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

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The study

Fereɛ ne owuo dee, anka fanyinam owuo
 Between disgrace and death, rather choose death
 (Kaakyire, a respondent)

There was a sharp contrast between this one particular journey and those I had embarked on earlier to the homes of people accessing antiretroviral therapy (ART) in the Ashanti Region, Ghana. It was April 2008, about six months into fieldwork, and I had observed that the alleys to most of the homes that I had visited in Kumasi and its environs looked unkempt, and that the HIV positive people I spoke to lived in very small rooms in big compound houses. The case of Ahoɔɛ was different. She lived in a relatively nice neighbourhood, with well demarcated housing and good roads. Her room was well furnished, with locally made rattan furniture beautifully matching her curtains and rubber carpets. By her choice of clothing, which was relatively expensive, she appeared to be someone who was very particular about trends in fashion. As she put it, “I have money, and I comfortably take care of myself.” In her early thirties, she prided herself so much on her beauty that I gave her the name ‘Beautiful’ (Ahoɔɛ).¹

Before Ahoɔɛ found out about her HIV status, she was keeping several boutiques in the major towns in the Ashanti Region, mainly Kumasi and Obuasi, stocked with bags, belts, shoes, jewellery, and assorted clothing for both men and women. She claimed that her suppliers were Ghanaians living in Europe who shipped products to her seasonally, while her clientele were mainly middle class

¹ All of the names of the respondents used in this book are pseudonyms.

young professionals who worked in these towns and had a taste for European products.

Nobody knew about her infection; not even her fiancé. Their relationship had, however, grown sour about eight months after she received the diagnosis and later broke down. AhoƆfe explained:

We were in the process of setting a date for our marriage when I decided to find out my status privately. The first two tests were positive. Then the third was negative. Then all the others, about ten more, were positive. I became confused. I could not tell anyone. For my fiancé, I felt if the relationship will continue, I needed to tell him about it. I couldn't imagine the terrible feeling I would have had watching my innocent partner living with a virus and not knowing about it. The thoughts made me more confused. I could not sleep well. I could not attend to all the demands of my business. I rather spent much time and resources having one test after another just to confirm the negative result. When all proved futile, I decided to find help.

She spent much time going from one healer to another, especially *mallams*², because she suspected something other than just a physical cause, namely a spiritual attack. She later found out about and started getting treatment from one of the ART facilities in the region, about fifty-five kilometres from her home (even though there were more than five treatment facilities between her house and the one she attended). Nevertheless, she still utilized the services of one of the *mallams*. She indicated, about a year after her diagnosis, that she had responded very well to treatment and “does not feel sick.” She is nonetheless faced with other difficulties. During a conversation, she queried:

How can I go on living like this [without informing anybody about her HIV status]? Who do I rely on when I need to talk about something related to my infection? At times I feel very dejected because I don't have anyone to discuss such intimate matters. Can I continue living without a partner since I fear that I may infect whoever comes along?

And there was, in addition, much pressure on her from her family and friends to not only “enter into a relationship,” but also to “get married, and have children.” She noted:

Initially, I thought I could handle this. Now, the pressure is too much. No one understands. Why would a beautiful young woman refuse to get married? And you see [aside from the pressures from family and friends], I also want to experience love, have a partner with me who I can share love, have babies, and enjoy family life. It is becoming more difficult. I don't know whether I would really succeed [to continue] living this way.

² *Mallam* is usually a term for Islamic scholars, but is commonly used to refer to adherents who practice folk medicine in Ghana. In this context, *mallams* are said to be concerned with communication with the spirit world and are believed to have the power to retrieve the lost soul of the ill person. This is because of the relationship between the physical and the spiritual in terms of the causes of illness. Apart from their ability to heal spiritually, those who visited the *mallams*, such as AhoƆfe, explained that they have a special gift of giving charms and amulets to clients, based on Quranic verses, to ward off evil spirits.

I return to Ahofoe again in Chapter 4 and 8 of this monograph, but suffice it here to draw from her case the conclusion that being infected with HIV is more than a medical issue to be treated with antiretroviral (ARV) medicines and other medicines that claim to cure it. HIV/AIDS is a complex disease. It poses social, psychological, material, and spiritual dilemmas. All infected people find themselves in a position that requires them to take strategic decisions, and they must face issues of aetiology, perceptions about contracting the virus, testing and coping with test results, issues of disclosure, the implications of being infected on one's health, social status, and economic well-being, fear of negative reactions from family and friends, the search for therapy (including spiritual³ help), living conditions, and social networks and support.

This study is about the experiences of people living with HIV (PLHIV), based on their own accounts and stories and observations made over a period between 2007 and 2011. It describes the procedures and processes of taking up voluntary counselling and testing (VCT) and ART. It focuses especially on how HIV positive persons found safety amidst high levels of stigmatization. The objective is to explore in depth some of the key issues that inhibit and/or motivate people in Ghana to take up VCT and ART services, from the perspective of those who (should) demand the services. The study elucidates how, more than two and a half decades after the first clinical report of HIV was made in Ghana, people infected with or affected by HIV experience and cope with the infection, while strategizing to retain respect in a constraining environment and society. As the monograph will show, the prime issue in this study is about people's preoccupation with safety as a basic need, and safety is related to other equally important matters such as (re)gaining respect in one's community and society. Most of the research took place in Kumasi and Offinso, two communities in the Ashanti Region, the most heavily populated region of Ghana with around four million people.

³ The term 'spiritual' is presented here not in the context of associating oneself with any religious order, denomination, or particular doctrine, but in terms of how people make meanings out of and act on their relationships with the supernatural. Though religion can provide a strong base for one's spirituality, being spiritual in this context does not necessarily mean that one is religious. In other words, a person could believe in the fact that supernatural powers underline a particular situation and may use supernatural means to understand, tap into, and even alter the situation. This person, however, may not subscribe to a particular set of beliefs and practices, as pertains to a religious doctrine, denomination, or order. One's spirituality may therefore affect one's decisions in life, such as health seeking behaviour, when and how one will plant one's fields, and whether or not to participate in risky but potentially beneficial social action (see for instance VerBeek 2000, Dei 2002). Spiritual therapy is thus used here to mean subscribing to the use of magico-religious concepts, acts, and symbolism in the bid to find relief and/or a solution to a health predicament.

