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

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## Summary and conclusion: Safety in the midst of stigma

HIV/AIDS is one of the many diseases that are heavily stigmatized in Ghana. AIDS, like cancer, has a “strong attribute of dread” associated with it, and both are stigmatized because of their high mortality rates (Bolund 1990, Antwi & Atobrah 2009). This association with death notwithstanding, HIV/AIDS is stigmatized for various other reasons that may not characterize responses to cancer. This study analysed the experiences of HIV positive people as they themselves expressed them and as observed by the researcher, as well as the experiences and attitudes of others associated with the infection, such as families and communities. The study took place between September 2007 and August 2008 and again between November 2009 and January 2010 in communities in and around Kumasi and Offinso in the Ashanti Region, Ghana, using conversations, observations, in-depth interviews, focus group discussions, and a household survey to elicit data. Significantly, this study shows how all people – both those infected with and affected by HIV/AIDS – attempt to find safety amidst the high levels of stigma associated with the infection.

Being HIV positive is a social as well as a medical issue, and HIV positive persons require more than medical care and support. It is an even more serious problem in communalistic societies than in individualist ones. Miller & Rubin (2007) show that people from highly collectivist communities are more likely to be concerned with harmony and equality in the group. Stigma is therefore expected to be high in these communities as a penalty for deviancy, and finds its origins in sub-cultural beliefs, religion, or individually conceived causal processes (see Campbell *et al.* 2007). Most Ghanaian communities are collectivist, with

the majority of family structures having extended kinship ties, many living in compound houses, and people are expected to behave in ways that are socially acceptable. Stigmatization of individuals for deviation from societal norms excludes them from participating in the social good, making such stigma a major concern for everyone in the community. Stigmatization is the greatest challenge facing counselling, testing, and treatment provision for HIV/AIDS in Ghana (Radstake 2000, Mill 2003, Poku *et al.* 2005, Ulasi *et al.* 2009). Antiretroviral medicines and other forms of medication can help to alleviate the physical symptoms, however what is needed for the social situation is rather more complex. Stigmatization remains one of the main challenges that must be surmounted in order to curb further spread of the virus as well as the social problems associated with the epidemic.

As the study has shown, a consequence of the high levels of stigma associated with HIV/AIDS is that people are afraid to test. Those who do test are afraid to disclose, because they may lose their life chances as families disintegrate and both the infected and affected have their lives altered due to accusations, discrimination, physical violence, and abandonment (see also Greeff *et al.* 2008, Miller & Rubin 2007). Indeed, the destructive character of the epidemic has affected individual and collective attempts to organize daily life. Significantly, this book shows that the possibility of being stigmatized and the real effects of stigmatization mean that the vulnerable do not only find ways to avoid stigma but also develop strategies to cope with it, all in order to live safely in society.

The objective of this last chapter is to summarize the contents in this book by showing how stigma is visible in all stages of the HIV trajectory – pre-test, counselling and testing, and treatment, care, and support. That is, this chapter explores the general state of HIV positive people before, during, and after testing, as well as the role of stigma in all three stages. This is done through the experiences of the HIV infected and affected respondents in this book. It shows that the bio-physical aspects of HIV, reflected in the human body, are influenced by social, cultural, and psychological factors that one way or another shape the illness trajectory, what Alonzo & Reynolds (1995) term the stigma trajectory. This trajectory involves the pre-test stage, the test, and post-test stage. Emphasis is put on the post-test experiences to highlight the accounts of HIV positive persons and their families. In the end, extrapolations are made about how the situation can be normalized to improve access to counselling, testing, treatment, and care and support services.

### The pre-test stage

As Chapter 3 showed, the majority of Ghanaians have not tested for HIV (see also GDHS 2008). People are generally reluctant to go for VCT because of fear

of being stigmatized if the results prove positive. Most of those in the study who had found out about their HIV positive status were usually tested without their consent, after they had become sick and had gone to the hospital. After initial receipt of the result, instead of disclosing their status and seeking biomedical treatment, many at this point pursued several alternatives, including herbal medicine and spiritual therapy, before arriving at the health facility at the end-stage of the HIV trajectory. This is because a positive test result is linked with immoral and deviant behaviour (cf. Knodel *et al.* 2002), which in Ghana includes 'bad sex' (such as sex with prostitutes) and having multiple sexual partners (which, although it may be prevalent, is not socially accepted, especially for females). Being HIV positive is thus perceived as having been self-induced. Studies show that in communities where HIV positive people are often thought of as having contracted the disease through their own actions or moral weaknesses and have thus been duly 'rewarded' for their irresponsibility, the stigma attached to HIV is very high (Shehan *et al.* 2005). Such is the case in Ghana.

