, you are motivated to also get well. It is sad to go to the clinic and be told that someone known to you (*asomasi*) is dead. It is really sad.

During the fieldwork period, some PLHIV were taken to alternative sources of healing, such as prayer camps and local medicine men, because they were taken ill and none of their immediate family members knew that they were on ART and thus needed to be sent to the ART centre. Memunatu, who managed to return to the centre after a visit from a peer educator, mentioned that she was too weak to get to the centre on her own so she simply had to accept it when she was taken to a local healer by family. "By God's grace (*Nyame nkye adee*), I got better and rushed to the clinic," she clarified.

Those who were living in the same neighbourhood as other HIV positive persons they knew helped one another easily and promptly in such situations. They also developed a close bond of comradeship. In one neighbourhood in Kumasi, during most of my visits, including the impromptu ones, I saw the same group of PLHIV gathered together in one of their houses. Most interviews among this group took the form of a group discussion, since I met all of them together. This bond of friendship was a source of inspiration and filled them with a will to live. When a member was sick, the others informed the nurses at the hospital or arranged to get her/him to the hospital. As most family members were unaware of their status, these smaller groups, usually formed after meeting at the hospital, provided the care and support which otherwise would be provided by the family.

These warm relations among the PLHIV continue even after the death of a group member. Usually, it is those members who are in close contact who hear about the death, and in turn inform the other members at the hospital. The details

of the funeral rites are made known to the members and arrangements are made to attend. When the deceased is a client of a particular ART centre, it is not unusual to see some of the other clients travel to the funeral to pay their last respects. During some of the funerals attended during data collection, these PLHIV were found to be very active, just like families and friends. These observations show how close these PLHIV felt to the deceased.

*Extension of 'meeting one's kind'*

People living with HIV often meet one another at the hospital and start relationships that are extended to their homes, depending on their accessibility and proximity to one another. This relationship is further extended when they meet at associations that are formed to cater for their general well-being. As explained by Baba, a leader of the Preach the Word association, these groups are mainly formed by PLHIV who, based on "their knowledge and own experiences with living with the infection, bring together a number of the *plawas* [PLHIV]<sup>4</sup> and work together to ensure that they live positively with the infection." Some workers at the ART centres also collaborated with some of their clients to organize such associations. In the two communities studied, only one of the five associations was organized by someone who was not HIV positive or who worked with PLHIV. It must be noted that the PLHIV preferred fellow HIV positive persons to lead the organizations because they were afraid that other people might leak their status due to stigma (and even self-stigma).

All of these associations were registered as NGOs and therefore sourced for national and international funds to run the group. The main objective of all these groups was to create a support network for PLHIV through regular home visits and monthly meetings. Although it was the core objective of these associations to pay regular visits to members, it was only the leaders of the group who were mainly responsible for this task. The HIV positive people were more receptive to home visits by members of their associations and other leaders who were not medical personnel, than to the visits by the hospital staff.

As in all associations, those specifically set up for PLHIV had rules and regulations governing members, ranging from the necessity to attend monthly meetings to turning off phones during meetings. Even though the members are expected to pay monthly dues, the majority nevertheless do not pay. Most importantly, the members are forbidden to join more than one group at a time. Transfers from one group to another were possible, however, since all of the

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<sup>4</sup> Many of the PLHIV in these associations use the acronym PLWAs (people living with AIDS), pronounced *plawas*, probably because of their encounters with the various policy makers and NGO workers in the field.

various associations were under one national umbrella, the National Association of People Living with AIDS (NAP+).

### *The monthly meetings*

Each association met once a month, as agreed by its members. The leadership arranged the locations of meetings with the agreement of the majority of the members. These locations included school classrooms (usually during weekends), hospital premises, chapels, and the conference rooms of government departments. The meetings usually lasted two to three hours, and began at varying times (usually between 6 a.m. and 1 p.m.). The details of the meetings were generally similar to one another, with the main objective being to engage members in addressing their problems encountered in accessing ART. These problems were handled spiritually, emotionally, and physically.

Usually meetings start with a period of singing praises and worship songs and prayers that last between thirty and ninety minutes, at the discretion of the leader. After this, resource persons, mainly pastors who have been invited to preach hope and encourage the PLHIV to choose to live, talk to the members for again between thirty and ninety minutes. Most of the messages given are about the resource person's own life experiences, or the accounts of others, of coming out of very difficult situations. All of this precedes the physical aspect of the meeting, which consists of marking attendance, interactions between members, and the receipt of financial and food aid.

