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

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## Ethnography in a highly sensitive setting

Since the beginning of large scale systematic efforts by the Ghana Health Service (GHS) to provide ART to people living with HIV/AIDS in 2001, more than 140 sites have been set up to provide counselling, testing, and antiretroviral services countrywide. About a fifth of these sites are located in the Ashanti Region, and include Kumasi South, Bomso, Komfo Anokye Teaching Hospital, Obuasi Government Hospital, Pramso, St. Patrick's Hospital, Offinso, Obuasi AngloGold Ashanti Hospital, Adansi West MOH clinic, among others.<sup>1</sup> Our research was centred in the Ashanti Region, with case studies conducted in Kumasi and Offinso. Communities around the Komfo Anokye and St. Patrick's Hospitals in Kumasi and Maase Offinso respectively were used for the study. This chapter explores the communities studied and how data for the study was collected.

### Getting clearance

Under the present regulations of the GHS, research that requires multiple interviews and prolonged observations must be subjected to scrutiny by the Ethics Committee of the GHS Health Research Unit (HRU). Established in 1990 by a policy of the Ministry of Health, and later incorporated into the GHS in 2002, the HRU has the mandate to coordinate and conduct research into health-related issues to facilitate policy formulation and programme implementation. The process of obtaining clearance from the HRU started in advance, before the

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<sup>1</sup> Find the full list of Ashanti Region VCT/ART sites in Appendix 1.

period for data collection was due to commence, with the sending of a letter of introduction from the Amsterdam Institute for Social Science Research (AISSR) along with the research proposal. After a series of reviews by the committee, permission was granted. However, additional clearance was needed for the institutional aspect of the project. The Internal Ethics Committees of Komfo Anokye and St. Patrick's Hospitals also granted clearance after a series of reviews. A detailed description of the process of gaining access to the hospitals can be found in Dapaah (2012: 19-22).

### *The respondents*

This study sought consent from the main actors accessing VCT and ART services in the Ashanti Region. These included HIV positive persons, their close relations and friends (mainly caregivers and associates), care and support groups in the communities, and key informants comprising those who could provide information deemed necessary for understanding the phenomenon under study. The process was such that after I had gained access to the participants, the objectives of the research were relayed to them, mainly in the *Twi* language. They were also informed about the possibility of withdrawing from the project any time they wished, with or without directly informing me. It was only when the potential candidate understood and consented, mainly verbally, did the research begin.

The absolute confidentiality of all the respondents was assured. The participants were, for instance, duly informed that once I had their personal information and socio-demographic data, this knowledge would be presented in the report such that each person's identity would be hidden. In this report, therefore, all the names presented are pseudonyms and all sensitive information that might reveal the respondents' identities has been withheld. All those I interviewed were aware of my intentions and agreed to cooperate. In some circumstances, however, confidentiality of the clients was broken for the good of the client; these were mainly cases where I judged the respondent(s) to have been in danger. For instance, the actions of a particular health worker in one of the hospitals were preventing some clients from fully accessing ART. Though the respondents feared victimization if they reported the case, I found ways of engaging the medical doctors in order to rectify the problem. The said health worker was cautioned, and the client whose identity had to be made known to the doctor in order to justify the report resumed therapy afterwards. In other cases, some respondents were found to be taking alcohol and having unprotected sex with uninfected (or untested) partners. These issues (though not the individual respondents) were reported to the leaders of the associations for PLHIV, so that

more attention would be drawn to such issues during the meetings, albeit in general terms.

Some potential participants refused to go on with the process after the objectives had been spelled out. Their reasons were mainly related to doubts about the confidentiality of the research process. A few, however, came back to be enrolled later as they realized that the status and safety of their colleagues already in the research was not being jeopardized. In all, forty-nine HIV positive respondents – thirty female and nineteen male – were followed over a period of more than fifteen months, and about the same number of people were casually and informally conversed with during the same period. Unless otherwise stated, the major descriptions of PLHIV in this book are of the forty-nine people who were followed extensively. Because of the purposive nature of the selection of these respondents, it may be assumed that their stories represent to a large extent the greater population of HIV positive people in the Ashanti Region.

Between 2008 and 2011, only about a fifth of the population of PLHIV in the Ashanti Region were male, based on information from the Ashanti Region leadership of the National Association of Positive Persons (NA+). Their ages ranged from under one year to seventy-five. Of those sampled for in-depth study, four fifths were between fifteen and forty-five years, while only two females were below fifteen years. The age profile of these HIV positive people is typical of a young population – with a mean and modal age of thirty and twenty-seven years respectively – characterized by high fertility: the majority had between three and six biological children. This is also true for the general population (GDHS 2008). Data presented for this study cut across and thus represent all stages of life of an HIV positive person.

About half of the males and a quarter of the females had a level of formal education and were literate in English and/or Twi, the majority having a Middle School Leaving Certificate or a Junior High School equivalent of formal education. None of those followed had received a tertiary education. About ninety percent of respondents said that they came from southern Ghana, with the majority being Akan. The remainder came from northern Ghana, and two from the Volta Region. Only one person had not travelled outside of her current place of residence. The majority had lived in bigger cities, and a fifth had lived outside of Ghana: in Nigeria, Cote d'Ivoire, Benin, and Togo. Two had lived outside of Africa. Mobility therefore characterized their lives. Consequently, these HIV positive persons may have been exposed to other cultures and ways of life outside their milieu, and therefore may not have felt so subject to customary sanctions, especially those they considered archaic, arduous, or time consuming (see Kwansa 2005).

About half of the PLHIV followed were Christians, the other half being Moslem. A few said that they were either traditionalists or did not belong to any religion. Of the larger population of PLHIV, on the other hand, it seemed from the membership of the five PLHIV associations that I worked with in the Ashanti Region that the majority were Moslem. In their search for healing, however, they made pragmatic choices in their use of ‘spiritual therapy’, in order to give meaning to their predicament or extend their coping mechanisms (see Kwansa 2010). The term spiritual therapy is used here to indicate subscribing to the use of magico-religious concepts, acts, and symbolism in one’s bid to find relief and/or a solution to a health predicament. In Ghana, these include soliciting therapy from *akɔmfɔɔ* (traditional priests; *ɔkɔmfɔɔ*, singular), *asɔfɔɔ* (mainly pastors from the Pentecostal Charismatic Churches; *ɔsɔfɔɔ*, singular), *adunsifoɔ* (traditional healers known to use spiritual therapy for diagnosis, treatment, and protection; *odunsini*, singular), and *mallams* (men learned in Quranic studies, including Islamic healers; *mallam*, singular).

## Fieldwork methods

This study aimed to discover people’s attitudes and practices with regards to HIV/AIDS, and especially to explore the motivations for accessing VCT and ART services. The main objective when collecting such data was to find a way to grasp, understand, and convey participants’ understandings of the issues at stake. Great tact and circumspection was needed because of the highly sensitive nature of HIV-related issues in Ghana. To arrive at the infected peoples’ perspectives, therefore, anthropological tools including observation, listening to life histories, expressive autobiographical interviews, and focus group discussions were used to elicit information. In this section I specifically highlight the methodological issues relevant to community research, arranged in three stages. The first section, about gaining entrée, discusses the selection of respondents and how I settled into the field; although I am myself a Ghanaian, because I am not from the area I was not familiar with the setting and needed to undergo a process of re-socialization. The second section discusses life in the field and data collection. The third section discusses post-fieldwork experiences. First, however, I provide a cursory look at the communities studied, in order to understand the interconnectedness of much of daily life.