This study shows that the general public's perception of how an HIV positive person should look contributes to the stigma. Some people who look fit and strong on the outside, even if they are HIV positive, are not discriminated against since the public do not perceive them as HIV positive. Thin and emaciated people, however, are often perceived to be HIV positive and are consequently stigmatized, even if they have not undergone the test. Those who are stigmatized at this stage are "people who are regarded negatively, some for having violated ... rules, others just for the sort of people they are or having traits that [are] not highly valued" (Birenbaum & Sagarin 1976 in Alonzo & Reynolds 1995: 304).

Stigma at this pre-test stage is mainly based on the perception that someone *may be* infected. Although several efforts have been made to encourage the general public to find out their HIV status, the majority still do not test because of the fear that in the event that they test positive, people will devalue and discriminate against them and their families. Since the benefits of early testing are considered to be less than the perceived losses, the pertinent question that the majority ask regarding HIV testing is therefore "What for?" What is there to be gained by taking the test? The near one hundred percent awareness of the existence of HIV/AIDS in Ghana (GDHS 2008) therefore does not always mean full knowledge of the disease, nor does it translate into the uptake of VCT.

It is also worth noting that although stigma may have a temporal dimension, in that in some cases the labels are ineradicable and irreversible – as the terms ex-mental patient or ex-convict imply – this present study shows that where the negative attributes cannot be substantiated any longer, people may change their perceptions and stop attributing a spoilt identity to the person in question. As shown in Chapter 3, for instance, Maakua, who everyone in the community knew

to be positive because her husband had died of AIDS and the family had announced it to the community, is now living normally with her HIV positive child without the usual suspicions because she no longer looks thin. With the growing availability of antiretroviral medicines, and the possible increase in the knowledge of HIV/AIDS issues when more people get to know about the effects of ART, negative opinions will likely begin to change. But until then, HIV positive people such as Maakua are making the best out of a bad situation.

As a coping strategy to minimize the effects of stigma at this stage, most people refuse to test. Those in this study were afraid either to “lay their eyes on the nasty positive result” or that “other eyes will see the nasty positive result.” They therefore refused to test and, if HIV positive, suffered the disease quietly. Many who ended up testing at the hospital got there at the end-stage of the HIV trajectory, making recovery more difficult. Others who may have been feeling sick tried other forms of treatment, including local and herbal medicine and spiritual therapy. So although VCT is a required entry point for treatment of HIV and AIDS, many felt unable to use this option. The majority of people in this study who tested thus did so through the initiative of the facilities themselves. In fact, the ‘V’ of VCT hardly applied, as most people did not voluntarily go for testing. Voluntary testing continues to remain a major challenge in Ghana.

### The test: Confronting reality

At the testing facilities, the procedures to test involve pre-test counselling, the test itself, and then post-test counselling. The rapid test kit is the most used testing method, though some respondents erroneously mentioned that a CD4 count had been used to detect the presence of the virus. Although the procedure itself generally puts some people off from going for the test, a more significant concern among the respondents was during the dissemination of test results. Indeed, some of the counsellors found it difficult to tell the clients that they are HIV positive. This difficulty in relaying the serious nature of the sickness may be based on the belief that bad news may cause a sick person to ‘sink deeper’ and perhaps consider suicide (Mill 2003). In this study, the counsellors often used the phrase “there are worms/small animals in the blood,” which though morally neutral turned out to be ambiguous and left room for clients’ misinterpretation. Such misinterpretation, for instance, led Rahim to take de-worming medication instead of pursuing ART, a reaction of denial to the positive result (see Chapter 3). Generally, the reactions to an HIV positive diagnosis were confusion and caution, and more often than not the persons concerned mainly considered their next line of action to be to conceal their status from those who should not know.

The stigma prevalent at this stage is primarily self-stigma, either felt and/or imagined. Newly diagnosed HIV positive people may not have any real experi-

ences with discrimination or loss of respect as a result of their status, however the fear that these may possibly occur influence their decisions and actions. Many feel bad for themselves. A number consider suicide, though only a few in this study were found to have gone through with it. As discussed in Chapter 3, however, a significant number killed themselves in the long run, by refusing to enrol on ART and/or resorting to other alternative treatments, not only because of denial but also out of fear of being seen using ART as well as inadequate financial resources to sustain the therapy. For these people, the fear and ideation of what might happen to them becomes a reality as they move from a pre-stigmatized (though nevertheless at-risk) status to a diagnosis of HIV positivity (Alonzo & Reynolds 1995).