### *Meeting the spiritual needs*

Most meetings start and are interspersed with much singing, such as in a church service. Members sing in parts – soprano, alto, tenor – and the few men give out the crooked bass popularly known as *abotsi part*, which cannot be found on the keyboard. Most of the songs they sing seem to be meticulously selected to provide hope and encouragement to members, no matter what their differences. Below are the lyrics to one of the songs:

<i>Yeda w'ase a efata</i>	If we give you thanks, you deserve it
<i>Yeyi w'aye a efata</i>	If we give you praises, you deserve it
<i>W'ayi yen afiri owuo mu</i>	You have delivered us from death
<i>W'ama yen nkwa enni awiee</i>	And have given us everlasting life
<i>Nti yeda w'ase a efata</i>	So if we thank you, you deserve it

Martha (profiled in the case study below), the leader of two PLHIV associations – Life Assurance and Hope for the Best – explained that there is a conscious effort in her group to encourage members to sing good songs since it is a way of providing comfort, and the words are chosen carefully to send a particular

message. She explained that the song above is always sung to make the members focus on the purpose of existence and not on their suffering. She explained:

If God has delivered you from the hands of death, He can take you out of any problem or difficulty, if you wholly depend on Him. Those who depend on God, everything works out well, and ends well with them. It wouldn't be out of place if He performs a miracle on you

In the associations they devote a lot of time to prayers for forgiveness of sins and commitment of their selves into God's care. This is because many of the members think that their circumstance might be the result of their sins, and thus in order to be healed the sins must first be forgiven. Prayers are also said for their fellows who are not well and for the medical staff who take care of them. There is furthermore a constant reference to medicines and care by medical staff as an example of God's way of helping them out of their condition.

After the prayers, the resource persons take the stage and "share the word." The messages tend to follow a trend, where the focus is on providing members with hope in the midst of their current predicament. For instance, at the *Nkunikuo* (Victory association), a pastor who was brought in one day to encourage members used the biblical story of Jesus' encounter with a woman caught in adultery (see John 8: 1-11), stressing its implications and relevance to the association members. "No one can lay any stone on you so I won't do so ... and don't allow anyone to do that. But remember that Jesus also added, go and sin no more." The pastor asked them to all repeat "Go and sin no more." He then cautioned the group to "remember where you fell to get up. Go but don't get yourself in the same situation that got you the sickness."

All the resource persons whom I observed speaking at the association meetings also talked about an "eternal bliss out there for the members even if this world may not have dealt well with them." Osofo Maame, who is the 'resident pastor' for the Life Assurance association, once queried and commented:

What happens if you gain the whole world and lose your soul? It is God who has extended your life for a purpose. There are a lot of people who are in the same situation but do not know what is happening to them. They are wandering about looking for a cure, and they are not fortunate to be here to benefit from this. Remember what happened to Job. God allowed Satan to attack his body and not the soul. It is your bodies that are suffering but protect your soul.

Osofo Maame concluded by telling the members that there is hope (*anidasoo wo ho*), and asked them to repeat the phrase "there is hope." As can be seen above, repetition of words of hope are often used to uplift the souls of members. In an interview with Pastor Hagan, who visited the Christ our Hope Foundation, he explained that when the members pronounce these words of hope, "they claim these promises and it goes a long way to ginger their withering spirits and pep them up to face life. They may not know at the instance the effects of the repetitions but it works."

All of the members spoke highly of these words of encouragement that they hear monthly. Abiba, who belonged to the Hope for the Best association, said that she finds great delight in listening to the words of advice and encouragement. Although a Moslem, she travels a long distance from another region where she lives to attend the meeting. She indicated that the words of encouragement from the association “are very helpful and keep [her] going through the month,” and that it makes her “long for meeting days.” In fact, she explained that “I am always the first to be there and I don’t think it is going against my religion. A little from here and a little from there will keep us going.” She reckons, however, that but for her current ill health she would never have been open to the Christian teachings. She finds more solace in it now. Generally, the spiritual lives of these HIV positive people were characterized by the crossing of denominational and religious boundaries through compromise, reorientation, and sometimes conversion (see Kwansa 2010).