### *The physical setting*

Offinso is located about thirty-six kilometres to the north of Kumasi. Maase Offinso is a rather small town with a population of about 100,000 people, but boasts the St. Patrick’s Hospital, which serves the local community and the numerous others in its over fifty kilometre catchment area. St. Patrick’s is a

Catholic Mission Hospital, and one of the few hospitals that is not government owned that provides VCT and ART services in the Ashanti Region. Offinso Newtown has a well planned layout. A concentration of buildings housing government offices and the palace of Nana Offinsohene, paramount chief of the Offinso traditional area, ushers one into the town. The secondary roads are still untarred. Most of the buildings in the central part of Offinso Newtown are cement block buildings of up to three storeys, while the majority of the buildings in the other suburbs are mainly mud houses, vulnerable to the frequent down-pours of rain. Offinso, compared to the bigger cities such as Kumasi, is less noisy and represents a steadily expanding town due to the recent springing up of branches of government agencies and financial institutions there.

Kumasi, on the other hand, was founded in the seventeenth century on an ancient trade route, which connected trans-Saharan trade with the southern coast. It has a long history of being inhabited by immigrants and has thus been a multi-cultural terrain (see Maxwell 1928, Schildkrout 1970). Billed as the 'Garden City of West Africa,' Kumasi is zoned into commercial, industrial, and residential areas. Kumasi is also popularly called the commercial capital of Ghana, with the *Kejetia* market rivalling *Onitsha* in Nigeria as West Africa's largest open-air market. It is the Ashanti regional capital and represents a youthful, densely populated, active, and noisy locus of Ghanaian urban life. The central business districts of *Adum*, *Kejetia*, *Central Market*, etc. are characterized by brisk trading activities and vehicular congestion.

The major streets of both towns are lined with small enterprises, mainly stores built in homes, kiosks, and table top sellers. These shops are made of either plywood or metal sheets nailed or welded together into hexagonal shapes, with doors or windows cut into them for access and ventilation. Companies, chiefly telecommunications and food, have branded these shops with their products for advertising. Compared to Offinso and other towns in the Ashanti Region, Kumasi has more modern infrastructure and facilities such as nice houses, good roads, electricity, sanitation, post offices, markets, police stations, and lorry stations, and amenities like water facilities, among others.

Housing is effectively controlled by the private sector, whether through private renting or individual construction on land obtained through the traditional land allocation system. In the residential areas in Kumasi, houses are built close together, and the streets are mainly paved, tarred, or gravelled, making more obvious its beautiful landmarks. Remarkably, many houses are clustered in such a way that you find one or two of the spacious homes of professionals or business people located in the midst of the small zinc roofed houses of the lower class. The majority, however, are compound houses inhabited by the extended families of locals and foreigners alike, with an average of five families living either in

single rooms or 'chamber and halls'<sup>2</sup> on one compound. A significant number of the homes visited in this study were those that the respondents had either built themselves or partly helped to build. More than half of the households consisted of members of the conjugal family and relatives who were somewhat permanent members of the household, such as in-laws, parents, and the children of siblings.

None of the homes visited had floors finished with tiles or terrazzo, and only about ten percent were finished with rubber carpets, though the majority of the floors were cemented. More than ninety percent used charcoal and wood as their main source of fuel for cooking, with about a fifth, mainly those in Kumasi, using liquefied petroleum gas (LPG) in combination with charcoal and/or wood. A significant portion of those in Offinso and a few in Kumasi used earthen pots for cooking. Very few claimed to have separate kitchens, and the majority of the houses visited showed that food was mainly prepared in the open. There is very little privacy in these homes, and as the reader will notice, for the HIV positive persons who kept their status secret, these arrangements affected their daily routines such as taking pills, and in terms of keeping their atrophic bodies away from the gaze of housemates.

In these compound houses, a particular household shares utilities depending on the usage. The more members of a particular household and the more gadgets one uses (in the case of electricity), the greater the share of the bill one is likely to pay. Cleaning of the house, mainly the common places such as toilets, pipe stands, bathrooms, and the compound, is rotated among the tenants in a particular house. Women and children were most likely to undertake those tasks. Single men may be exempted from these domestic chores, although observations showed that they compensate their fellow housemates financially by, for instance, giving tips to those who do the work. Single men may also allow members of the house to come and watch movies and/or particular programmes on television, mainly soap operas, since they may be the sole owner of a television in the house. Many of the houses visited had television sets and radio-cassette players; the majority being second hand products obtained courtesy of the massive dumping of used products from Europe (for re-usage), mainly electronics, in the country. People enjoy the intimacy of living together through regular contact at home and through other group activities such as watching television together. A few had CD and DVD players, the latter of which they use to show mainly Nigerian and local Ghanaian movies. Appreciation of the importance of this arrangement is necessary in order to understand in later discussions how awful it is to be shunned as a result of living with HIV.

It was also not unusual to find some household members rearing animals in their homes, even though in some of the homes the animals cause a foul smell.

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<sup>2</sup> Chamber and hall are used in Ghana to refer to the bedroom and living room, respectively.

The practice of animal husbandry is not uncommon in other parts of the country; these animals may be sold or slaughtered and eaten to augment the family's source of protein in their diet. Related to this are also backyard gardens where vegetables and other foodstuffs are grown to add to the family's food basket.

While piped water is available in most parts of the city, the majority of poor households did not have individual connections and so depended on purchasing water from private taps at prices considerably higher than the costs through the Ghana Water Company. Others obtained water from polluted streams. Water provision is particularly poor on the urban periphery where there is rapid urban growth. Even where there is a piped network in the area, water pressure is often inadequate and the service is not continuous. These inadequacies impinge particularly on the poor, not just in terms of cost and time spent collecting water, but also in terms of undermining informal sector businesses such as food processing, which depend on good supplies of potable water. Many of the women in the study who operated such businesses had to spend much time and effort searching for and collecting water, usually at night.

The government has long been the main provider of public facilities and service utilities. In the late 1920s, Maxwell (1928) noted how government provisions in the areas of markets and sheds, abattoirs, incinerators, and latrines had greatly improved sanitation in the region. The region has continued to benefit from government provisions, and quite recently from the share of Heavily Indebted Poor Countries (HIPC) funds, by getting a number of public toilets and boreholes to boost sanitary conditions. During the time of fieldwork, waste collection was provided door to door only in high income areas. Generally, sanitation and drainage remain totally inadequate, with pollution and flooding posing serious problems in the communities. Only thirty percent of observed households had satisfactory sanitation arrangements in their homes, while fourteen percent used very unhygienic systems, including latrine buckets. Nearly forty percent of residents depended on public toilets, for which there are often queues. The majority complemented use of public toilets with use of fallowed or yet-to-be explored land, which are never inadequate, especially outside of the capital Kumasi. The environmental sanitation of some of these areas is therefore poor.

Regarding electricity, supplies are more widely available, with ninety percent of the communities observed in Kumasi and the surrounding villages, including Offinso, being covered by the network. The supply of electricity to these communities, like all connected to the national grid, was not reliable, however, with the tendency for electric power to go off any time without notice. Voltage drops were very common in the early evening. One noticeable feature of the use of electricity in the region, and in fact in Ghana as a whole, is the use of overhead

poles, which in the region compete for airspace with the many aerial television antennas flying high in the sky.