HIV/AIDS in Ghana

Since March 1986, when HIV was first identified in Ghana, the country has retained a comparatively low HIV prevalence rate, and the scale of the infection and associated suffering is not comparable to that of countries of East and Southern Africa. Ghana's 2011 figures estimate that there were approximately 260,000 people living with HIV nationwide (a decline from 350,000 between 2004 and 2008),⁴ or just over 3% of the adult population. Adult prevalence over the last decade has been relatively low, and has been decreasing: 3.4% in 2002, 2.7% in 2005, and 1.9% in 2009.

The majority of infections (nearly 90%) are within the age group twenty-five to forty-nine years, with about two out of three cases affecting women and girls. Transmission of HIV infection in the country is primarily due to heterosexual contact (80%), followed by mother-to-child transmission (15%), and then finally other transmission routes (5%) including transmission through contaminated blood (blood transfusion) or through the sharing of needles or blades that have been in contact with the blood of an infected person. The National AIDS Control Programme has warned that although national HIV prevalence has been decreasing over the years, the general populace must guard against complacency in order not to experience reverse trends, which could erode all the successes chalked up over the years.

To prevent potential hazards, even before the first case was identified in the country, the HIV/AIDS pandemic was dealt with as a disease rather than a development issue in Ghana. The national response was therefore placed on the agenda of the Ministry of Health. A National Advisory Committee was established in 1985 to advise the government on HIV/AIDS issues. In 1987, the National AIDS Control Programme (NACP) was established within the Ministry of Health to undertake both implementation and coordination of HIV/AIDS programmes. Short term plans were developed between 1987 and 2000 to manage the disease, and a national HIV/AIDS/STI Policy was initiated in 1999. In May 2001, the Ghana AIDS Commission (GAC) was established as a supra-ministerial body by Cabinet decision, to be responsible for policy formulation, supervision, resource mobilization, and coordination. The GAC was given its legal status by Act 613 of Parliament in December 2001.

Since 2001, the National Strategic Frameworks I and II have guided Ghana's national response to HIV/AIDS. The strategy, among other things, emphasizes the use of a multi-sectoral approach involving governmental ministries, departments, and agencies, faith-based organizations (FBOs), non-governmental

⁴ Find a comprehensive demography of people living with HIV/AIDS in Ghana at: http://www.indexmundi.com/ghana/hiv_aids_people_living_with_hiv_aids.html.

organizations (NGOs), and the private sector; scaling up existing programmes; capacity enhancement; and using existing decentralized administrative structures to monitor and supervise HIV/AIDS activities.

General awareness of HIV/AIDS in Ghana today is nearly universal among men and women of reproductive age (GDHS 2008, Antwi & Oppong 2003), which is largely the result of a massive public education campaign aimed at the prevention of new HIV infections. This campaign has also included the promotion of VCT. Counselling and testing allows individuals to receive pre-test counselling at a specialized health facility, have blood drawn for testing, and – thanks to the advent of rapid testing kits – receive their test results along with post-test counselling within about thirty minutes.

For about eight years now, ART has been available to help the prevention of mother-to-child-transmission (PMTCT) of HIV. In order to be eligible for PMTCT, however, a woman must know her HIV status. Until recently, therefore, the key target of counselling and testing campaigns had been pregnant women. Up until about eight years ago, the cost of ART for the treatment of HIV infections (as opposed to PMTCT) was far too high for most HIV positive people in sub-Saharan Africa, so there was little chance for the average Ghanaian to even consider receiving these lifesaving drugs. However, an enormous increase in global resources is now being set aside for HIV/AIDS control. As a result, policies are shifting throughout Africa – and Ghana is among those countries that are scaling up access to ART for all in need. People are eligible if they undergo counselling and testing, are found to be HIV positive, and have a CD4 count of less than 300. Currently, there are more than 500 VCT centres and 140 ART centres throughout the country, and there is a plan to expand services to ensure that there is at least one VCT and ART site in each of the country's 170 districts. Given that testing and knowing one's status is a prerequisite for accessing ART, VCT services can be seen as a gatekeeper for ART. This study therefore focuses on the uptake of VCT and ART services by the general public, and especially by people living with HIV with CD4 counts below 300. The programme does *not* study the uptake of counselling and testing by pregnant women for PMTCT, as this has already been studied in Ghana (see for instance Baiden *et al.* 2005, Addo 2005, and Holmes *et al.* 2008).

Large scale systematic efforts to provide ART to Ghanaian PLHIV began in 2001, and in 2002 the Ghana Health Service set out plans to provide ART for 6,000 PLHIV. However, funds were forthcoming for only 2,000 people, partly because of concerns – from donors and from the Ghanaian authorities themselves – over absorptive capacity within Ghanaian health services. As of December 2004, 1,200 people were receiving ART through two urban providers, with a further 800 cases receiving treatment via two rural providers in the relatively

heavily affected Eastern Region of the country. In other words, issues of ‘supply’ were significantly limiting uptake. This was disturbing given the scale of the problem: a study on behalf of the WHO in relation to the ‘3by5’ initiative⁵ proposed a target of providing ART to 30,000 of the 62,000 PLHIV in urgent need of treatment by the end of 2005.⁶ The government secured funds from the Global Fund to fight AIDS, Tuberculosis and Malaria in 2005 to scale up VCT and ART services to fifty percent of the 170 districts in Ghana by the end of 2007, and to all district health facilities by 2009 (NACP 2007). The main objective was to solve the problem of lack of or inadequate facilities and personnel for the provision of services, in the hopes that the availability of services would translate into use. Since securing these funds in 2005, there has been a remarkable scaling up of services. By 2007, the number of ART sites had almost doubled to ninety-one, comprising public, private, and faith-based health facilities, compared to forty-six in 2006, and only four in 2004 (NACP 2007). In the case of counselling and testing and PMTCT, 422 sites had been established at the end of 2007 (NACP/GHS 2008), compared with only twenty-five operational sites in 2005 (GHS 2005).

Uptake of services by the public did increase following the scale-up of VCT and ART sites. Treatment for adults and children increased from 7,338 in 2006 to 11,534 in 2007, a 63.6% increase, while the number of people tested for HIV increased from 71,307 in 2006 to 183,866 in 2007 (NACP 2007). These increases notwithstanding, only about one third (28,387) of the roughly 87,000 people in need of ART in Ghana were accessing it as at the end of 2007 (Ibid.). Aside from the initial limitations to testing and treatment uptake as a result of inadequate facilities, uptake was also limited from the ‘demand’ side – that is, people not wanting or being able to access the services. Accordingly, the ongoing scale-up of VCT and ART services is hampered by under-utilization (Ibid.).