The members mentioned that one of the most enjoyable moments at the meetings is when the floor is opened for them to ask questions about issues bothering them. Some of the issues addressed here are about their religious lives, and how this relates to being HIV positive. “Everyone is allowed to ask her/his question, and none was declared stupid. The leaders are more understanding and accommodating since they appreciate better what we go through,” Ephraim explained. Below is a glimpse of the proceedings of the open forum during one of the sessions:

Member 1 [question to a pastor, resource person]: You say, and I believe, that when you rely wholly on God He can save you from every predicament. Some pastors advise that we fast when we go there [to consult with them for prayers]. Can we too do that?

Answer 1 [resource person]: You know, I’m not an expert in your medicines. I cannot say whether you should take or stop your medicines. What I can say is that fasting is between you and your God. You need something from your God.

Answer 2 [leader of the group, a Moslem and also a PLHIV]: You don’t have to do that [fast] under any circumstance. God knows and understands that you cannot fast. The medicines do not go with fasting. As for prayers it is good. Prayer is good. You see, the advice we received from the pastor is making all the Moslems think about converting to Christianity [he said jokingly *Se akromfoɔ mpo rekɔwia adee, ɔbɔ mpaɛ ansa na wakɔ* – Even a thief prays before he goes to steal], so we must all pray. But please don’t fast. [This led to explanations on default on first and second line drugs.]

Issues such as fasting, all night prayer sessions, and going to and staying at prayer camps, took centre stage each week in all the associations. They ranged from questions about such practices to reports about experiences with specific pastors and churches. The members therefore learned a lot from the presence of these resource persons and the experiences of other members.

### *Meeting the physical needs*

The physical aspects of the meetings commenced with the checking of records to take stock of membership. Those who have explanations as to why some members are not present or why they had not been present for some time are given the chance to provide these, while plans are made to go and look for absent members.

The first impression one gets in attending these monthly sessions is the sense of camaraderie exhibited by the members of the groups. There are greetings peculiar to each group, but all seemingly reinforce the need for solidarity among members. For instance, the Preach the Word association has its greeting as *Onua do* (meaning brotherly/sisterly love), with the response *entena ho daa* (always remain with us). This greeting was repeated as often as possible during meetings, both by the leaders and members. It was also exchanged when members met in town, giving each member a feeling of belonging. Another common theme was that of solidarity, often reiterated in all the groups, and exemplified in the statement of Chief Appiah, leader of the Christ our Hope Foundation, during one of the meetings:

We belong to different tribes, religious denominations, professions, etc., but one thing that brings us together is this sickness. You see in here your brother and your sister, and that is how you should live.

The names of most of these associations emphasize a feature that they stand for in the lives of the PLHIV. Hope for the Best, Life Assurance, Christ our Hope, and *Awurade beye kuo* (God Will Do It) are examples of the names of these PLHIV associations, which are created with the intention of bringing hope to the members.<sup>5</sup>

Also of importance is the emphasis they put on responsibility to oneself and others. The first responsibility is to choose to live. Baba, a leader of Preach the Word, regularly says, “If you are advised and you don’t take it you will die. If you are supposed to take your medicines, and you don’t, you will die.” For Martha, since the leaders of the associations are HIV positive, but also look very healthy, their counsel on choosing to live, and the practicalities involved in that, make more sense to the members, even more than when others (including medical staff that are not HIV positive) give such counsel.

Members of PLHIV associations are also made aware of the responsibilities they have to minimize the further spread of HIV. Statements such as “It will never happen that I will die alone” (*Se me nko ara mewuo deε, emmaso da*), which reflects a dominant perception about HIV positive people that they want to infect others so as not to be alone with the sickness, were discussed and coun-

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<sup>5</sup> For a list of all the associations in the Ashanti Region (as of 2008), see Appendix 5.



tered at the meetings. The members were also encouraged to talk about the infection with others when the opportunity arises. Mr. Nkansah contributed the following during a discussion in one of the associations:

Many people, especially the young ones, do not believe that this [the infection] is real. We owe it as a duty to advise our younger children who may be wandering about. We shouldn't make this happen to them too. It would be unfair if we allow it. Let us do our part and there would be a difference.

Baba also chipped in that:

... those days when our mothers came back [from their sojourns] with the illness, we say they crossed the river Bobosomewhere in Elubo [the border between Ghana and Cote d'Ivoire] and they had this sickness. But now we know. Let us take every opportunity to educate those we can so that people do not die unnecessarily like our mothers did.