Public transport is also almost entirely a private sector activity and can be seen in the use of *trotros* and taxis,<sup>3</sup> though very recently a government owned bus service has been introduced by the newly created Metro Mass Transport Limited. Although there is competition, public transport is heavily dominated by two rival motor transport unions, the Ghana Private Road Transport Union and the Progressive Transport Owners Association. On the whole, public transport appears to be accessible to the poor, although operators are sometimes able to exploit the great demand for their services (for example, by cutting journeys short and demanding an additional fare to restart the journey). The people in this study used mainly public transport as the majority belonged to the lower-middle wealth quintile.

The country's net enrolment ratio in primary school increased from 81% in 2006/07 to 88.5% in both 2008/09 and 2009/10, while the gross enrolment ratio reached 95% in 2007/08 and has virtually remained at that level for three consecutive years (figures from MoE 2009). Figures for the Ashanti Region for 2009/10 were 82.9% and 92.3% for net and gross enrolment respectively (MoE 2009). These figures are higher than in previous years, especially in this era of FCUBE and the Capitation Grant<sup>4</sup>, when children of primary school going age are expected to be in school and also fed at least one meal. In 2009, the government again introduced a policy to provide school uniforms for all basic schools,

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<sup>3</sup> *Trotro* is a minibus which take up to fifteen passengers who travel together, and this is the main means of transport. Taxis in Ghana are not used by passengers exclusively unless 'chartered' or hired. The normal situation is for a taxi to pick up at least four passengers, and to drive to a specified location following a specific route. Passengers are free to alight anywhere along the route. In case a passenger wants a taxi to take her/him to a place outside the route or when s/he wants to have exclusive use of the taxi, s/he negotiates with the driver and an amount is agreed upon. In some localities, however, the fee for short distances is pre-set. For instance, at the time of the first phase of fieldwork, all short distances in Offinso cost GHS 1.50. See Chapter 6 for pictures of *trotros* and taxis in Kejetia, Kumasi.

<sup>4</sup> In 1996, the Government of Ghana introduced the Free Compulsory Basic Education (FCUBE) programme, applicable to every school aged child. The FCUBE programme is being implemented in fulfilment of the Fourth Republican Constitutional Mandate (Chapter 6 Section 38 Sub-Section 2). The main policy goal of the FCUBE programme is to provide opportunities for every school age child in Ghana to receive quality basic education. The Government of Ghana is solely responsible for funding the FCUBE programme using a number of instruments, including the Capitation Grants, District Assemblies Common Fund (DACF), and the Ghana Education Trust Fund (GETFUND). In 2005 the Government of Ghana, through the Ministry of Education, abolished school fees nationwide for basic education and introduced a Capitation Grant for all basic schools, after a successful pilot in 2004. The main objective of the Capitation Grant is to effectively address poverty – one of the main barriers to access to education. The grant demonstrated that eliminating school fees has a substantial impact on enrolment. The increase in enrolment, however, has led to a number of emerging challenges, including shortages of teachers (especially in remote areas), inadequate school infrastructure, and implications for financing that could negatively affect the quality of teaching and learning, and thus learning outcomes.

and it is hoped that this will further increase enrolment. Enrolment and retention rates are particularly low among poor migrant communities from the north, however, and are significantly lower for females than for males.

### *Life in the localities*

In Kumasi, as early as five a.m., honks from the horns of mainly commercial vehicles can be heard loading and transporting traders and other travellers to the centre of town. Shops are already getting ready to open by half past six. By half past seven, the locality will be noisy and busy as traders (both men and women) walk through the streets carrying their wares. Most women carry wares on their heads, while the men use a cart. Others sit in front of their houses at their table top, or in their kiosk or shop, displaying their wares – clothing (both used and new), processed foods, cooking ingredients, electrical parts, etc. In Offinso, however, life is slower. The majority leave home to go to their work places, mainly farms and stores, after seven o'clock.

In the mid-afternoon, clusters of uniformed schoolchildren wander home-wards, while most workers in the informal sector also prepare to leave for home. The football parks are filled with exuberant youth, the majority of whom watch the day's matches between area champions, while others discuss previous matches played either in the domestic premier league or the foreign leagues. In both communities, the activities of drinking bar operators, vans (including those of the Information Services Department), and trucks advertising wares such as traditional medicines, mobile telecommunication products, and CDs/DVDs, add more life to daily activities. Many trucks have giant public address systems mounted on them and music blares from the speakers to deafening heights, while people dance on, beside, behind, and in front of them.

During the night one sees the flickering of the kerosene lamps of traders along the streets selling food such as fried rice and chicken (*check check*), *kenkey* and fish, and fruits. In Kumasi, some electrical and CD/DVD shops also work through the early periods of the night. Most families gather around their television sets watching programmes, including the news and (mainly Nigerian) films. Those without television sets crowd around those found in provision shops, communication centres, and drinking bars to enjoy their favourite evening programmes and films.

From Thursday to Sunday, one finds mourners at funerals, mostly gathered in school parks or sitting outside the house, under the shade of a large tarpaulin, accompanied by the blaring sounds of giant speakers. The numerous church organizations found in these localities announce their presence with their morning, afternoon, and evening prayer, healing, and deliverance sessions on specific days, and Saturday and Sunday worship sessions. Screaming, chanting, and

ecstatic singing and band ministrations characterize most of these homes and communities. Rich people are therefore socially adored since they are expected to grace these programmes and offer their donations.

### My stage of re-socialization and selection of respondents

During this stage, I found, was offered, and accepted lines of communication and vantage points through and from which I was permitted to participate. It was at this stage that the character, scope, and emphasis of the problems being investigated were determined. The following section considers these for both the Offinso and Kumasi communities.

#### *Gaining entrée into the Offinso communities*

Given the interconnectedness of so much of social life, I tried to live with or near the people I was studying during the entirety of their daily lives. My agenda, as in all fieldworks and as Baumann (1996: 2) puts it, “... [was] to live locally, socialize locally, find local things to do,” and find possible ways of getting access to the participants without erecting the otherwise obvious suspicions. The original plan was to get to know the people living with HIV through Dapaah’s (my colleague undertaking the hospital perspective) links in the hospitals. This, however, did not prove feasible in the beginning. Nurse Rose, the nurse in charge of the facility in Offinso and of home visits, claimed that she had used her own funds to conduct the last round of home visits and was therefore waiting to be reimbursed before she resumed them. She was not prepared to let me pay for the trips, not even after much insistence on my part, because “the hospital [was] not living up to its responsibilities.” In addition, the ART facility was understaffed and she could not also “create time out of [her] busy schedules to go for home visits with funds that would not be refunded.”

On some occasions when I was at the hospital trying to arrange home visits, Nurse Rose suggested that I help her out with her duties, which included registering new clients, taking vital signs, and running errands. I was compelled to ‘help’ since I could not look on while she became overwhelmed with her duties, especially not after her request. I also felt that it was one way of personally creating a rapport with Nurse Rose, to perhaps encourage her to rethink her decision about the home visits (after some weeks, Nurse Rose did indeed finally agree to help me out). The original plan to keep entirely away from the hospital premises therefore changed.