### Post-test: The stage of liminality and apparent manifestation

The post-test experiences of HIV positive persons depend on the degree of physical and emotional deterioration that occurs as a result of the positive diagnosis. Two general distinctions can be drawn: the stage of liminality and the stage of apparent manifestation. The former – the stage of liminality – is characterized by the dilemmas of feeling well (i.e. free of symptoms and sickness) yet simultaneously unwell (because of the HIV positive diagnosis), and of feeling normal (i.e. healthy) yet abnormal (because of the dos and don'ts regarding living positively with the infection). In the case of the latter – the stage of apparent manifestation – this refers to those who are sick and displaying apparent physical manifestations of the symptoms of AIDS, or those who do not respond positively to the antiretroviral medicines. The majority in this latter stage are those who did not report early to the ART facility for treatment. These people are often sickly and emaciated and some do not recover. A significant majority of the respondents in this study can be classified as belonging to the former category, and their condition is discussed below.

#### *The stage of liminality*

As Chapters Four to Seven show, the majority of the HIV positive people in this study responded very well to the antiretroviral treatment. They were therefore 'sick' yet 'not sick' and they felt 'normal' yet 'abnormal'. This is what I term the stage of liminality. This stage posed several challenges to these HIV positive people as they tried to avoid both internalized and externalized stigma in terms of disclosure, their social relations, and medical dilemmas.

#### *Disclosure*

As shown in Chapter Four, when a person becomes aware of her/his HIV positive status, the perception of possible maltreatment from family, friends, and

community members alike surfaces. A number of these people do in fact face stigma and discrimination from those close to them. Faith-based organizations and other institutions may also discriminate against their members who are HIV positive (Kwansa 2010). These PLHIV therefore decide to hide their positive status, revealing it only to a few trusted people if at all. Such actions of concealment are done so that they can maintain their respect and good name in their community and avoid stigmatization.

One widely publicized health recommendation has been for HIV positive people to disclose their positive status to others, especially those who might be at risk of infection themselves. Many people with HIV do disclose their status, but with mixed results. In this study, although some people who disclosed were accepted and received the desired support, many others were rejected or subtly (and sometimes not so subtly) denied love and support. Since the latter cases remain dominant, many people, regardless of the counsel they receive from the treatment facilities and the experiences of others whose disclosure went well, fear that they risk a stigmatizing response if they disclose. This study shows how complex a process this is. HIV positive persons in this study were found to have very restrictive attitudes and were thus very protective of their privacy.

From the experiences of most of the PLHIV in this study, the decision to conceal their status seems justified because they have witnessed other HIV positive people whose marriages have failed, whose entire community discriminates against them, who are denied financial help to get better, and whose families have rejected or quarantined them after finding out about their positive status. The tragedy of this concealment is that several of the spouses of the HIV positive persons in the study did not know about their partners' infection. Though HIV positive persons are encouraged by health workers to disclose, especially to their spouses, the fear of possible consequences, both real and imagined, prevents them from doing so.

Generally speaking, some groups of persons are found to be more likely to disclose than others. Studies on patterns of disclosure have shown that people who feel that they have been exposed to the virus through stigmatized 'high risk' actions, for instance prostitution, are less likely to disclose. In addition, people living in rural settings are less likely to disclose because of having less knowledge of the infection, more conservative moral values, and greater fears about the loss of anonymity (Casteneda 2000, Shehan *et al.* 2005). Non-disclosure in the context of this study can be linked to the association of the infection not only to stigmatized behaviours (such as promiscuity) but also to the fear of loss of anonymity. Although Kumasi and Offinso cannot be referred to as small communities, their characteristics are similar to such communities because of the close-knit kinship ties that prevail there. The people in these communities

are thus also afraid of courtesy stigma – that their status, when known, will lead to their families being stigmatized too. This was the case of Maakua (Chapter 5), who tried every means possible to prevent the hospital staff from visiting her HIV positive daughter due to fear that people would find out about her status and the entire family would be affected.

Shehan *et al.* (2005: 187) have also shown that education may influence disclosure through its impact on felt shame and the need for support – instrumental support (meal preparation, market shopping, etc.) and/or socio-economic support (such as assistance with the costs of treatment as well as the need to discuss feelings about the disease). This, the authors explain, is because lower levels of education are often linked to having fewer socio-economic resources to help in times of illness. This study did not have enough educated respondents to make a comparison in order to corroborate this assertion, although there was a strong link between having socio-economic resources and non-disclosure. Although the study showed that the well-to-do may not disclose because they do not need to reveal their status and thus gain familial and community support, the poor were also found to be likely to fear disclosure because it would cut them off from the social good and they would feel the brunt the most. There was therefore no clear link found between education and access to socio-economic resources and the likelihood of disclosure.