Reports from representatives at the regional and national associations of HIV positive persons are read out and discussed in meetings. Members who have gone for workshops or conferences within the past month are also made to report back to the group. On one occasion, for instance, a representative came to share her experiences and report back on a training session on family planning for HIV positive people.

Furthermore, very personal issues weighing on the hearts of HIV positive people are brought up and discussed during meetings. These are mainly considered taboo subjects to broach in the hospital setting, and so even though they are bothered by them, the PLHIV do not talk about these issues with health workers. In one instance at the Hope for the Best association, when members were asked if they had any questions, the following interaction ensued:

Member question: Can we marry or not?<sup>6</sup>

[Other members start murmuring and from those sitting around, I could hear that they were saying "This same question is always asked when they come for meetings." But the resource person explained that everyone is free to ask whatever questions bother him or her.]

Answer [leader]: Of course, everyone is free to marry. I am married, as you all know. But as you know too, because of our condition you don't just get up and marry. There are some procedures to be followed and we often get resource persons here to teach us. So be rest assured, if you want to marry, it is possible but we will arrange and teach you all what to do first. You know we often talk a lot about family planning here; we will invite another resource person to talk about this later.

During the meetings in some of the associations, such as Life Assurance and *Nkunikuo*, members who have started love relationships are introduced, and the procedures that they had gone through to arrive at this stage where they are preparing for marriage are explained.

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<sup>6</sup> Marriage seemed to be a real and passionate concern of most of the HIV positive people, especially the younger ones of childbearing age. In-depth discussion on this can be found in Chapter 7.

Massa noted that these interactions, “apart from making them [PLHIV] part of the whole process, show that they are still human beings who have something to contribute somewhere, unlike what the other world seem to think about people infected with this sickness.” These associations seem to be the only places where PLHIV see themselves as normal human beings again. They were seen to be very happy singing, praying, sharing jokes, making fun of one another, and most importantly to them, contributing to the furtherance of the association.

Some of the members also go to the leaders privately, during and after meetings, to ask about and voice their concerns. Furthermore, many conversations and interactions were observed between members before, during, and after the meetings. Individual cliques were observed, and close friends busily updated one another on secrets, episodes, and experiences. People with similar experiences, and those who live together, tend to be closer. New friendships are started and new members are continually bombarded with questions. Most of the interactions are on strategies to manage the infection, at home and in the community. It is not unusual to start a conversation with someone at a meeting with the question “Are you on medicines?” or “Do you also experience [a particular side effect]?” I was asked on a number of occasions by some of the members whether I was on medicines, which often led to a discussion about my study. At the associations, “even when you don’t want to talk, the atmosphere created by the members would make you talk,” the rather reserved Serwaa indicated.

All of the associations were at one point or another engaged in income generating activities (IGAs), including mushroom farming, soap making, tie-dying, and livestock rearing. During the meetings, therefore, a substantial amount of time is devoted to outlining improvements and dealing with problems encountered in these IGAs. Although the IGAs are mostly initiatives by members to augment donor funds to run the associations, it was observed that a usual source of controversy and apprehension is about how the profits from these activities are shared. At the Preach the Word association, for instance, these misunderstandings had led to the termination of the soap making venture they were undertaking. This was because, as Baba explained, some of the members felt that “others were benefiting more, though [they] all contributed the same money towards the course.”

The behaviour of some of the members is sometimes openly detested during meetings. Such behaviours range from (extensive) coughing with uncovered mouths and spitting indiscriminately during the meetings, to non-adherence to the treatment regulations, including drinking alcohol, having unprotected sex, and deliberately infecting unsuspecting partners.

It was obvious during these meetings that the members were also highly suspicious of people whom they did not know to be one of them. Oftentimes the

leaders thus had to draw a link between the resource persons and the association members when introducing them, to eradicate this mistrust. Strenuous efforts were made by the leaders to let the members feel that the resource persons were one of them. For instance, once, when Baba was introducing a resource person who is a pastor, he explained:

He is one of us. He has removed whatever robe he is wearing and taken ours upon himself. Do you remember Madam [so and so], the counsellor who some time ago was coming to our meetings? She is very busy with the other association we are forming in Techiman. But today, we are lucky to have her husband here to speak to us. He's become one of us. So don't be scared that he is coming to see you here and then tell others about it. No! He wouldn't do that.