This change in strategy, however, had both negative and positive consequences. On the negative side, since I was involved in the normal schedules – picking up folders, taking vital signs, registering new clients, etc. – the respondents from the outset identified me as hospital staff and later on I frequently had to relay my

researcher role to them. Gradually, they got used to this and afterwards used me as a middleman to get more information about HIV infection, treatment, and other issues that they could not (or did not) get answers to from the hospital staff. My presence in the hospital initially led to my research veering into the hospital-based study of Dapaah. This we corrected later on, after I stopped going to the hospital to get respondents. On the positive side, and as envisaged, my presence at the facility provided a good rapport with Nurse Rose in particular, as well as with the other workers, who felt obliged to return the favour by helping me to access the clients in their homes. In fact, after about three weeks of working at the facility, Nurse Rose went out of her way to take me to the clients, even before she had received her refund. In addition, I also had personal contacts with the clients due to my interactions with them at the hospital and developed a good rapport, which paid great dividends in the field. It also ensured that they got to know me and the objectives of my research prior to the home visits, and thus they readily accepted me into their homes. This also provided the clients with an explanation to give to members of their household concerning my mission. Some explained freely that I worked in the hospital where they were being treated and I had been charged to see to their welfare, accounting for the frequent home visits, which made them to feel safer about sitting with me and discussing issues without fear of giving up their secrets.

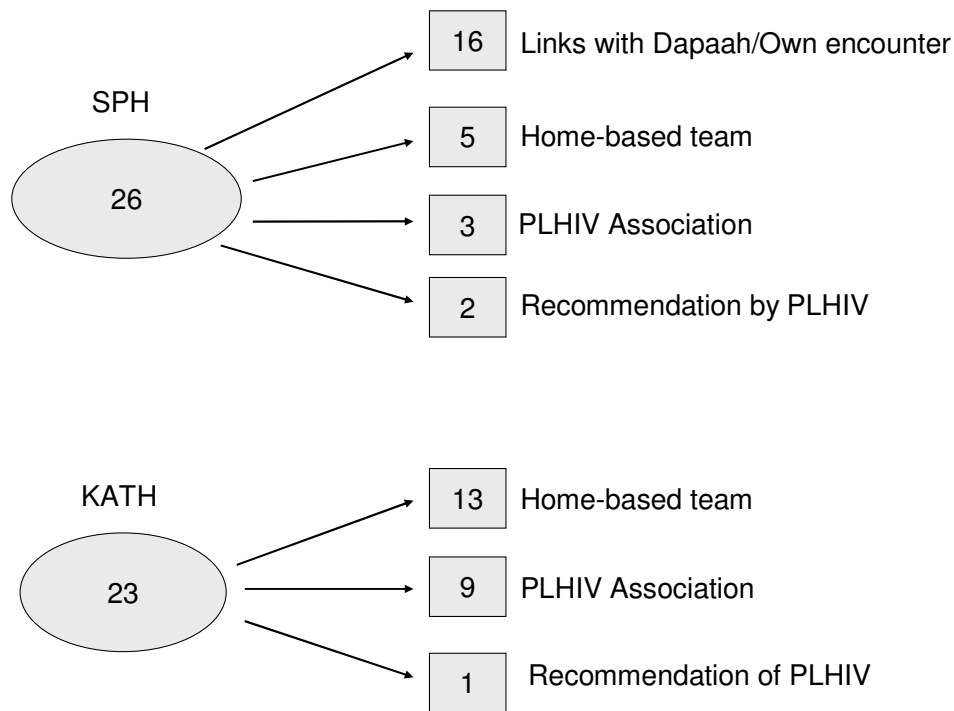
This notwithstanding, there were a few occasions when I was compelled to go to the facility to meet a respondent, for instance where I had consistently not been able to meet the client at home. On such occasions I liaised with Dapaah and/or Nurse Rose at the hospital to meet them on their next appointed day. In another specific case, Afranowaa, who lived across from my house, could not identify any other place for our meetings where she felt safe enough to talk. We therefore decided to meet at the facility during her appointments in order to have our conversations.

By January 2008, about three months into the study, Nurse Rose and I had visited more than twenty-eight clients from St. Patrick's Hospital, ten of whom had been selected for systematic study based on their rich level of knowledge *vis-a-vis* the purpose and focus of the study (Patton 1990, Punch 1998). In all, out of the twenty-six respondents recruited from the communities that were served by St. Patrick's, sixteen were enlisted through contacts from the hospital (see Figure 2.1).

The selection of candidates for the project was based on considerations of the social setting and the area of study, as well as the relevant concepts, all of which outlined some criteria of interest. Selection of the respondents was primarily based not only on finding cases that were similar but also those that were considerably different from each other. In addition, cases were selected when the

potential to provide logical generalizations of the experiences being studied had been established. Very few of the cases were based on considerations of the various variables, chiefly religion and ethnicity.

Figure 2.1 Sources of recruitment of respondents from the two hospitals



As can be seen in Figure 2.1, snowballing was another sampling method used to identify participants for the research, through the use of respondents recommended by already recruited PLHIV and the home-based care team. This happened after the earlier members had talked about some of the benefits they had in participating and about how safe they felt confiding their ‘secrets’ to an ‘unknown’ researcher. An advantage of using this method was its efficiency in finding persons whose attributes were central to the research question. It enabled me to build a sample that represented an active social network among my respondents (cf. Lindlof 1995).

Five other respondents, whom I had not met at the hospital prior to the visits, were also enlisted through the efforts of Nurse Rose and the home-based care team. These were mainly those who had specific life stories and experiences that were deemed significant for the study. Initial contacts with this group were

relatively cold, but I persevered tactfully to lessen the fears and suspicions that such encounters produced.

Initially I stayed in Offinso Newtown, which was quite close and provided good access to all the rather small surrounding villages where the respondents lived – Ahenkro, Asamankaman, Newtown, and Namong. All of these communities were between five and ten minutes' drive from my house. A few respondents, however, were identified in communities that were very far afield – Abofour, Nkenkensu, Boamang, etc. Data collection in Offinso proved very successful, mainly because even though I lived in the same cultural milieu as the clients, I did not live on the same compound, so they were comfortable and willing to open up their lives. For most of the men, for instance, it was a 'boys-boys' relationship, where my visits were mostly seen as one from a 'good friend', which was safer both for them and their families, since it camouflaged their HIV status and the real purpose of my visits. The fact that I lived in the same community as the majority of respondents, but not in the same compound, did, however, have some important side effects. It was clear that when I lived closer to the respondents, they were more reluctant to tell me if they knew of a person who knowingly had the infection but was not going for treatment. The clients were also more willing and comfortable to talk to me when they knew that there was no way someone in the community could draw the link between my work and their HIV status. Some of the clients who lived closer to me avoided making or attending the appointments made, probably because they did not want to be associated with me. Such was the case with Afranowaa, who lived right opposite my house. I did not get to interview her even once at home. Another problem with collecting data mainly in the communities served by St. Patrick's Hospital was that, try as I might, I could not get the six people (two of them in the same community in which I lived) who knew that they were infected but were not accessing ART services to talk to me.

Others who were not necessarily clients but who were very accessible gave me some general information that was relevant for the study; for instance, the carpenter who helped in providing basic furniture for my room in Offinso, and another young gentleman whom I met in Namong helped to provide basic information about the people and the area under study (see discussion of key actors below).

#### *Gaining entry to the Kumasi communities*

Getting access to the respondents in Kumasi was very different compared to Offinso due to numerous factors, including the period required for obtaining internal clearance from the Komfo Anokye Teaching Hospital, the comparatively formal system of operation, the large number of staff, and the fact that home

visits were made by volunteer peer educators instead of staff nurses. In Kumasi, Dapaah linked me to Baba, the main man in charge of home visits, who is very devoted to his work and thus – after agreeing to work with me – made getting access to clients quite smooth.