Several scholarly works (such as Serovich 2001 and MANET 2003) have also added that symptom severity – from asymptomatic or variously symptomatic – not only influences an HIV positive person's decision to disclose but also affects their willingness to ask for and accept both instrumental and socio-economic support. According to this theory, those whose illness has progressed to the end-stage of the trajectory, who are incapacitated and/or unable to work, are more likely to feel compelled to and will disclose. In this study, however, due to improved medications, especially the highly active antiretroviral therapy (HAART) and its consequences of producing less glaring HIV symptoms and side effects, no direct link was observed between disclosure and a long period of infection (as several scholars such as Mansergh *et al.* 1995 and Mason *et al.* 1995 have argued). As this study shows, many HIV positive people devise coping mechanisms, including avoidance, to live safely in the midst of stigma. Those who have no coping mechanisms are more likely to disclose.

People living with HIV might attempt to avoid or minimize actual stigma by closely controlling who knows about their HIV status, and by avoiding or withdrawing from potentially awkward social situations. Such information control techniques are an important component of stigma management (Sandelowski *et al.* 2004). Trust is very important in information disclosure by PLHIV. In this study, trust – implying anticipation that the other will not betray the



informer's confidence – is the significant factor. Thus, PLHIV trust only those considered worthy to have access to information about their sero status. People therefore create informational sub-systems in terms of making decisions about who should have access to their HIV test results. Greene & Serovich (1996) refer to such behaviours as 'informational barriers'. Some people are simply not viewed by the HIV positive persons as appropriate to have access to information about the results of their HIV test, and such people are barred from getting the results.

In the study by Greene & Serovich (1996), PLHIV classified the people in their environment with whom they would share their HIV status and related information into three distinct groups (given here in order of appropriateness): immediate family members (spouses, former spouses, lovers, sons, daughters, mothers, and fathers), extended family members (aunts, uncles, cousins, and in-laws), and non-family members (employers, potential employers, co-workers, teachers, general public). In some cases, immediate family members were said to be more appropriate for disclosure since they are more likely to offer support, although in other cases the PLHIV felt more uncomfortable telling immediate family members, because of the worry that if one were to know, the whole family would come to know. In addition, other scholars, such as Greeff *et al.* (2008), have argued that nurses and health care providers are less likely to be trusted with a positive test result. In this current study, however, the situation was different. Many HIV positive persons did not choose to confide in family members or others. They did not perceive spouses, former spouses, lovers, extended family members, employers, etc. as appropriate recipients of disclosure. They preferred to keep their status very secret. They feared that their partners would leave them or that they might not get the needed support if they disclosed. This strategy of non-disclosure makes more sense if one appreciates the power differentials at work here. The majority of the PLHIV in this study (and the region in general) were female, and in the lower wealth quintile of the population. They feared possible divorce, ill treatment, loss of privacy, etc. if they disclosed to their partner, let alone to any other person, and lacked the resources to live independently if the disclosure backfired. As is argued in Chapter Six, the HIV positive persons in this study trusted three groups of people with their positive status – the medical staff, other PLHIV, and home care professionals (including PLHIV associations).

Due to the particular circumstances of the HIV positive people in this study, they had to confide in the health care professionals involved in their care and treatment. Disclosure to health care providers is especially significant in order to access treatment, care, and support services. However, concerns about protection of confidentiality were a major concern among the respondents. Individuals often

rely on doctors and medical practitioners to protect information about their sero status, but in some situations members of the medical staff do inform others, such as family members, sometimes in the firm belief that the family need to know (Dapaah 2011: 66-69, Malcolm *et al.* 1998). In this study, there was an instance where an HIV positive person threatened to abandon treatment (and eventually did) because a nurse at the hospital had shared her status with a community member without her permission (see Kakra's case in Chapter 4). This is of particular concern since several studies have shown that breaches of confidentiality often occur in the treatment facility, with medical personnel being the culprit (see for instance MANET 2003 for the situation in Malawi). Although several studies, such as Deetlefs *et al.* (2003), conclude that the attitudes of nurses, especially in developing countries, toward HIV positive patients are mostly negative, Dapaah (2012) has shown that the situation is different in the study areas of this research, where the main concerns of PLHIV regarding the health workers were about home visits by nurses and community health workers, especially in hospital vans, and bitterness over preferential treatment in the facilities.