Another time at the *Awurade beye kuo* meeting, the leader kept reasserting that the resource person "is not like those you hear about. He is here to tell you his own experiences, unlike the people who come on radio." The pastors on the radio are, according to the PLHIV, known to be unsympathetic to their plight. In the messages of the resource persons, they were therefore mindful to associate themselves with the members. As one said, "One of the people who taught me in Bible School was living with HIV. You will never know unless you are told," and another also mentioned that her "older brother died of AIDS after living in denial for so long."

At the end of the meetings, a monthly amount of GHS 8 is given to all registered members. This is meant to cater for some of their ART expenses – chiefly the GHS 5 for the antiretroviral medicines – as well as transport costs to meetings and to the ART centre for treatment. As and when food items are available, they are also shared amongst the members. Unlike the food sent to their homes by the hospital, which they were uncomfortable about receiving because of the possibility that it may expose them and their secrets to others, they liked to receive food at the PLHIV association meetings since people outside of the group would not know about its source.

Below is an in-depth case study of Martha Osei, founder of the Hope for the Best and Life Assurance associations. The Hope for the Best and Life Assurance PLHIV associations both came out of the Single Parent Foundation (SPF), an NGO focused on single mothers and their children, and all three organizations were founded by one woman, Martha Osei. Martha began by teaching in a disabled school opened by her husband, where blind, deaf, and physically challenged people were given vocational training. SPF was originally founded on humanitarian grounds, because children in the community were often hanging around the disabled school, at times from morning until evening, in order to partake of the food offered to the students. Below is Martha's description of how she set up the various groups, services, and forms of assistance they offer, as well as the challenges they face.

I got to know that their parents died of HIV/AIDS and their plight was just representative of that of a wider segment of children in the community. I adopted these children, starting from seven in number to forty in the next year, and now about four hundred. After screening these orphans and vulnerable children (OVC) I realized that the majority of them were orphaned by HIV/AIDS. The parents of the children we had first in the group were traced to have contracted the illness from their stint in Cote d'Ivoire. Most of them too had spouses who had gone to Abidjan. Apart from looking after the kids, we also gave the parents some skills to live leading to the formation of the SPF.

That was how I first got involved with AIDS issues. I reported to the Social Welfare Office and they asked me to write a proposal to the GAC [Ghana AIDS Commission] in 2003. We realized that the rate of HIV infection was higher and yet there were no programmes in our community on it. We linked up with the District Assembly and that was when the Focal Person helped train me. I was later advised by friends and relatives to turn it into an NGO because of the growth, in order to get additional support to sustain the humanitarian grounding. That led to the formation of the Hope for the Best and the Life Assurance. We started with durbars, meeting chiefs and sensitizing people on HIV. During the sensitization campaign we make people aware of where to get CT [counselling and testing] and medicines. I became so busy that I didn't get time again to teach my kids [at the disabled school] so we employed others. I therefore started to focus solely on HIV and SPF entirely.

GAC gave us a medication – V-1 – which we gave to all those who were diagnosed HIV positive. By then, ARVs were not accessible in Offinso. This medicine is a magnesium dietary supplement product that increases CD4 and CD8 lymphocytes in normal and HIV infected adults and can also result in decrease in viral load. It also reverses weight loss and prolongs survival of people with HIV/AIDS. Earlier on we had herbal preparations from a hospital in the north [of Ghana].

Through the durbar, many people came to our office, and all doctors around directed their patients to us. The main problem was that they send the sick people around but not to the hospital. By the time they get to the hospital, they may have lost everything. They use their properties to take loans so at the death of the patient they are unable to look after their kids. In some of the cases, we will have to go home and cater for the patients – bathe them, and even feed them. We look after them till they die. And because of rejection we have to continue looking after the kids.

I don't really know why families continue to stigmatize their members. They still consider it as *akohwie yadee* [a disease for hopeless people], so you don't have to waste your time on them. One client who had support from a sister

because she thought she had shingles received all her love and support, but when her sister suspected she had AIDS she started giving excuses, such as by the time she dies she may have lost all her possessions. The reason why they refuse to care for them [HIV positive people] is that such people are seen as *egwamanbofoɔ* [immoral people], or people who have been cursed. In the past, we heard that there is a river in Cote d'Ivoire that you are cursed with. They say the god is so powerful that even if you keep someone's change, it can give you this disease. Also some make use of prostitutes and get an STI, which they linked to curses.