In the Yilo and Manya Krobo districts in Ghana, where a pilot study for VCT and ARV provision was conducted on an experimental basis in 2002, a number of problems emerged. These included lack of information on the services available, people’s fear of disclosure of their HIV positive status, fear of the stigma attached to being HIV positive, worries over community and family rejection, as well as fears of economic and social insecurity. Although VCT is a required entry point for ART, many are unable (or unwilling) to use VCT facilities in order to avail themselves for treatment. This study attempts to

⁵ As a step towards the goal of making access to HIV prevention, testing, and treatment accessible for all who need it as a human right, UNAIDS and WHO in 2003 launched the ‘3by5’ initiative. This outlined a global target to provide three million people living with HIV/AIDS in low and middle income countries with life prolonging antiretroviral treatment by the end of 2005.

⁶ For Ghana’s specific objectives and targets for the ‘3by5’ initiative, see www.who.int/3by5/support/june2005_gha.

understand the current limitations in the provision of VCT and ART services, about a decade after this pilot study. As this current study will show, HIV-related stigma and discrimination still remain an enormous barrier to accessing care. Issues of stigma, how HIV positive people and their families cope with and negotiate the system in order to access services, as well as how they live safely in their communities, therefore take centre stage.

Study objectives

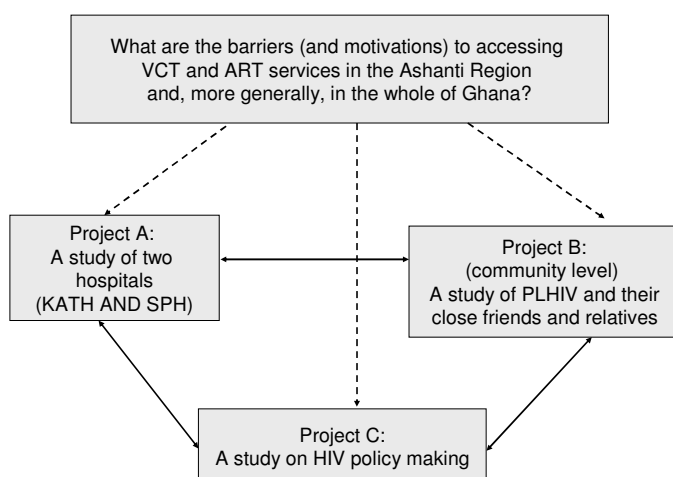
One of the assumptions in the debates about HIV/AIDS has been that the growing availability of ART may decrease the stigma of the infection and make people more interested in undergoing VCT. This led to the main research question of this study: What are the barriers (and motivations) to accessing VCT and ART services in the Ashanti Region, and more generally in Ghana as a whole? The central objective of the research is therefore to contribute to the increase of uptake of VCT and ART in the Ashanti Region and in Ghana as a whole. This study was one part of a three tier project that considered this problem from various perspectives: the institutional perspective, the community perspective, and in terms of policy implications. This monograph is the result of the community study.

In order to provide the most comprehensive answer possible to the main research question, the programme included a number of innovative approaches. First, it assumed a multi-level perspective. This approach permitted examination of the problem from the perspectives of different stakeholders (Van der Geest *et al.* 1990), based on the assumption that different actors are likely to have different needs, expectations, and agendas. The multi-level design examined the issue of VCT and ART uptake from the perspectives of: (i) health professionals who provide VCT and ART in the Ashanti Region; (ii) community members and leaders, and PLHIV and their families in the Ashanti Region; as well as (iii) national and international policy makers.

The three projects worked concurrently, each providing support and insights relevant for the others. Projects A and B worked in the same two areas of the Ashanti Region – Kumasi and Offinso – and Project C focused on the national and international levels. Project A, '*HIV/AIDS treatment in two Ghanaian hospitals: Experiences of patients, nurses and doctors*', was carried out in Komfo Anokye Hospital in Kumasi and St. Patrick's Hospital in Maase Offinso. It aimed to map out the channels and mechanisms by which health care providers offer VCT and ART, to describe the problems faced by health workers as a result of the scaling up of HIV/AIDS care efforts, and to examine how HIV positive persons cope in the hospitals (see Dapaah 2012). Project B (the study upon which this monograph is based), '*Safety in the midst of stigma: Experiencing HIV/AIDS*

in two Ghanaian communities’, worked at the community level. Project C, ‘Increasing uptake of VCT and ART in Ghana: A policy analysis’, synthesized the findings of projects A and B, related them to district, national, and international policies, and translated them into practical recommendations to policy makers (Spronk 2012).

Figure 1.1 The larger research programme



As a starting point towards evolving a multi-disciplinary approach for the research programme, a planning workshop was held in Accra in March 2005, with the intention of contributing to study design and methodology, and also discussing the possible applicability of the findings. A feedback workshop was held in Kumasi in December 2009 to share and receive feedback on the results of the three projects. Senior Ghanaian professionals from academia, the government, NGOs, and health care institutions attended, representing a wide diversity of disciplines: medical anthropology, clinical psychology, medicine, public health, pharmacy, and health policy. During the last workshop in particular, stakeholders who participated in the research – such as PLHIV, nurses, and policy makers – were invited.

The specific study (Project B) upon which this dissertation is based looked at how the experiences of HIV positive persons, and those of their close friends and relatives, influence the uptake and use of VCT and ART services. The study therefore recorded the accounts of people who have (or have not) undergone counselling and testing, people who have tested for HIV and are negative or positive, people who are HIV positive and are (or are not) on medicines, and people who are one way or another affected (or not affected) by HIV/AIDS. The concerns, agitations, reservations, and apprehensions of all these people are

highlighted, and the ways in which they motivate (or inhibit) people's access to services are extrapolated. The situation of ART provision is delicate. On the one hand, the majority of those who participated in this study and who were clinically eligible to access ART were not doing so because of a number of problems, though the main reason was fear of stigma. On the other hand, as Dapaah (2012) – my research colleague in Project A – shows, the approximately seventy treatment centres countrywide, and the twenty-one in the Ashanti Region in particular, are also stretched, with the medical personnel largely overworked. So depending on how the situation is viewed, ART provision can either be said to be under-utilized considering the possible demand, while at the same time the providers are overburdened because of site limitations.