In HIV disclosure discourses there is the danger of interpreting disclosure only in negative terms due to the role of stigma, because it can lead to added stress due to neglect, isolation, disruption of personal relationships, and other discriminatory acts against PLHIV (Derlega *et al.* 2000, Petrak *et al.* 2001). In this study, disclosure was indeed the main source of stigma – felt, perceived, internal, external, and courtesy stigma. However, there is enough scholarly data to support the contention that there can be a therapeutic effect of disclosure, particularly as a way of garnering important social support that can mitigate the negative effects of stress. These positive consequences of disclosure have been found to be mainly psychological. As Greeff *et al.* (2008: 316) show, after disclosure:

there is a heightened sense of understanding, healing, and authenticity in their relations with others; an enhanced sense of accomplishment and pride, empowerment, and purpose; a welcome relief from the burdens of secrecy and rumours; and the ease of further disclosure and support.

Disclosing one's HIV status to another could simply be seen as a way to reduce anxiety and stress by gaining social support. Many of the PLHIV in this study could thus be seen as losing a lot through non-disclosure. The fear of finding out one's HIV sero status and then of others finding out about the positive result, coupled with insufficient knowledge as to what to do with a positive result and a lack of trust in the institutional systems' responsibility for protecting confidential information, are some of the factors that inhibit people from accessing counselling, testing, treatment, and care services. Many HIV positive people feel that their reasons for not sharing their HIV positive results

far outweigh those for disclosure. They rather strategize to live safely in the midst of stigma, with its associated individual and public health concerns.

### *Social relations*

Everyday life is translated into acts of respect and shame, and its resultant honour and disgrace respectively, so the PLHIV in this study acted in order not to lose respect and status in society. All their actions and behaviours, including hiding or disclosing, deciding whom to trust, and whom to give care to and whom to receive care from, were all done to maintain or regain their status in society. For instance, having money and putting it at the disposal of friends and family, as a fulfilment of kin and communal responsibilities, ascribes a lot of respect to the individual. As members of kin and of the community, HIV positive people also have responsibilities, aside from those for their own (conjugal) families, to care and provide for the needs of others, including their own relatives, the relatives of spouses, and other community members. So those who do not work and therefore have no money are frustrated about their inability to reciprocate, and hence the loss of independence and respect they experience in society.

In order to maintain or regain status and be safe in the midst of stigma, the majority of PLHIV in this study lived as if they were not infected. They used their seeming 'normalcy' to get money (for basic life necessities – food, clothing, shelter, education, medicines, etc.) and also to satisfy pressures from society (getting married, having sexual partners, having children). Having money and 'living normally' guaranteed respect. The invisible infection did not differentiate them from any other person in society. As shown in Chapter 7, some of these actions were the result of societal pressure and expectations.

These sexual and reproductive behaviours – as displayed by the PLHIV in this study – nevertheless contribute to a sense of acrimony among community members, who feel that HIV positive persons on antiretroviral medicines 'intentionally' spread the infection to others. Some call for quarantine of HIV positive persons, while others mention banning the antiretroviral medicines so that those who become infected can be easily made out. Based on the findings from this study, the concern about deliberate and indiscriminate transmission of the infection (the 'we don't want to die alone' syndrome) remains on the level of rumour and gossip, although there was evidence that some PLHIV do knowingly have unprotected sexual relations.

How should this lacuna between the public rumours and the situation on the ground be addressed? Should there be criminal liability for spreading the infection through indiscriminate sexual activity, for instance? What are the implications when a person who is known to be HIV positive refuses to undergo counselling and treatment and does not inform his/her spouse? What about

persons who engage in reckless conduct likely to spread the infection, such as herbalists, traditional birth attendants, *wanzams*, and barbers using unsterilized instruments in the course of their occupations? Some of these questions were already being asked some two decades ago (see Mensa-Bonsu 1995), yet they remain unanswered as far as implementation is concerned. In some jurisdictions, as shown in the study by Mensa-Bonsu, failure to inform a sexual partner of one's HIV positive status warrants criminal liability (see Kirby 1993 for the situation in New South Wales). In Ghana, the Ghana AIDS Commission (GAC) made proposals in 2012 to a Constitutional Review Commission advocating for legislation to punish people who deliberately spread the HIV virus.<sup>1</sup> This, they hope, will regulate the activities of PLHIV, to check the spread of the disease, without infringing on their human rights.