At that time, we didn't know anything about HIV, so we were unable to help them. So many deaths in the past could be attributed to that. They still travel to Cote d'Ivoire and bring back the disease. The men travel a lot, even these days. The majority of our members [more than 90%] are women. I think the women are more concerned with the future of their children so they do everything to live. For the men, shyness is the main factor. They are not comfortable with the fact that people will associate them with the infection. The few men who have come have just felt the need to resist that.

Hope for the Best was started in 2003 with twenty-one people and financed initially through poultry farming. We have had several trainings in income generating ventures such as soap, cream, and powder making, which we also use to fund our activities. In 2005/6, we received funds from GARFUND [Ghana AIDS Response Fund] and gave every member about GHS 100 as start-up capital for their own business. We also received some food products from Kristo Asafo [maize] and Catholic Relief Service [*Tom Brown*]. When the ART centre started here the CRS provision for food stopped because it was a catholic hospital and thus became the recipient of the items for our district.

The whole family [spouses and children] is involved in our activities. Due to the increase in membership and also the distance of some of the members, the group got divided – Hope for the Best maintained the meeting place and times, and those north up to Nkenkenu joined the Life Assurance. We have four meetings now in a month; 1<sup>st</sup> Saturday – SPF, 1<sup>st</sup> Monday – OVC, 3<sup>rd</sup> Monday – HFB, 3<sup>rd</sup> Saturday – LA.

We are careful how we deal with our members. Many people have tried to form NGOs to deal with PLHIV but have not succeeded because when infected people don't feel secured, they wouldn't join no matter the benefits. Our advantage is the SPF. It is the umbrella under which we have HFB, LA, OVC. We, the executives and members, only know about these but all others think because of the numbers we have divided the meetings days.

Some of the members who feel unsecured about a particular difficulty are addressed. For instance, one lady who met our resource person who knew the group was for the SPF asked us to relocate her, but that wasn't possible since we

don't have enough funds to pay her transportation. So she was advised to answer when queried by the resource person that she lived with someone who had lost his parents so she is representing them. That helped since the resource person was related to her husband.

When we started, because we had lots of the V-1, the private clinic [QCC] that had most of the cases referred them to us. We had other medicines – life oil and tablets – which was also used for the rashes associated with being infected. When the ART came in, we stopped. Previously, we were the first point of call – people who suspect they are infected at times come to us in secret. Usually, these people come at the end-stage of the sickness. Previously, when we had to travel to Kumasi, it was tiresome. It has helped the clients too but I think that most clients prefer travelling away from their communities. When people come to the meeting and meet others they don't want to see, they stop. At times they ask to be relocated. At the meeting, some of them share their experiences. Some are members and yet do not want to be on treatment. We pay everything for them and yet some do not want to go for the medicines. Some say it is stressful to take your medicines for life. So those who have benefited are made to share their stories, especially those who were near death. Some say they are tired of the medicines, especially when they start looking good. They stop going to the clinic and even the meetings.

So we offer our members the care they don't get from their family as a result of their infection, including visitation, food, money for medicines, and a job through IGA [income generating activities]. Initially, there was no ART centre here in Offinso so we paid their transportation for treatment in Kumasi. We bring resource persons who advise them on various issues, including nutrition. Also we bring in pastors to encourage them. The members think that when they stay home, they will die of worrying, so they are better off coming to the meetings.

Our main problem is about death. A number of our members are dying, mainly because of the side effects of the medicines, and also the effects of their secret lives. It is a great disincentive to our work. You want to see the fruits of your labour resulting in better, happier lives, and not death.

Some people too say on radio that they have a cure, that appeals more than the ART, which only manages. They don't advise them to take herbal preparations. We tell them that ART is not compatible with herbal treatment. We realized that herbs are not good for them because of the strength of their lungs and kidneys. It was found in the homes that they still take it at home. They make use of spiritualists. Due to these ideas that they have, we study the word and pray because we believe that whatever medicines you use can only be potent with God. And the worries too are taken care of.