It is imperative that high quality research is conducted in order to inform the ongoing scale-up of services throughout the country. This multi-tier research programme intends to make a significant scientific and public health contribution, with each of the three individual projects offering their own unique perspective. It now remains for me to define the meaning of the leading concepts used in this particular project, exploring the perspectives of the community.

Leading concepts

Stigma is identified as the main factor contributing to difficulties in accessing counselling, testing, and treatment services. It affects not only a person's ability to access these facilities, but also their possibilities for availing themselves of the services rendered, and most especially their life after using the services. Use of the concept of agency is therefore necessary to help understand the mechanisms and strategies that those affected with HIV adopt in order to live with the constraints imposed as a result of HIV/AIDS-related stigma.

Stigmatization

Stigma is a complicated concept to define and to measure as it may mean different things to different people in different societies. Stigma leading to discrimination and marginalization can be found in all societies and can be related to different issues, the substance of which is not necessarily generic. For instance, in Western societies such as the Netherlands there are negative attitudes towards people who are overweight or obese (weight stigma), which in turn affect their personal and social relationships. However, such characteristics of overweight or obesity are cherished in other parts of the world, such as in Ghana, where being fat is seen as a sign of good living and wealth. Stigma is thus shaped not only by individual perceptions and interpretations of micro level interactions but also by larger social and economic forces (Campbell *et al.* 2007). In general, stigma can be understood as reducing the person to whom it is applied from a

usual person to a tainted, discounted one because of an attribute that is deeply discrediting (Goffman 1963). This is quite significant because of its impact on the life experiences of individuals; in this case both people infected with and those affected by HIV (Taylor 2001).

Goffman (1963) notes that stigma arises during social interactions when the social identity of an individual is 'spoiled' by attributes that mark the person as deviant from the group norm; for example, as being incapable of fulfilling the role requirements of particular social interactions or conventions. Who you are is thus overshadowed by what you are – a sickness, disability, etc. HIV/AIDS is a problem in Ghana because people suffering from the sickness lose their previous identity and become a person 'spoiled' by HIV. I therefore use stigma in my research to indicate the severe social disapproval of personal characteristics leading to negative attitudes towards persons associated with HIV; a situation that dramatically influences the interpersonal interactions of those affected. The construction of HIV/AIDS as an agent that spoils infected and affected people, based on beliefs about contamination, sexuality, and religion, plays a crucial role and contributes to the force of stigma attached to people associated with HIV in society.

In the literature on HIV/AIDS, the role of stigma cannot be overemphasized. In their work 'Conceptualizing Stigma', Link & Phelan (2001) show four forms of stigma: labelling, stereotyping, status loss, and discrimination. Mbonu *et al.* (2009) explain that labelling involves some identifying characteristics that can be used to recognize people correctly or erroneously; for example, loss of weight, skin rash, and so forth (cf., Goldin 1994, Miller & Rubin 2007, Greeff *et al.* 2008). These negative characteristics associated with HIV are perceived as belonging and applying to specific targets constituting stereotyping; for instance, in Ghana any person diagnosed as HIV positive is perceived to be or to have been immoral (see also Greeff *et al.* 2008). HIV positive people are stigmatized because HIV/AIDS carries many symbolic associations with danger and improper sexuality. Attribution of contagion, incurability, immorality, punishment for sinful acts, and death is common in many societies (Campbell *et al.* 2007, Niehaus 2007, Kwansa 2010). This polluting quality of HIV and fear of the disease are translated into stigmatizing responses such as avoidance and isolation. The consequences are that the stigmatized person is usually distanced, disempowered, or manipulated by the stigmatizer. In this process, there is a change in the relationship or interaction between stigmatizer and stigmatized, with the latter losing her/his status as a 'normal person' in society (Campbell *et al.* 2007).

Status loss is synonymous to loss of respect. Respect is an important notion in Ghana (see Van der Geest 2004). Respect towards older persons is an important

element in interpersonal relationships and is taught from childhood; opposition to the advice or decision of senior family members is, for instance, reprimanded (Van der Geest 1998, 2004). Children must respect adults, and adults must also behave in ways that command the respect of children. Where children are deemed to behave in ways that are exceptional (that is, behaving in ways above and beyond average expectations), they may command the respect normally due to adults, as expressed in the proverb “It is the child who knows how to wash her/his hands that eats with adults” (*Se abofra hunu ne nsa hohora, ɔne mpanin-foɔ didi*). Though age commands respect, it is more about how a person behaves in the community and how s/he contributes to the overall welfare of the family and the community that assigns respect. Words deemed vulgar or inappropriate are not said in public or in conversation. These include insults and the mentioning of private parts or any other taboo thing (such as the death of a King – see Hagan 2001). Some phrases are acceptable only when prefixed with “excuse me to say” (*sebe*); for instance, “Excuse me to say, what you did is nonsense” (*sebe, dea woyɔe no, nyansa nnim koraa*). In cases where a person behaves in a way contrary to that which is deemed respectful, such a person risks losing respect (though where HIV is concerned, people risk total avoidance and isolation). People are therefore wary about their words and actions since antisocial behaviours can limit or totally eradicate the respect they receive from others in society. An adult without respect may therefore become less than a child in terms of social ranking.

Labelling, stereotyping, and status loss as the result of a person’s suspected or confirmed HIV positive status can remain covert, in terms of there being no physical effect on the stigmatized person. However, such prejudices can lead to active discrimination directed toward these persons, as well as the social groups and persons with whom they are associated. Discrimination here involves the actual acting out of negative behaviours resulting from stigma. For instance, some individuals may decide to brave the storm and ignore society’s labelling, negative stereotypes, and status loss, and instead live a ‘normal’ life. However, they may still face the wrath of society when it comes to accessing social goods; in health facilities, for example, service providers may offer lesser quality services, or totally fail to provide services altogether (Busza 2001, Reidpath *et al.* 2005). Such attitudes towards PLHIV may prevent them outright from accessing health facilities; after all, some people may consider that they would not be any better off even if they did access such services. In other words, discrimination is acted out externally, while stigmatization can be covert or constitute libel, slander, or defamation (Gilmore & Somerville 1994). This process of social exclusion and discrimination, it has been noted, is the endpoint of the process of stigmatization (Last 2000).