One significant thing worth noting is that negative experiences and behaviours in life are shameful only when they are out in the eyes of the public. Thus the stage where this takes place is the world of public performance. This is not unusual in collectivist societies, where members are concerned not only about their own image but more significantly that of their family and larger community (Gyekye 1998). This collective concern shapes a person's behaviour, especially in public. Rumours about an individual's private life can be the cause for casting insinuations, although public shows of disrespect, stigmatization, and overt sentencing of the individual etc. mainly take effect where the actions are made public. Thus when people do not get to know about an inappropriate behaviour or action, and when families are not involved, the act is not shameful. Respect and honour in unmarried women, for example, rests in chastity and virginity. A girl who is considered industrious, intelligent, caring, and neat, but who is engaging in premarital sex, can still be respected as long as her 'misdemeanour' is not made public (by, for instance, getting pregnant or being exposed by a rival). Equally, a man who may be having secret affairs with many girls may still be respected, as long as people in the community do not know about his adventures. So in this era of widespread availability of antiretroviral medicines, where the clinical symptoms of HIV/AIDS can be averted by the majority of those on therapy, and where there is much social pressure to live 'normally', PLHIV consider it safer to live 'normal' lives by engaging in sexual relationships, and having a family and children.

Because an HIV positive person is labelled as 'the other' by the community, people try to secure social harmony by casting out offenders or reaffirming societal values (Gilmore & Somerville 1994). Sometimes PLHIV are assumed to be unable to contribute to societal development (Greeff *et al.* 2008), and as this

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<sup>1</sup> News item found on <http://news.myjoyonline.com/health/201005/46813.asp>. Accessed on 28 May 2010.

study shows people may refuse to buy food from them (see also Simbayi *et al.* 2007). However, as the PLHIV continue to live 'normally' and without any clinical symptoms, these perceptions may change. In the case of Maakua in Chapter 7, after six years of seeing no further deterioration in her health, her business recuperated and flourished once again. The majority of the PLHIV in this study had in fact succeeded in making the people in their communities feel that they are 'normal'.

According to convention, friends and other community members usually provide food, shelter, and clothing to a sick person, or with their visits keep the person company and give them reassurance. As members of a family and a community, people expect that in their time of incapacitation, help will not elude them. The majority of the study respondents were poor and therefore when they became sick they became more dependent on the time and material resources of family and friends alike for survival. Oftentimes, they did not seek treatment at the ART facility early in the course of their illness, arriving there only after several attempts for healing at prayer camps, traditional healers, etc. They sold their properties and belongings, including their work tools and other implements and their lands for farming, all in the pursuit of a cure for their ailment. Even once they started ART, however, the expenditures kept mounting. As Chapter Six shows, the PLHIV on treatment had several additional needs, including food to satisfy their increasing appetite and money for transportation and other medical expenses.

The majority of the PLHIV in this study did not receive adequate care and support from the expected sources to satisfy their many needs. Since they could not exactly tell their family and friends what their problem was for fear of being rejected and abandoned, the care and support they desperately needed still eluded them. More importantly, friends and family were more likely to give care and support to people in return for a favour or in expectation of a future favour. The majority of the participants, however, incapacitated in their productive years and at the heart of both their economic and social activities, had not made sufficient social investments and could not guarantee any for the future. For others evaluating whether to provide them with care and support, investing in them was not considered worthwhile and was therefore to a large extent non-existent.

Another significant aspect of these relationships was evident from the reactions of family and community members following disclosure (forced and voluntary). They were mostly negative. The HIV positive persons were labelled as having loose morals and of being promiscuous, and were denied familial care, chased from home, and blamed for bringing shame to the family. Some families hid their sick member for fear of public embarrassment. Disclosure also negatively affected some intimate relationships: between lovers, siblings, children and

their parents, as well as other less intimate relationships such as between doctor and patient, employer and employee, and landlord and tenant. Disclosure may thus go a long way to determining people's access to – or denial of – some of life's necessities, including housing, an occupation, health, etc.

In effect, HIV positive people find themselves in a dilemma as they face the difficult situation of trying to disclose to obtain certain benefits while avoiding the negative consequences. Their lives are filled with the worry and suspicion that other people know their status, either by inferring it from particular situations and drawing their own conclusions, or by being told by someone who knows. Consequently, a number of the PLHIV in this study took their medications without food while others travelled very long distances to ART centres where they were least likely to be known. Others skipped their treatment appointments because they did not have money for transport or had not eaten and so did not have enough strength to walk the distance to the facility, while others also resorted to cheaper treatment alternatives including local medicines. These were all strategies to keep their HIV status hidden from close friends and relations. However, all these strategies and challenges took their toll on the HIV positive people's health and recovery. Predictably, some of the clients died during the course of the study when it was obvious that if they had had support and care, they may have been able to live.