Also, funds are not forthcoming, even from GAC, making us struggle to keep our programmes running. We cannot pay for the right personnel to even write proposals for more funds. The introduction of the health insurance has helped not just the clients but we the NGOs too. People infected with HIV get sick very often. We decided to pay for all their medications but it has become problematic with increase in members. We had so much arrears to pay. The NHIS [national health insurance scheme] has been helpful. NHIS does not cover everything, though only a small fraction is not covered. For the GHS 17 premium per member, we use monies received from ANCP [Australian NGO Cooperation Programme] to pay for that. We all agreed to cut down the allowance on meetings and use the difference for health insurance. Those who have already used their monies to register, we refund for them.

Another problem we have is with the health workers. Some of them act unprofessionally. You expect them to know better but branding people as AIDS people at the OPD is not the best [*se wonnim obi na wohyia no a, wofre no akoa bi*]. Even at home, when someone is sick, you pamper the person, you do everything to help out. This sickness is not easy. When you are told you get confused. I am told a member couldn't remember her age after she was diagnosed. None of the questions asked on her first visit was answered correctly. At that stage, nothing works well. Some do not come back if not treated well. After all, they will die anyway.

## Conclusion

Traditionally, the family is the main care giver of a sick person, with women bearing the greater responsibility. However, these traditional ways of caring for the sick have been influenced by modern biomedical treatment and religious beliefs and practices, as well as particular beliefs about specific illnesses. Other factors, such as the greater involvement of women in formal paid employment, widespread disruption of traditional gender roles, and the increasing instability of conjugal relations (Oppong 2004), have also affected family care for a sick person. Therapy management by families bequeathed as a result of the communal nature of Ghanaian society thus poses a dilemma for PLHIV. On the one hand, this communal life ensures help and care for sick people (Ulasi *et al.* 2009, Okoror *et al.* 2007). On the other hand, it can bring about stigmatization in the form of HIV positive persons not being allowed to interact with the family, owing to fear of exposure to the infection (Greeff *et al.* 2008, Iwelunmor *et al.* 2006, Hartwig *et al.* 2006). Stigma may also occur and the sick person may even be abandoned when the situation of the HIV positive person is deemed 'hopeless' (Manuh & Quashigah 2009), or when the family feels that caring for a sick

member might have adverse repercussions for the general well-being of the family, for instance in terms of finances or social status.

This chapter explored the shifting of familial responsibilities for the care of sick members onto others, as PLHIV exercise their agency by engaging and disengaging in particular relationships. Friends instead of family members perform the traditionally expected obligatory roles in therapy management. Friends therefore take on the role of family members, giving truth to the Akan saying that “some friends are better than siblings.” These friends include hospital staff, other HIV positive people, and home care professionals (including PLHIV associations), all of whom know the status of the HIV positive person.

When a person receives the diagnosis of being HIV positive and goes to the ART centre, s/he decides on whether to trust the information received from the nurses and doctors – namely that if they adhere to the prescriptions of the medical staff, they will regain their life. Mitchell & Loustau (1981) note that:

When a patient-client enters the hospital ... he looks for behaviour, which suggests that a particular person merits his trust. When trust has developed, the individual will be willing to share his thoughts, feelings, and experience; he will be confident and comfortable in asking for help or accepting help when it is offered. If the ratio of mistrust is high, the patient-client may be guarded in what he shares with you or other members of the staff.

Such an attitude may explain why the first experiences of PLHIV at the ART centres are usually ones of nervousness, anxiety, and suspicion. At this stage, the nurses and hospital staff in general adapt their professional duties to the patients' realities, thereby gaining their trust. When the HIV positive persons come to terms with their situation, start believing in the regimen, and find reasons to confide in the nurses, doctors, and fellow PLHIV, they open up and may develop very cordial relationships, all as a consequence of trust. They lose certain aspects of their habitus while seeking and finding new ones: doing without relationships they find threatening and engaging in new ones with new friends. They are guarded in what they share with the majority of their family and with the friends with whom they have older relationships, because they may not trust such people with their secret. At this stage they interpret sympathy from these associates as merely an expression of stigma (see also Coleman 1986).