Rankin *et al.* (2005) also distinguish between internal stigma (which is felt or imagined) and external stigma (which refers to the actual experience of discrimination). The former often comes in the form of the shame associated with HIV/AIDS, where HIV positive people fear being discriminated against (Greeff *et al.* 2008). Here, PLHIV may not (yet) have actually experienced the stigma, but may allow their fear of possible stigma to influence their actions and inactions. Mbonu *et al.* (2009) note that internal stigma is a powerful survival mechanism aimed at protecting oneself from external stigma, and often results in thoughts or behaviour, such as the refusal or reluctance to disclose an HIV positive status to others.

Another characteristic of stigma with regards to HIV/AIDS is that it affects people associated with the disease: care givers, friends, and others related to the HIV positive person. Goffman (1963) calls this ‘courtesy stigma’. Goffman (1963: 20, 28) further distinguishes between two groups of ‘sympathetic others’:

... [those who know] from their own experiences what it is like to have this particular stigma, ... [and] the ‘wise,’ namely persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it, and who find themselves accorded a measure of acceptance, of courtesy membership of the clan.

The first group are the PLHIV themselves, who may be stigmatized because of their association with another HIV positive person, while the second – the ‘wise’ – are relations and friends who know about the HIV status of the former. Because of the special relationship that these wise persons have with the stigmatized individuals – as care givers, for instance – they may also be stigmatized. In this research project, these ‘sympathetic others’ are part of the focus, together with the HIV positive persons. The former are discussed mainly under the term ‘fellow PLHIV’ (see Chapter 5, for instance), while the latter are referred to as those ‘affected by HIV’. Together, those infected with and affected by HIV are also referred to as those ‘associated with HIV’.

One of the effects of stigmatization is its repercussions on societal relations. The basic nucleus of society is the family, which has its broader ramifications and strata in the extended family, clan, tribe (ethnic group), and sometimes community systems. Marriage, funerals, chieftaincy (traditional rule), initiation rites, welfare, and social security systems are expressed through these social units. Gyekye (1998) defined personhood in Ghanaian society as constituted by the social relationships in which one finds oneself. He notes that the sense of the community that characterizes relations between individuals is a direct consequence of communitarian social arrangements (Gyekye 1998: 318). Several statements found in the communities studied, such as “without the group there would be no individual person” and “a single straw of a broom can be broken easily, but the straws together are not easily broken” (*praye wɔhɔ yi, woyi baako*

a na ebuo, se wokabɔmu a emmu) are used to buttress this point. In other words, what happens to one person concerns the whole community. People are therefore expected to be responsible for one another and to help each other in times of happiness and especially misfortune. Attendance and financial donations at funerals are ways in which people show their solidarity with other community members. This sense of communality expected from members of society also brings about other expectations – sharing, reciprocity, respect, and proper behaviour (see for instance Agawu 2007).

Transformations in society as a result of globalization, monetization of the economy, migration, and speedy urbanization have, however, affected these societal norms and values. The ramifications, among others, have been disruptions in family life (see Oppong 2001, Moore 1994). Antwi & Atobrah (2009: 139), for example, show how those who are traditionally expected to provide care to a sick family member “will not be available to honour this expectation, or will not be able to render it effectively, or will exhibit negative attitudes, such as stigma.” Stigma therefore influences the role expectations and enactments by community members. In-depth discussion of these disruptions in traditional values and their ramifications in the lives of people associated with HIV runs through the thematic chapters, beginning from Chapter 3.

Reidpath *et al.* (2005) argue that community membership is determined on the basis of the perceived social value of groups and individuals, and stigmatization is the marking of individuals and groups who are unworthy of social investment. As a result of their HIV positive status, the services of PLHIV in the community – for instance, in contributing their resources and services during birth, marriage, and death rites – may not be accepted. With this loss of status, these people in turn are no longer considered deserving of any social benefits, which may include care and support in times of ill health (see Chapters 4 and 5). Stigma is thus used as a mechanism to determine the beneficiaries of limited social resources and virtues through a process of controlling community membership or ensuring social exclusion. The strength of the stigma is illustrated by the extent to which families and communities go to disguise the cause of death when AIDS is suspected (see Chapter 4). Anarfi *et al.* (2000) note how in Ghana, female migrants, mainly those who return sick, are completely shunned by their village communities upon return from their travels and branded as HIV carriers. Stigma therefore sets certain persons or groups apart from the normal social order, and this separation implies devaluation (Gilmore & Somerville 1994, Greeff *et al.* 2008).

In Ghana, there is a significant association between stigma, family, and community. An anthropological study on home care for PLHIV in the Ashanti Region showed a nervous secrecy surrounding HIV/AIDS (Radstake 2000).

PLHIV and their relatives never mentioned the name of the disease for fear of stigmatization, preferring silence as the only acceptable way of coping. The family is the main source of care and support for HIV positive people in most developing countries (see Parker *et al.* 2002, Aggleton & Warwick 1999), although responses to an HIV positive member vary depending on the family's reaction to the HIV/AIDS-related stigma. The family could thus be the source of stigma themselves, for instance by constantly blaming the infected person for bringing shame and disrespect upon her/himself and the family, through partial or total rejection, or by vehemently refusing to provide care or support (see Parker *et al.* 2002). This may occur because the family are more likely to be associated with the HIV positive person and thus be stigmatized too.

In situations where those associated with HIV/AIDS are unable to bear the pressures of stigma and lack support within their immediate community, they internalize the stigma, which acts as a barrier to accessing much needed services and support (Daniel & Parker 1993). Internalized stigma, otherwise known as self-stigma, is the discriminatory voice in one's head. It is the state where the person associated with HIV has negative thoughts or feelings towards her/himself based on the fact that s/he is HIV positive, or where the person believes in the negative stereotypes linked with her/his condition. In this state, the person sees her/himself as the HIV infection, and not as a person living with HIV. This is exemplified, for instance, in cases where an HIV positive person decides against taking medications because s/he considers her/himself useless and more deserving of death than life.

Feelings of shame and guilt about oneself are associated with internalized stigma. Between 1987 and 1988, community and public health nurses in the Yilo and Manya districts in Ghana brought together 210 HIV positive persons as part of a project to assist people living with the infection. Most died within the period. They refused care and support and the project lost contact with them because of the effects of stigma, both perceived and real. This shows the depth of stigma in communities (Safo 1993). Awusabo-Asare (1995) also describes a similar situation during a community-based project in Assin-Fosu, a town located eighty kilometres north of Cape Coast. He notes that a year into the project, some of the PLHIV asked not to be visited at home for fear of stigma (see also Radstake 2000). The project management responded by setting up a pastoral care team, which visited and prayed with all sick and elderly people in the community, though it targeted PLHIV specifically for counselling, as well as providing care and support for their carers. From my observations in many of the treatment centres I visited in the Ashanti Region, HIV stigma is so severe that health workers must devise various strategies in order to reassure the infected persons of their support. In extreme cases, being unable to bear these pressures has led to

the untimely deaths of HIV positive persons through suicide (see also Gilmore & Somerville 1994, Hasan *et al.* 1994 in Parker *et al.* 2002: 8).