Baba agreed to lead me to respondents in Kumasi after more than two months spent making inroads in the Offinso communities. One problem with the Kumasi fieldwork, at least initially, was financial. Baba had met and interacted with my promoter during his field visit in November, but probably because Baba was eager to get the support of the clients to aid my work, he (mis)informed them that my visits would financially improve their lives. This made the respondents so focussed on their financial problems that it was difficult to redirect affairs to the objectives of the study. I tried to explain that I was not there to solve their financial problems, as they expected, but it fell on deaf ears. After reporting back to Baba and explaining how incapable I was to meet all their financial demands, he went back to the clients to relay my objectives, sometimes in my presence. It was obvious that he had the goodwill of the clients. At first, the majority were disappointed, since I was no more the ‘cash man’, but when I started visiting them they eventually opened up when they found my unswerving commitment to listening and offering little pieces of advice to them, and helping them in my own small way (at times financially, too) to manage their difficult living conditions.

Based on data from the hospital, and through my chief informant Baba in Kumasi, the suburb Tafo-Pankrono was identified for follow-up, which begun at the end of February 2008. Seven clients at Komfo Anokye were living there. Another five respondents were identified in Bantama, another suburb in Kumasi and duly followed. In all, twenty-seven people were enrolled to be part of the project in the Kumasi communities, comprising Tafo-Pankrono, Bantama, Stadium, and Suame. Thirteen had been enlisted through the help of Baba and other peer educators, nine from my activities with PLHIV associations, and one on the recommendation of another respondent (see Figure 2.1). Many others, who lived farther away from Kumasi, including in Barekese, Obuasi, Aheneman Kokoben, and Abuakwa, were informally conversed with at their homes.

One significant aspect of the Kumasi study was that I had access to a private laboratory that undertakes HIV tests (and at times counselling), which was identified earlier in the fieldwork process as a relevant site for recruiting clients who prefer private facilities to public ones. Generally, it was very difficult to get the identified clients to talk since the majority referred to the private laboratory did not know exactly what tests they were undergoing. I therefore resorted to observing the processes they went through and also the circumstances under which they came, whether voluntary or otherwise. These observations provided valuable data for analysis. Like the tests done in the hospitals, the majority were

diagnostic,<sup>5</sup> though there were several cases where, unlike those in the hospital, the clients came voluntarily to the private laboratory. An older woman in her mid-fifties, for instance, came to the private laboratory with a request for five different tests. She complained that earlier she had done several tests, so she wanted to be told exactly what tests she had been asked to do this time round. The technician later confided to me that “[I] couldn’t let the cat out of the bag since that could discourage her from doing the [HIV] test so [I] managed to evade the question.” The woman was later found to be HIV positive. I also managed to get some people to talk to me informally as they sat and waited for their test results. These were people who were visibly worried and were willing to talk. The majority were very pleased to be advised by a stranger as to their next course of action. Mainly, people who had suspicions that they were infected because of persistent illnesses (either their own or those of a close partner) patronized this facility. For instance, one lady wanted to know her HIV status because her husband’s girlfriend had lost a baby soon after birth and had thereafter been frequently admitted to hospital for one illness or another. Though it was rumoured that this girlfriend had HIV, the lady became more alarmed when her husband also started feeling unwell. When the girlfriend eventually died, she came to the private laboratory to check her status. “Men are dangerous,” she kept whispering as she waited for the test result, which led me to start a conversation: “Hmmm, why do you say that, Madam?” We continued from there.

In general it can be argued that through a combination of “creativity, luck, and a willingness to seize the moment” (Bailey 2007: 67), both the Offinso and Kumasi communities became fully accessible after about four months. It was and is nonetheless reckoned that for a research project aimed at increasing access to VCT and ART, the most crucial participants would have been those infected with HIV who do not access the facilities. Strenuous efforts were made to enrol these people, but because of the obvious difficulties in getting them to participate, the research worked with those who had already undergone VCT and were either clinically eligible to be on ART and were (or were not) on it, or who were not clinically eligible at the time of the research.

Also common to both communities was the fact that some of the issues discussed were initially thought to be irrelevant to the project, but the pieces, once put together, and through comparisons with earlier statements, opinions, and actions, line upon line with later ones, gave answers to many of the puzzles. For example, I had observed that Daniel consistently mounted yams on the family farm throughout the planting period. On some occasions, I had to learn to take

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<sup>5</sup> The majority had gone to the hospital with a problem other than HIV, but the health personnel used their discretion to recommend the test. Often, the clients did not know at the time the test was being conducted that they were in for an HIV test. More discussion of this can be found in Chapter 3.

responsibility for the mounts since it was obvious that he could not do it alone because of his deteriorating health. I could not fathom why he continued to farm when it was obvious that he was not fit enough. I had earlier linked his persistence solely to his non-disclosure and to the necessity to prove that he was still healthy. Later on, however, I gathered from discussions between his wife and her friends that he was in contention for a position as a sub-chief, and poor health – not to mention being infected with HIV – would be a reason for disqualification (though Daniel himself had never mentioned this to me). Daniel may therefore have been more concerned about disqualification from the race for sub-chief if he was seen to be unable to work on his own farm than he was about his deteriorating health and his farm *per se*.

Some of the respondents also had issues to discuss, so that even after booking appointments and agreeing with them on the day's agenda, they met me with their own (different) agendas. I later realized during the latter part of the field-work process that some of the respondents were testing my fortitude by playing hard-to-get in order to see my persistence and reactions before they committed themselves. Egya confided later that “after bombarding you [initially] with my problems, I thought you wouldn't come back again. I only agreed because you would not stop coming. But I must say that I would have been the loser if you had gone.”

#### *Key actors – the carpenter and the gossip*

In order to settle into the norms and activities of the communities and fully understand the meanings of actions in these new groups, I first engaged and established rapport with some people within the settings. This was so that I could rely on them for clarifications of confusing issues that arose, especially during the early stages. This period of socialization (and re-socialization) with the key informants also allowed me to perceive the major object categories within the culture and to understand the major types of relationships and interactions, which were – as expected – dissimilar to those which I was used to (living as I did mostly in Ghana's capital Accra). For the purposes of this section, two of the relationships are discussed: that with the carpenter and with the gossip.

After I had secured a room through my contacts in the district assembly, I required basic furniture. There was a man in his early thirties, married with three children, who had a carpentry shop two houses away. When I consulted him with the request, he gladly obliged to help the stranger who could pass for his twin in terms of age. Just like most Ghanaians may behave, he asked whether I needed other things (such as a shoe rack, wardrobe, sofas, etc.) in addition to the book-

shelf, trap door<sup>6</sup>, and study desk that I had asked for. I requested for him to pass by after work to see my room and then we could agree on what to fill it with. During that night we talked about family, education, societal norms, courtesy and respect, among other things. Subsequently, we met frequently, usually at night when he had finished work. Later interactions with the carpenter were mainly about the general beliefs, norms, practices, and traditions of the people in the community. His role waned as I became very busy and spent less time at home. Consciously, I also decided to cut down on our meetings because he became increasingly inquisitive, especially about the reason for my stay in Offinso.

I first saw the gossip, on the other hand, in a community where the district's AIDS Day celebration was being marked. I later traced him to his home in Kumasi. His remarkable knowledge about residents in his community was my motivation to talk to him; he was the chief supplier of community gossip. Although my acquaintance with him was beneficial, it was also risky because of his rather infamous notoriety as a gossip. Interactions were therefore chiefly limited to our 'secret' meetings.