The fact that HIV treatment is a lifelong process helps in this regard, since PLHIV are likely to make the acquaintance of other HIV positive people in the course of receiving therapy. Through these acquaintances they may develop new relationships and maintain their own networks – with medical staff, fellow positive persons, and home-based professionals, including members of PLHIV associations and NGOs working in the field of care and support. All of these are categories of people who are aware of the HIV positive person's status, and are for that reason trusted. They all offer reassurance and assistance, as well as the status and respect that PLHIV may have lost due to the infection. The HIV positive persons therefore find in these new friends a sense of acceptance, belonging, camaraderie, and conviviality, something which they may no longer receive from their past relationships. They rely on these new relationships for their physical, familial, material, spiritual, emotional, and psychological needs and support, and especially the financial resources to live safely in the midst of stigma.

On the part of PLHIV, they do everything to maintain these new relationships and also to avoid possible disclosure to others of their status; the latter concern is an acknowledgment of these new relationships' potential fragility. For instance, some of the PLHIV in this study who gave gifts to the medical staff were found to do so not only to show appreciation for their services (though this was fre-

quently expressed) but also in order to receive preferential treatment. Due to the enormity of the consequences of a breach of trust, many PLHIV are still suspicious. Any actions on the part of these new friends that may lead to doubts about their trustworthiness and fear of the loss of their privacy are thus detested. For instance, carrying food rations from the treatment facility or PLHIV association meeting grounds is done with utmost tact in order to avoid giving any reason for suspicion from others. As shown in Chapter Six, furthermore, the PLHIV in this study were visibly apprehensive any time they saw new faces at the association meetings. The leaders often had to emphasize the link between the visitor and HIV/AIDS before they could relax. Others did not join some of the associations' programmes when they suspected that it would jeopardize their privacy, as in Kaakyire's case in Chapter Six. All of these strategies are done to ensure that they are safe.

The activities of the PLHIV associations cannot be underestimated, as they come in to restore to a large extent the shattered lives and pride of PLHIV. It was clear from the respondents that where an HIV positive person envisaged the possibility of access to support – economically and even spiritually – s/he seemed more open to confront his/her situation and access help. The majority were therefore heavily involved in the activities of PLHIV associations as a means to not only remain active but also to enjoy the communal love and support of other members. They also received some money that kept body and soul together, since the majority were not working and earning a living. Even those who did work used such support to augment their income. Income generating activities by these associations – such as farming, soap making, and animal husbandry – also helped to provide a new lease of life for these HIV positive persons (though, as described in Chapter 5, they were not without their association problems of rivalry and mistrust over the distribution of generated income).

It must be noted that nearly all of the PLHIV associations were founded and run by PLHIV themselves. The activities in the associations offer PLHIV a new meaning to life different from the gloomy one expected of them in general. Some of the association leaders travel the world over, and enjoy the luxury that comes with going to big conferences (such as sleeping in cosy hotel suites). Other PLHIV work with the medical personnel in the treatment centres. They try to find meaning in their new lives, while utilizing the possibilities of their new status to live worthier lives. The supporting role played by these associations, in the form of giving food and money, assisting PLHIV to access ART services, and offering spiritual help in the form of prayers, goes a long way to ensure that the clients access and are retained in treatment and support services. The interactive experiences at the PLHIV associations help members make gargantuan strides in their healing process.

The gloomy prospects of PLHIV nevertheless remain, even when they are being treated successfully with ART and engaging in PLHIV association activities, since they find themselves unable to live 'normal' lives due to the numerous dos and don'ts that come with being on ART. These dos and don'ts include 'healthy practices' such as hygiene (personal and domestic cleanliness), diet (encouraging certain dietary habits while prohibiting the intake of certain foods), social behaviour (such as not engaging in quarrels and not worrying about their condition), spiritual life (joining a religious group and praying), and medical issues (regular intake of medicines, and abstaining from alcohol and (unprotected) sex). PLHIV often find the regulations about diet and sex particularly difficult to adhere to.

Living safely in the midst of stigma presents a dilemma. On the one hand, the lives of HIV positive persons pose a lot of questions, many of which have been addressed in this book. Since PLHIV do not live in isolation, and their lives affect others in society, what should their responsibility to society be? When an HIV positive person refuses to share information about their status with their spouse, what should the duty of the doctor be? Should the person's spouse be informed anyway? Are the parents and other close relatives of an HIV positive person entitled to be informed of their condition? What about employers who are contemplating investment in training for an employee? Must school authorities be told of a child's condition? On the other hand, the dangers posed by HIV/AIDS are such that reactions to PLHIV – in the form of stigmatization or discrimination, or any criminal sanctions that may be invoked to punish or deter HIV positive people from deliberately spreading the infection – may instead lead them to live in secret. HIV stigma must therefore be handled tactfully.