People living with HIV experience stigma throughout their lifetime (Mbonu *et al.* 2009). Do these infected people therefore have no capacity to act independently and make free choices, and must they necessarily follow these pre-patterned arrangements that seem to limit their choices and the opportunities available to them? Put differently, do they succumb to the social pressures of stigmatization and live their lives based on the perceptions, beliefs, and disease aetiologies of others? In this era of widespread availability of antiretroviral medicines, where clinical symptoms – the main cause of stigma amongst the majority of PLHIV – can be averted, how do HIV positive persons react to stigma? What is their reaction to stigma during this liminal stage, when they are ‘normal’ because they are asymptomatic, and yet ‘abnormal’ because they have to adhere strictly to a lifelong treatment regimen?⁷ This study acknowledges the capacity of people associated with HIV to influence their own life chances and those of others, while playing an additional role in the formation of the social realities in which they participate. It is this capacity to make a difference, by making decisions and acting them out in order to live safely in the midst of stigma, which is referred to as *agency* (Cooren 2004, Latour 2005).

Agency

Stripped of its dynamic social, economic, gender and historical context, culture becomes a rigid and constraining concept which is seen somehow to mechanistically determine people’s behaviours and actions rather than providing a flexible resource for living, for according meaning to what one feels, experiences and acts to change (Ahmad 1996: 190).

The experience of stigmatization by PLHIV, and folk interpretations of the causes of the disease, can be seen to influence an HIV positive individual’s own identity, as well as her/his decision making and the way in which s/he interacts with others. Karlsen & Nazroo (2002: 4) argue that “individual decisions about who we are and our lifestyle choices, while appearing to be unbounded and, therefore, solely a consequence of agency, are, in reality, made within social constraints.” Norms, beliefs, kinship ties, and communal rules and regulations may affect a person’s decision making prowess. In effect, where people are socialized in an evolving set of roles and relationships in a society (field), they internalize these relationships and expectations, which, over time, form their ‘habitus’ (Bourdieu 1977). They then externalize this habitus back into the field.

⁷ The concept of liminality is often used to represent the ambiguity that occurs in the middle stage of rituals, when participants no longer hold their pre-ritual status but have not yet begun the transition to the new status they will hold when the ritual is complete. First developed by Arnold van Gennep (1960) in the classic *The Rites of Passage*, and later by Victor Turner (1967), the concept is used in this study to refer to the stage after a person has begun ART, when the infected persons describe themselves as being normal and yet abnormal.

As Bourdieu shows, there is thus a constant interaction between ‘internalizing the external’ and ‘externalizing the internal’.

Because of stigmatization of persons associated with HIV, people devise strategies, such as not disclosing their positive status while continuing to live normal lives. How (and why) are people infected with or affected by HIV/AIDS stigmatized? How do people manage their HIV test results? How do these people live in a community that is more likely to stigmatize than help them? In this study I explore the processes of internalizing stigma after people find out about their HIV positive status, and then how they externalize it through their coping mechanisms.

A way out for these infected and affected people would be to find strategies in order to be safe. In Maslow’s (1954) *humanistic theory*, where his hierarchy of needs is discussed, he arranges five needs in order of relevance to physical and psychological survival. According to Maslow, physical needs, though lower, are stronger and more tangible than the much higher (psychological) needs. He mentions that needs must be satisfied in hierarchical order, beginning with the lower needs and progressing to the higher ones: physiological (including thirst, hunger, sex), safety (physical and emotional), love (sustained intimacy), esteem (personal competence), and self-actualization (growth). This theory has, however, been heavily criticized, ranging from the inappropriateness of the chosen subjects for the study⁸ (Fleit 2008), to concerns over the exact order of the needs (Wahba & Bridgewell 1976), the ethnocentric nature of self-actualization at the apex of the hierarchy (Hofstede 1984), and Maslow’s failure to distinguish individualistic societies from collectivist ones (Cianci & Gambrel 2003).

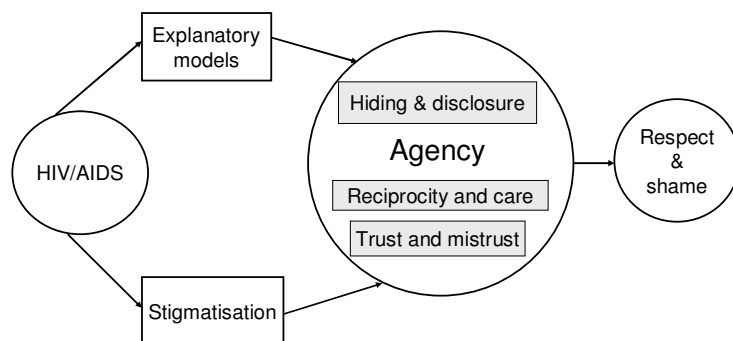
These critiques notwithstanding, other scholars such as Porat (1977) have used the Guttman scale analysis statistical technique to confirm the empirical nature of Maslow’s hierarchy of needs. Some recent research reports also appear to validate the existence of universal human needs, although the hierarchy proposed by Maslow is sometimes called into question (see Tay & Diener 2011). After analyzing the needs derived from the work of Maslow *et al.* (2000), Ryff & Keyes (1995), and others such as De Charms (1968) and Csikszentmihalyi (1988), Tay & Diener (2011: 355) settled on the “basic needs for food and shelter; safety and security; social support and love; feeling respected and pride in activities; mastery; and self-direction and autonomy” as universal needs. The association between the fulfilment of basic and safety needs is, however, varied. This study identifies safety as chief on the agenda of PLHIV and the many others affected by the infection. Safety is tied to respect and honour, so everyday life is interpreted in this regard. For those associated with the infection, therefore, the

⁸ In positing the theory, Maslow used exemplary people, such as Albert Einstein and Eleanor Roosevelt, and that has remained the chief basis for criticism.

need at the apex of their agenda is to live safely, especially in the midst of stigma.