Eugene, the gossip, later revealed that he had worked on two HIV/AIDS sensitization programmes in a community in the Ashanti Region. He also had first-hand experience of living with an HIV positive person, as his older brother had died of the infection. Interestingly, as a funeral decorator, he had decorated his deceased brother's corpse for burial, and he explained that the experience had helped him to be able to identify anyone who is infected in the community. He once challenged me to go around with him and he would show me the people who have the infection. He claimed that he could identify them by just looking at their soles of their feet, the area above the cheekbone, and also their faces in general. Since he had lived in the community for most of his adult years, it was obvious too that he perceived the social (and sexual) lives of the HIV positive suspects as the catalyst for their infection.

Later during the fieldwork period, other actors were recruited for specific purposes. For instance, an elderly man (the maternal uncle of an HIV positive respondent) was recruited to explain more about Ashanti norms and customs regarding caring for the sick, because of his extensive work at the Ashanti Regional Centre for Arts and Culture (Cultural Centre) in Kumasi. In field research, key actors often make interactions with others in the field setting easier by their introductions and help in gaining entrée, establishing rapport, providing explanations, and performing a host of other useful tasks (Bailey 2007). However, the role of the carpenter and the gossip was limited to providing explanations. I relied on the peer educators, heads of PLHIV associations, and other NGOs

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<sup>6</sup> 'Trap door' in Ghana refers to a netted door usually fixed onto the frame of the main door, to prevent mosquitoes from entering the room or allow for fresh air when the main door is open.

working in the field of care and support for HIV positive persons for the other functions.

Since the perspectives of the key actors may run counter to those of other community members, and a close relationship with them could run the risk of isolating other members within the setting, I had to be very tactful in the extent to which I identified with them. Those in the foreground, such as the leaders of the PLHIV associations, had access to the centre stage and were more vocal; they also had the ability to give more apt descriptions of the HIV experience since the majority had lived for many years with the infection. They were, however, more likely to give policy framed perceptions and phrases coined in NGO jargon, since they had been to a lot of such workshops and conferences. The study therefore tried to involve the majority of people in the background who had not yet encountered this heavily policy-influenced group, yet who had experiences that spoke for the ordinary person infected with HIV.

Thanks to the tact, patience, and cooperative nature of the respondents and their significant others, it was easier to make friends with them. I became involved in family groups and organizations, and worked with them on their farms, quarries, and other places of work. It is reckoned that mistakes and misrepresentations that may have arisen initially may have been forgiven because of the cordial nature of the friendship, and most importantly as the respondents found me very willing and open to learn and practice their culture. These experiences, consciously and unconsciously, helped me to learn some etiquette and proper social responses that influenced the fieldwork proper, including appropriate greeting terminologies, responses to greetings, and the use of the word *sebe* (excuse me) for sensitive words and phrases, which I hitherto would have said loosely.

## Data collection

Over the period of fieldwork, I collected a lot of stories from both the print (newspapers) and electronic (television, radio, internet) media that were of relevance to the study. These secondary sources helped to see the fieldwork data in the wider context of Ghanaian society. The primary research, however, integrated a multiple mixed methods approach (Saunders *et al.* 2007), which made use of quantitative and qualitative research at the same time. According to Tashakkori & Teddlie (2003), the use of multiple methods provides better opportunities for the researcher to answer research questions set out for the study and allows for better evaluation of the research findings, which can be trusted and inferences made from them. The use of multiple methods of data collection is a form of triangulation that is central to ensuring quality research (Bailey 2007). During the early periods of fieldwork, all the HIV positive respondents

were told about how data would be collected in order to get to their experiences with HIV. They were told that I would live in the same community with them, visit them very often in their homes, converse, ask questions, participate in their daily chores where possible, and observe their everyday lives. All these techniques were used with the sole objective of distinguishing between cultural ideas and actual practices, public and private conduct, and prescribed and voluntary behaviour (see Parker *et al.* 2002). The following discusses in detail the various primary sources employed for data collection. These tools included observations, structured and unstructured interviews, in-depth interviews, conversations, and other methods such as focus group discussions and photography.

### *Observations*

For an ethnographic research project such as this, where the studied population lives virtually in secret, participant observation was found to be one of the main tools to elicit data. A cardinal instrument of my approach was the development of an ability to listen and learn from my respondents so as to see new things and closely observe the environment in which I was operating. This was done in order not to take anything for granted. I therefore took part in the daily events of the participants while observing. The boundary for the observations was determined by the life of the participant in question, and whether s/he had disclosed her/his HIV status. That is, wherever and whenever I was with the participants, observations took place. Through this, the respondents' networks of relationships were observed. It also included non-members who only briefly entered the scene or interacted with the regular participants. Seeing was the primary observational tool used, but it also involved listening, touching, and tasting, where necessary. There were several times that I shared a meal with clients while conversing, for instance.

Although my activities may not have been as perfect as (or even near to) how the participants did things – for instance, since it was my first hands-on encounter with such activities, my skills when working with participants on their farms or in a quarry were notably limited – these activities paved the way for me to be accepted into the lives of these participants, which otherwise may not have been possible.

In most of the cases the observations were informal, focusing on what was deemed relevant as events unfolded – the respondents' utterances and feelings and how these changed, the physical settings, activities happening in the setting, relationships and how they were activated and deactivated, among other things. There were cases, however, where specific themes were singled out to be observed amongst specific respondents. For instance, after I got to know that Kaakyire had informed his nephew Nsiah about his status, I observed their

relationship, especially during visits to their house, to see Nsiah's reaction (see Chapter 7 for details of this case). During observations, non-verbal messages conveyed by the body language of respondents provided a lot of communication signals about the truthfulness of the interviews (cf. Hiltrop & Udall 1995). Both Nsiah's speech and actions, for instance, provided backing for his uncle's statement about trusting him not to disclose his positive status.

*Picture 1-2* Researcher harvesting plantains on a respondent's farm



Notes were made on the things observed for further discussion, where appropriate. The observation in fact formed the major basis for most of the questions explored during informal conversations. At the PLHIV associations, for instance, observations on who did most of the talking, whose suggestions were followed, as well as those that were rejected and ignored, were used to ascertain power and status ranking among the HIV positive persons, and also to understand better the role of HIV positive men and those who are relatively influential in these associations.

All in all, the objectives of the observations were, as Bailey (2007: 91) puts it, to “find out what people do, how they go about doing the things they do, why they are doing these things, how they feel about doing them,” and most especially how this explains why they do or do not access VCT and ART services.

### *Structured interviews*

As part of the data collection, an interview schedule was used (see Kottak 2003). With this, I talked face to face with the interviewees, asked questions, and wrote down the responses. A structured interview guide was used. The essence was to probe for specific details on issues that the interviewee was competent and knowledgeable in. Specific questions in the specific order of my interest were asked. Though some follow-up questions were also prepared, I built up on issues that cropped up. This was mainly used for key actors and the significant relations of the HIV positive persons, church leaders, community leaders, technicians in private laboratories, and the heads of NGOs working in the field of care and support for people living with HIV.

On average, the interviews lasted about one hour per session. Most of these interviews took two to three sessions because the study provoked more interest than expected and all the interviewees were very willing to continue the discussions later. In a few cases when rapport was very good, the interviews developed in a kind of 'non-directive' way, in which the interviewees raised their own topics for discussion that were pertinent to the main themes of enquiry. There were also some follow-ups to the interviews in cases where I needed further clarification and explanation of previously gathered information. All these interviews were conducted in the homes of the informants or in my home, since these were the preferred options when they were asked to choose a place that they found comfortable and convenient.