As this chapter has shown, the main consideration for accepting new friendships amidst the high levels of stigma associated with HIV is trust. The PLHIV may have internalized the stigma, and therefore as a reaction they easily mistrust other people's behaviours. Several scholars, including Sarpong (2009), have noted that in order to support a person with a serious sickness, it is important for care givers to establish trust. Trust is engendered by confidentiality and expected, consistent, and predictable reactions. This trust forms the basis of a continuous and consistent relationship (Meize-Grochowski 1984), rests on feelings of inner satisfaction that are an offshoot of the relationship (Topalis & Aguilera 1978),



and develops based on the experiences in the relationship (Erickson 1963). Only with those whom the PLHIV trust, therefore, do they share their secrets. Families were least trusted by the HIV positive persons in this study because they either did not want to be stigmatized by them or they did not want their families to experience the courtesy stigma due to their infection.

There is also a strong element of reciprocity in care for the sick. Someone who has been helpful cannot – and should not – be abandoned when they need care and support in times of ill health. Some of the HIV positive people therefore expected care and support from families and friends whom they had helped prior to their infection. However, due to the fact that HIV/AIDS is highly stigmatized, the persons whom they may have helped feel under no obligation to reciprocate it, and furthermore the HIV positive persons cannot demand it since they have lost the respect of society (Link & Phelan 2001). They have thus lost any social investments previously made because of their current predicament. Secondly, the majority of the PLHIV had not contributed enough social capital to rely on in their time of need. Their siblings therefore shun them on the basis that it would be a drain on their own scarce resources – resources that would be wasted on those who had not contributed much and had no signs of doing so in the future.

Another aspect of reciprocity is the giving of gifts. People in Ghana give gifts for several reasons. In the public sectors people are known to give gifts in order to speed up the usually slow bureaucracies in the system. Since the issue of gift giving to hospital staff was greatly linked to the receipt of preferential treatment, the gifts can be explained as similar to interactions in the normal social and institutionalized bureaucracies. Furthermore, in their bid to keep some people (including hospital staff) close so that they will not disclose their status, some of the HIV positive persons, under the cover of a show of appreciation, give gifts. The fear of the possible leaking of their private information by someone they have trusted makes them feel responsible to ‘show appreciation’, even when they do not have the means. Inability to fulfil this responsibility actually keeps some people from going to the ART facilities for treatment, while others refuse home-based care because they cannot offer any gifts of appreciation. The practice of giving gifts as a genuine show of appreciation for the good work of friends should not, however, be underestimated. Friends are a source of joy and the essence of living for the majority of PLHIV. Most especially, such friendships help re-establish the sense of respect that PLHIV have lost in society, since they help them to “feel human” again. In activating and deactivating relationships, the HIV positive people therefore find strategies, such as gift giving, to maintain or regain their lost honour in society.

Accepting to enrol in ART, going to the treatment centres, joining PLHIV associations and participating in their activities, shunning previous relationships

with family, friends, and love ones, and committing to new ones, may all be explained as the result of trust in the medical staff, treatment regimen, fellow HIV positive persons, NGO staff, as well as an attempt to maintain or redeem their lost stature in society. The HIV positive persons therefore find in these friends a sense of acceptance, belonging, camaraderie, and conviviality, which they may not have had in their past relationships. They rely on these new relationships for their physical, familial, material, spiritual, and especially emotional and psychological needs and support. The PLHIV also acknowledge the fragility of the lives they have entrusted to these friends, and the risks involved in these new relationships. Due to the enormity of the consequences of mistrust, they are thus still on the lookout and try to prevent their status from being found out. Any action that may lead to suspicion or mistrust was thus detested. They activate and deactivate relationships depending on the extent to which they can trust the other party.

It is often unheard of to imagine societies known for their communality, such as most African societies, to abandon their members in times of serious sickness. The usual cliché is that of families who sell their property, take out loans, and even risk family cohesion in their effort to restore the health of one member, however hopeless the situation might be. Caring for a sick member is perceived as a sacred responsibility, to be accounted for to the Supreme Being, and most especially to the ancestors who are the custodians of the family and its properties, including all the members (Crentsil 2007). Even though evidence from this chapter shows that the majority of HIV positive people had to rely on persons other than family members for care and support for their sickness, there was ample evidence of families and siblings who drained their resources to care for their relative. Nonetheless, in the majority of these cases, the siblings and family members did not exactly know that their member was HIV positive.

The next chapter discusses the financial experiences of people living with HIV. It shows that money is one of the main challenges in living with the infection, and highlights the fact that money (or the lack thereof) in some cases leads to vulnerability for PLHIV, while in other cases it protects them. It kills some, and keeps others alive.