Confronted with this HIV/AIDS menace, HIV positive persons understand, experience, and interpret their sickness through the lens of their local beliefs, perceptions, and disease aetiologies,⁹ and most especially the stigma connected with the disease. Through various forms, such as hiding and disclosure, reciprocity and care, trust and mistrust, they exercise their agency in order to continue to enjoy the respect of society and be safe from its scorn. Where they are unsuccessful, they are shamed. This is expressed in Figure 1.2.

Figure 1.2 Concepts



Even though the norms, beliefs, customs, traditions, perceptions, and ideologies may shape a person's thinking and behaviour (see Ahmad's quote above), individuals and specified groups affected by the HIV infection, such as PLHIV associations, exercise their capacity to (re)construct their own worlds. This study therefore explores the ways in which individual PLHIV, their close relations and friends, and groups (such as PLHIV associations) exercise agency in relation to the roles expected of them due to beliefs, perceptions, disease aetiologies, and stigmatization. It elucidates how, more than two decades after the first clinical

⁹ Arthur Kleinman (1980) uses the term explanatory models to refer to interpretive notions about an episode of sickness, diagnostic criteria, and treatment options that are employed by all those engaged in the clinical process. This model shows how and what people themselves conceive of as the origin and character of the problem; that is, what meanings are given to the symptoms of a disease, in this case HIV/AIDS. In Ghana, these would include beliefs about virginity, commercial sex, pre/extramarital sex, condom use, polygyny/polycoital relationships, and other routes of transmission. Identifying possible dangers and fears of an infection is one of the commonest advantages of using explanatory models for HIV, and many studies describe exaggerated misconceptions about the mode of infection (Akinsanya & Rouse 1992), which helps explain attitudes of stigma and discrimination. Such disease aetiologies are, in a very significant way, translated into health seeking behaviours; either self-medication, use of folk medicine, biomedicine, or a combination of these (Hardon et al. 2001: 27). These explanations for the HIV situation in Ghana therefore help us to understand better the issue of the high levels of stigmatization of PLHIV and their reactions to their situation.

report of HIV was made in Ghana, these agents cope with being infected with or affected by HIV, and how they retain respect in a constraining environment and society. As seen in Figure 1.2, this study shows that PLHIV and those affected by the infection respond to stigma by resorting to either hiding or disclosing their secrets, accepting or denouncing the norms of reciprocity and care, and choosing who (and who not) to trust, all in order to feel safe.

Hiding and disclosure

Internal stigma can be a powerful survival mechanism that people use, consciously and unconsciously, to protect themselves from the possible negative reactions of others (external stigma) (Rankin *et al.* 2005). PLHIV who use this mechanism often translate it into thoughts or behaviours, such as denial of HIV/AIDS and unwillingness to accept help (Miller & Rubin 2007, Greeff *et al.* 2008). In addition, PLHIV may not even take the initiative of checking their sero status in order to avoid being exposed to the dilemma altogether; and if they do finally take the test, they may decide not to disclose their positive status to others.

This is often true for PLHIV in Ghana (Ulasi *et al.* 2009). Non-disclosure may be a conscious strategy on the part of the HIV positive person to avoid stigmatization, in order to enjoy a normal life and continue to have the respect of family and friends. Due to the perceived reactions of friends and relations, which are often negative, many HIV positive persons hide their status or disclose only to specific people as a means of avoiding stigma. Even when the family response is positive, fear of being stigmatized by the community may mean that the individual does not reveal his/her status outside the home. On the other hand, Ulasi *et al.* (2009) found that family members of a person who had died of AIDS, or family members living with an HIV positive person, were themselves stigmatized (courtesy stigma). Some family members therefore encouraged their HIV positive members to remain silent about their status in order to avoid social rejection. Some families may also want to conceal and deny the fact that a member is infected. In these cases, they may resort to other non-biomedical means to find a solution, for example when the quandary is linked to witchcraft.

Hiding and disclosure to trusted people are two ways in which people associated with HIV exercise their capacity to go against the norms and expectations of society, amidst the high levels of stigma, in order to feel safe. The consequences of non-disclosure, however, are grave. An individual might not seek help at all and may grow weaker until s/he is overpowered by opportunistic infections, or s/he may prefer to travel long distances to places where it is least likely that s/he may be known in order to access ART facilities, all of which stress the family

budget. S/he may also engage in risky behaviours, such as unprotected sex, to hide the sickness, and may thus pose a threat to society at large.

Reciprocity and care

Since most people in Ghana become infected between the ages of twenty-five and forty-five, these people may not have yet contributed enough or built up sufficient social capital to rely on in times of need. Several social theorists have noted that, apart from improvement in relations, there is an inherent obligation in relationships where one person gives something of value to another (Mauss 1990, Bourdieu 1977, Bok 1995). Reidpath *et al.* (2005) argue that such obligations of reciprocity, when fulfilled, are regarded as having a higher value (earning one the needed respect), and thus those who are poor at reciprocal exchange are marginalized. Families (and communities) are more likely to care for and support someone who has in the past given something of value to them. It was therefore crucial in this study to find out whether PLHIV really expect anything from their relationships, in light of their low investments prior to discovery of their infection and the stigma attached to the infection. The concern was to investigate how people associated with HIV strategize to get the needed care, support, and respect, in particular where there had not been commensurate investments warranting such an expectation. Here, the relationships with family, friends, medical staff, and fellow PLHIV were all explored.

The study shows that non-disclosure was strongly linked to receiving care. It also indicated that PLHIV to a very large extent determined who they would get (what type of) care from, for example by choosing to live different lives in different places. If an HIV positive person had not disclosed to a family member, for instance, s/he may not expect the family to accompany her/him to the hospital; s/he would, however, try to be present at all meetings of the PLHIV association in order to get money and transport to access ART. Reciprocity also has a strong relationship with respect; those who are bad at giving in return risk losing respect.

Trust and mistrust

Sarpong (2009) indicates the importance of establishing trust to support a patient with a serious sickness. As he describes, a prerequisite for supporting a patient is the importance for the persons taking care of the sick person to be aware of what the sickness is and what the person is going through, so as to know how best to assist her/him. However, as shown in the case of HIV in Ghana, it is not easy for infected persons to disclose their status because of the fear of stigma. As a result of their choices to either hide or disclose to a limited number of people, HIV positive persons lose, find, keep, and develop new relationships. An HIV positive person may, for instance, decide not to open up to a sibling because of fear of

possible further disclosure, although s/he may engage with new friends from the hospital or a PLHIV association. HIV positive persons do this in order to remain social beings, receive vital emotional and psychological support, and also to maintain their respect in society. As they hide and disclose sensitive information about their status, and receive or are denied care, they open up and close down relationships based on trust. The prime motivation in all these instances, as can be seen in the diagram above (Figure 1.2), is to maintain or (re)gain the respect of society in order to live safely in the midst of stigma.