### *Unstructured interviews*

Interviews where there was liberty to formulate questions around the research topic as and when they came to mind were also conducted, where the interviewees were given fairly free range to talk about any aspect related to the broad interests of the researcher (Bailey 2007). In such interviews, the first question asked of one interviewee might differ totally from the first question asked of the next interviewee. Several types of unstructured interviewing were deployed, including conversations, in-depth interviewing, and focus group interviewing, among others (Kumar 2005).

### *Conversations*

Most of the interactions I had with the participants were in the form of conversations, where the focus was not only to pursue my interest but also that of the participants. Though I had themes and guidelines for probing, the structure, procedure, and order of the conversations were flexible. Enough room was given for participants to sway and digress into other areas of interest, though the conversations did gradually veer back to subjects I was interested in, since those issues are largely private and they seldom had people to share those aspects of

their lives with. What was common among all the conversations was that they were not structured. On some occasions, I went to my respondents with my agenda, while they also had their own agenda. Usually, the clients got the upper hand. When I was not distracted, I began all the interviews on general health issues and with time drew the main study into the discussions, in order to ease the tensions often associated with talking about HIV.

The majority of the conversations were engaged in during visits at the homes of participants. Some conversations took place only once with a particular person, others a couple of times, but the forty-nine who were pencilled in for in-depth research were visited several times – averaging not less than twenty visits per person over the research period. These visits exclude the times that participants were met at social gatherings where the conversations sometimes continued. Some of the conversations started one-on-one with the person in question, but other family members, fellow PLHIV, etc. might join in. As noted by Bailey (2007), both the researcher and the participant during these informal conversations share feelings, impressions, ideals, and information. This form of collecting data is “more honest, morally sound, and reliable, because it treats the respondent as an equal, allows him or her to express personal feelings, and therefore presents a more realistic picture than can be uncovered using traditional interview methods” (Fontana & Frey 1994, in Bailey 2007: 97). Much time was spent, however, on very unrelated conversations, although it helped to create good rapport and maintain the relationship. The participants found in me a keen listener, and they were ready to talk about all aspects of their lives since “all seemed important” to them.

#### *In-depth interviews*

This part constituted the longitudinal study that ensured that a particular group of respondents were followed during the fifteen month fieldwork phase (which took place unevenly for longer and shorter periods: from September 2007 to August 2008, and November 2009 to January 2010). These in-depth interviews were conducted with all forty-nine HIV positive persons in the two communities (twenty-three in Kumasi, and twenty-six in Offinso – refer to Figure 2.1 above); a number of the cases were followed up in the hospital setting. This aspect of data collection and the conversations were used to collect the life stories of respondents. The life stories undoubtedly added a deeper, thicker, and richer texture, not only to sustain the interview process in times of rising emotions, but also to divert the attention of other people present at the place of conversation from any suspicion of our discussion of HIV. The motivation for collecting these stories was to use these individuals’ stories, and other personal materials, to understand the individual lives of those associated with HIV within their social

context. Life stories as a method for eliciting data emphasizes the importance of the subjective experience within the social context (Roberts 2002: 3). Through life stories, it is recognized that what is captured is a mediation between the personal voice of the respondent and wider cultural imperatives (Goodson & Sikes 2001). These stories thus facilitated me to capture, probe, and render understandable the perspectives of the infected people and their close associates, while also making it possible for the reader to get as close as possible to their actual experiences (Denzin 1989: 69).

Eight of the respondents followed (four from Offinso, four from Kumasi) were those who had undergone counselling and testing but were not clinically eligible to take ART. All the others were on antiretroviral medication. All but five of the interviews were conducted in places other than the interviewees' homes, including school parks, church premises, bars, market places, selling joints, farms, hospital premises, etc. In their homes, all issues were discussed except for those which would involve mentioning the disease or anything that could bring such inferences.

Field notes were made away from the place of the interviews and the interviewees. It was explained to the interviewees that no writing or recording would be done during the conversations and interactions, unless something greatly pertinent occurred. In such a case, the client was duly informed and her/his permission requested, and the notes or recordings were reread or replayed until the client was satisfied with the contents. Only a few of the in-depth interviews were tape recorded with the consent of the participants involved. In Kaakyire's case, for instance, he requested to listen to the recordings after the interview before granting authorization for the contents to be used.

Reports of the day's activities were therefore taken at night after the day's work. Some keywords or phrases were, however, noted in the field notes as reminders. Since all the interviews were conducted in Twi, more time was spent on the transcriptions to avoid translating out of context. The transcribed materials were coded and grouped into themes carefully selected to not only portray the exciting and empathetic views of the respondents but also to fit into the academic requirements of a dissertation (see Burawoy *et al.* 2000).

#### *Other tools*

Though not very consistently (since I spent most of my time away from home), I followed HIV discussions on the radio, in particular a recurrent discussion that talked about the link between witchcraft and HIV. In addition, discussions (related to HIV or otherwise) were also followed keenly in *trotros* and at drinking bars, where I took time to while the nights away in Offinso. These periods also provided valuable information for understanding the lives of PLHIV. For

instance, during some of these discussions, it was found out that some people (mainly men) do consciously consider the physique of their sex partners before showing any interest. This was because slim and skinny people (women) were identified as potentially infected with HIV. Many young ladies, according to another discussion on the radio, take food supplements and blood tonics (such as cortisones, according to one respondent) to gain more flesh and body weight, since slimmer women do not find marriage (love) partners (see more discussion of this in Chapter 3). These conversations provided some insight into the public's concerns regarding the issues under study.

*Photography:* Taking photographs played a role in my research as well. As Owusu Kwarteng (2005) notes, Ghanaians love to be photographed or filmed. It was, however, expected that since the majority of the respondents were keeping their HIV status a secret, photographing them would be refused. Even though respondents wanted their identity hidden, probably because of the trust they placed in me they often asked whether I had my camera around to take their photograph. On some occasions, clients called on me to cover some ceremonies they were participating in. For instance, Massa, who on one occasion was standing in as a father for his sister-in-law's marriage, called on me to take shots at the wedding. He had boasted to the family that they should not worry about photography for the wedding since his "friend who works at the hospital would come and take better shots for the occasion." All the pictures were developed and sent to them. This notwithstanding, only a few of those affected by HIV (i.e. friends and relatives of HIV positive persons) agreed (and only with the consent of the HIV positive persons) for their pictures to be used for presentations, but not in the final manuscript. None of the HIV positive persons wanted their pictures to be used.

*Gossip:* In the collection of narratives and life stories of PLHIV and their close relations and friends, I relied on seemingly idle talk or community rumours, especially about the personal or private affairs of others, told by respondents either directly to me or indirectly through eavesdropping. Usually, I found an opportune time to follow up on these stories to get the version of the accused, since I operated with the policy that there is no smoke without fire. For the majority of cases, I had the people in question explain the situation to me.

*Focus Group Discussions (FGDs):* During the research period in Offinso, I managed to organize one FGD with a youth group, mainly young boys and girls aged between nineteen and twenty-two years, who had completed Senior High School and were currently unemployed. In addition, I held two FGDs in Kumasi

– one with a cross section of young professionals, and the other with a women’s group. The discussions mainly centred on the perceptions, beliefs, and practices related to, and their attitudes towards, HIV and PLHIV.

### Field challenges, post-fieldwork, and limitations of the study

Prior to arriving in the field, it was envisaged that there would be an obvious difficulty in getting HIV positive respondents – who are sick, physically worn-out, emotionally disturbed, and destitute – to open up. I overcame this problem with the advantage of being both an insider and an outsider in the communities. As a Ghanaian, middle class, educated, and urban bound man, I understood the social and cultural milieu of the research and to a large extent played it to my advantage. Furthermore, the respondents opened up comparatively better to a near stranger (since I lived for the first time in this environment) who would vanish into thin air after the conversation, and thus their speaking to me did not pose the possible risk of seepage of their personal narratives into the public domain. In addition, after achieving the goodwill of a few of the respondents, I tried not only to concern myself with data collection but also with the general well-being of the respondents. During the research process, therefore, I counselled them as I had seen the nurses do in ways to improve their health – basic dietary routines, the value of basic exercises, and regular intake of medicines – and at times provided some small financial support. The fact that they realized that their participation in the research did not jeopardize their health condition made them a little more willing to offer themselves.

Although field research is possible in settings where the researcher is already an accepted member, in this case I tried to bridge the distances that appeared, including those of social class, educational level, religious affiliation, and language. On the one hand, the differences allowed me access to the clients, at least initially, since they found me an outsider. This gave me the opportunity to ask questions or behave in ways that may have been deemed stupid, blunt, or nosy were they to have come from fellow members of the community. They also knew that their lived experiences and narratives were safe with me since after the research period I would disappear. On the other hand, at the end stage of the fieldwork when I was leaving, some clients, especially those who were not followed during the research period, did not understand; they asked, “Where is he leaving to? ... he’s always been one of us.”

I acknowledge the possibility of my complicity in the deception of a number of family members (or significant others) of the HIV positive persons. This may have arisen because the majority of these positive persons had not disclosed the exact nature of their health problem to these people (see the discussion of ‘selling of sickness’ in Chapter 4). In order not to endanger the relationships of PLHIV

with their family members or significant others through revealing the former's real identity, I agreed to the description given to me by the PLHIV as "a worker at the hospital where they were being treated." This 'health worker' status was most convenient for both parties since it afforded me the opening to talk to these significant others about their beliefs and perceptions of different sicknesses, including HIV/AIDS, in order to fully understand the dynamics in related thoughts and acts. For the clients, it eroded the otherwise obvious curiosity that other people could have about my visits.

The emotional and psychological demands on me of the project required frequent discussions with colleagues and both internal and external supervisors. A case in point was that of Rahim (outlined in Chapter 3), who died after allegedly committing suicide not long after we met and conversed. It was very difficult disassociating his suicide act from our conversation, which was about his reluctance to pursue ART. The discussions with the project team went a long way to support me emotionally and psychologically, which in the long run ensured the success of the data collection.

Some of the ways in which fieldworkers know that it is time to leave the field are when "they feel they are not learning anything new," when the "things to do portion of the field notes grows relatively small" and when "they are drawing fewer and fewer analytical insights from active participation in the setting" (Bailey 2007: 122). For me, every new day brought with it new insights into the phenomenon being investigated. However, because of the time schedule and funding constraints, the fieldwork process had to fit into the scheme of funds available and not the other way round. This is not a new trend in fieldwork, as with such an investigation, if there were no timelines, the process could go on and on without end, relegating the equally much important aspect of analysis to the background.

So in August 2008 it was time to attempt closure. However, the main concern was how to disentangle myself from the relationships formed in the field. Very rich data had been collected, but as stated earlier, the respondents had become more than subjects of study; they were collaborators in the effort to unearth the whole experience of living with HIV in a highly stigmatizing setting. The overwhelmingly cordial relationship I developed with clients in both communities had ensured that they had become – what we call in Ghana – brothers and sisters, meaning close friends, with some coming to depend on me materially and emotionally.

One of the ways of minimizing the effects of crudely disengaging from the participants, according to several experienced ethnographers such as Carol Bailey, is to discuss and plan the departure with participants, and if possible promise them future contacts. This helps to manage the often arising situation

where the researched feel used after the process, and also to ensure that if possible they have the opportunity to respond to the findings in the report. Notwithstanding all these advantages, I could only tell the respondents that I was leaving but not the fact that I was travelling outside the country for the next stage of the project – data analysis and write-up. This was because I was scared of the many more demands that might come with it because of the conventional association of being able to travel outside of the country with being rich. I felt that I would not be able to meet all their demands for maintaining regular contact and support, especially emotional and psychological, financial, and even physical. It made me feel limited and guilty.

In general, detaching oneself from the research respondents is not as easy as it is at times suggested in textbooks. It was difficult, even more than managing to first get and keep the confidence of respondents. Worst of all, during the transcription stages, my mind often wandered away to the field, making me re-experience similar emotions and constantly wonder about the welfare of the respondents; especially those who were in critical health conditions at the time of leaving the field. For instance, the plight of my then five-year-old respondent Adu-Poku, who had just undergone two separate hernia surgeries, often kept me awake. This delayed the transcription, analysis, and writing process. However, with continued support from the project team, the process progressed steadily.

After September 2008, all the information I had obtained through interviews, observations, and conversations, recorded mainly in field notes and also with a dictaphone, were translated into biographical narratives. The survey<sup>7</sup> materials were also coded and entered into SPSS for analysis. Using both qualitative and quantitative methods, engaging in triangulation helped corroborate or nuance evidence. Where accounts did not agree, possible explanations were given. In the write-up, it was also hoped that some of the findings of the qualitative data would

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<sup>7</sup> As planned, the period of fieldwork ended with a cross-sectional household survey in the specific communities sampled for in-depth study, using mainly closed-ended structured questions (see Appendix 3). In addition, the questionnaire was administered in four Senior High Schools (SHS) in the two communities. The purpose of the survey was to test the findings and see how representative the conclusions from the observation and in-depth interviews were. In all, about 1,700 questions were administered (about 150 in each SHS, and 550 in each sampled community). Four research assistants who were Senior High School graduates in Offinso Newtown (two males and two females) were recruited and trained to administer the questionnaires in the communities. It was relatively easier in the SHS after permission was sought from the headmasters and Social Studies teachers for each school. The students were also required to answer one of the three essay questions below, which were asked to gain more information about what they thought about particular areas in the research: (1) You may look strong and fit on the outside and still have HIV. Discuss. (2) Our understanding of the HIV disease is the main factor for the spread of this menace. Discuss. (3) Write a short story that ends with the saying "... so you see, we all need to go for an HIV test today"! Though some of the students were overtly disinterested in either administering the questionnaire or writing the essay, or both, the outcome, especially of the essays, was very interesting. Unfortunately, for lack of time to fully analyse the data from the essays and the survey, the data presented in this dissertation excludes this information.

be pitched against the quantitative ones to either confirm or contradict the results. However, it was not possible to include the analysis of survey and essay responses because of time limitations for the analysis. It is hoped that future work will allow for such comparative analysis.

In December 2009, after a substantial part of the data had been analysed, a workshop took place to bring together all the stakeholders again to discuss the major findings in order to reconfirm their position as collaborators and not subjects just being used (see Appendix 4 for a report on the workshop). The details of the analysis are contained in the subsequent chapters of this study. All in all the fieldwork process was not only enjoyable, it was enlightening. Some of the respondents have become brothers and sisters, and their experiences have not only enriched my academic pursuits, they have also made me appreciate culture, health, and illness better.