Respect and shame

In the community, people are evaluated based on their actions and speech. A person is held in high esteem when her/his words and deeds are deemed honest, respectful, fair, and full of integrity based on the norms of society and the social order. Respect, honour, and shame are seen in everyday life – the way one talks, walks, dresses, keeps oneself, and one’s attitude towards societal norms such as marriage, work, and care for one’s family (and community). Whoever crosses these societal boundaries is said to be disrespectful (*ɔmmu adeɛ*). Everyday life is therefore translated into acts of respect and shame – and the resultant honour and disgrace respectively – to not only the individual concerned but also her/his family and the community as a whole. Respect can be ascribed (by age, knowledge and wisdom, education, etc.) and/or earned (good behaviour, generosity, honesty, etc.). Experiencing HIV/AIDS in the community is thus tied to respect, honour, and shame. Due to the negative stereotyping of HIV/AIDS (its association with promiscuity, punishment for antisocial acts, etc.), people with the disease lose their ascribed or earned respect and stature in society and are consequently disgraced by acts of stigmatization. It is in trying to obtain or maintain respect, and to avoid the shame resulting from the HIV infection, that HIV positive people strategize to keep their status secret. Where they are successful, they maintain their respect and are therefore able to live safely in their communities. Where they are not, they become outcasts.

Outline of the book

This book is about strategies: how HIV positive people experience HIV-related stigma and strategize in order to live safely in their communities. All the chapters portray the various strategies that the infected and uninfected, tested and untested, put up as a response to the HIV epidemic in Ghana. I explore the related considerations, negotiations, and daily struggles and dilemmas as people experience HIV counselling, testing, and treatment. This thesis has therefore begun by setting the scene for the research, with a brief description of the HIV/AIDS situation in Ghana (see above). Under the leading concepts, the problem of the

high levels of stigma is identified as the main cause of the psycho-social challenges that HIV offers in the Ghanaian context. It also considers how those associated with the infection strategize in order to cope with stigma – by making conscious decisions and acting them out (agency) in order to receive or maintain their respect in society. Chapter 2 then describes the setting for the research and the ethnographic methods used to collect data, bringing to the fore issues of gaining entrée to the communities and individuals studied, selection of respondents, data collection, and the limitations of the study.

The organization of the thematic chapters, Chapters 3 to 7, is partly based on the order of the experience of HIV/AIDS services – counselling, testing, treatment, and life on the medicines. A critical reader would observe, however, that there are no strict distinctions between these experiences, since the majority cut across the various processes. In each of the chapters, how the various actors – the infected and the affected – seek safety in the midst of the high constraints due to stigma, are explored. That is, the notions of hiding and disclosure, trust and mistrust, reciprocity, care, respect, etc. are discussed to show how people cope with, and exercise their agency in, a constraining environment.

Chapter 3 is about the general public's perceptions and experiences of HIV counselling and testing in Ghana. In this chapter, the reader is taken through the processes of having an HIV test and the emotional challenges involved. It shows that many people are unwilling to go for an HIV test unless it is mandatory. The consequences of not wanting to know one's status, however, is that by the time it becomes evident, most are in a very advanced or even end-stage of the HIV trajectory, making it difficult for treatment to be successful.

Chapter 4 explores how HIV positive people disclose or do not disclose their status. The chapter shows that HIV positive persons disclose their status when they are convinced that it will not jeopardize their safety. They therefore weigh the benefits against the costs of 'selling the sickness' (a phrase taken from a popular Akan proverb, indicating disclosure), an act which is oftentimes less desirable than secrecy. Although some PLHIV expect benefits from selling their sickness, the majority fear that the reactions of others will be negative. They therefore do not disclose at all, even to their spouses, for fear of possible stigmatization or its effects. Others, who are 'lucky' to have a co-infection (such as TB), may disclose by proxy; in other words, they disclose the unstigmatized sickness, while remaining silent about HIV, in order to receive help and support.

The effects of disclosure (and non-disclosure) are such that many people associated with the infection cannot keep up their relationships with family and friends as they were prior to discovery of the infection. This is due to the indifference that arises in these relationships after disclosure and/or the limitations imposed by non-disclosure. Chapter 5 thus explores three other types of social

encounters that PLHIV experience: with hospital staff, with other HIV positive people, and with home care professionals (including PLHIV associations). All of these three groups consist of people who are aware of the HIV positive person's status and who should, in theory, be trustworthy. These new relationships are, however, not without problems; not all can be trusted. This chapter highlights the concerns, agitations, reservations, and apprehensions of HIV positive people when it comes to accessing ART, and in life in general.

Chapter 6 explores the role that money plays in living with an HIV infection. The analogy of blood in the human body system is used to explain how important a role money plays in the lives of both the infected and the affected. Money impacts on every aspect of the lives of someone infected with HIV. It is like blood: as some people explained to me, if you do not have it you have no life. The chapter shows that in the eyes of the infected poor, they think that their problems would be solved with money; however, the cases of the well-to-do demonstrate that money does not guarantee everything. This chapter discusses the economic and financial situation of HIV positive people, and its ramifications on their significant others. For example, some deaths of the respondents in the study could have been avoided, but for the non-availability of money to cater for the increased expenditure due to ART.

In Chapter 7, the sexual and reproductive ambitions of people on ART are explored. It brings to the fore the complexities and negotiations brought about by being 'normal' as a result of the medicines, yet being 'abnormal' because of the numerous rules and regulations that come with being on therapy. Consequently, there seems to be a struggle within society, where on the one hand infected people try to live normal lives, including having sexual relations and babies in order to meet societal expectations, yet on the other hand people in society try to obstruct this seeming normality since they perceive it as contributing to their own insecurity *vis-à-vis* the virus.

Chapter 8 provides the summary and conclusion of the study. It shows that being infected with or affected by HIV is as much (if not even more of) a social as a medical issue, and those associated with it require more than medical care and support. In conclusion, it provides some suggestions – based on the lives of the HIV positive persons in the study and their relatives and close friends, as well as a review of relevant literature – for ways in which all stakeholders may live safely in the midst of stigma.