### *Medical dilemmas*

One difficult situation that those who go for ART face is the need for treatment monitors in order to enrol, a practice that was common in all the treatment centres in the study region. What this means is that before a person can enrol on ART, s/he has to inform a close friend or relative who will monitor her/his proper intake of the medicines and help out in times of difficulty. In effect, for PLHIV to live, they need to confide their greatest secret to at least one trusted friend or relative. This regulation has been put in place in the interests of the client, to help ensure that they are supported through the treatment process. It is hoped that this will help them to fare better on the medicines, thereby preventing complications – including severe symptoms of either the disease or the medicines – and thus eluding stigmatization in the first place.

Due to this requirement, some of the PLHIV in this study had to reveal their status to someone who they did not want to know it. In some cases, these



treatment monitors divulged the secret to yet others who the HIV positive persons did not want to know. Some of the PLHIV, cognisant of this and as a coping mechanism, picked (and sometimes paid) people they found ‘on the street’ (who they were not related to or even friendly with prior to the bargain) to fulfil this obligation for a treatment monitor, in order to receive the medicines and avoid the shame associated with being found out. In some instances, however, when the test occurred in the hospital and the person being tested was very ill, the test results were sometimes given to the care givers present instead of to the patient individually, or in similar instances the HIV positive person felt compelled by his/her incapacitation to disclose his/her positive status to the care givers present, and thus the option to ‘choose’ their treatment monitor was denied them.

Others in this study chose to live with their secret by using other strategies, such as resorting to spiritual therapy, which fed into the norms of society that hold that serious ailments have spiritual causes and need a spiritual approach to cure (Wyllie 1983, Awusabo-Asare & Anarfi 1997). Although the majority who used these tactics believed in the biomedical causative and curative aspects of the disease, they used spiritual therapy to win the support of care givers. By doing this they disguised the biomedical explanation for their predicament (which would be the cause of stigmatization). Some used spiritual therapy to complement ART (see Kwansa 2010). The group who were ‘lucky’ to be co-infected with other sicknesses, such as tuberculosis, and who disclosed their HIV infection by proxy (revealing only the less stigmatized illness), were the ones who predominantly used spiritual therapy.

As discussed in Chapter 7, being on antiretroviral medicines and feeling ‘normal yet abnormal’ also brought more dilemmas. As Abiba and Egya explained, for instance, another difficulty arises when PLHIV are unable to comprehend the logic of the antiretroviral medicines. For instance, how is it possible, as Egya put it, that the

... medicines reduce the viral load ... and as you continue taking your medicines, the probability of transmitting the infection [both to the partner and the baby] would be minimal [as it is in PMTCT]. If all these are true, then one can confidently say that the medicines, though they do not wholly cure you, secure you from infecting others. Why is it then that they say we cannot have unprotected sex?

In addition, being on the medicines for a long time brings a feeling of normality, to the extent that sometimes PLHIV doubt either the continued existence of the virus in their body or its potency. These seeming confusions influence how they cope with the infection, in particular as it affects adherence to therapy. Dangling between normalcy and abnormality also affects relationships with family and friends. HIV positive people may disengage from old relationships that they find threatening while engaging in new ones based mainly on trust. By

this, they make independent choices to avoid or limit the extent to which people can discriminate against them.

The medical dilemmas confronting HIV positive people have serious implications for prevention programs, because people who do not want to go for VCT, and those who go but do not disclose their positive status to their family, friends, or sexual partners, are more likely to engage in higher risk behaviours with serious implications for the further spread of HIV (Gilmore & Somerville 1994, Duffy 2005).

## Normalization of stigma

As this study has shown, HIV positive persons devise strategies to live safely in the midst of stigma, in all the stages – from accessing counselling and testing, to treatment and support services. But are they really ‘safe’? When antiretroviral drug programs were launched in (mainly southern parts of) Africa from 2000 onwards, it was theorized that the programs would naturally eliminate stigma and denial by making an HIV/AIDS diagnosis seem less frightening. By bringing treatment centres closer to the clients and reducing AIDS symptoms – the sores, rashes, and coughing, among others – it was also hoped that the antiretroviral medicines would help to reduce the fear associated with HIV positive persons. Although Strebel *et al.* (2006) and Simbayi *et al.* (2007), for instance, show how there are patches of success in some parts of Africa, reports in this book show that these efforts have not been wholly successful. This is partly so because the situation in Ghana is very unlike eastern and southern African countries when it concerns HIV/AIDS prevalence. Normalization is a matter of numbers, and the numbers remain low in Ghana, and as the disease remains relatively unknown it may prolong stigmatization. In the Ghanaian context, the disease needs to be demystified and stigma dispelled through the concerted efforts of the untested, tested, and those who are HIV positive.

The problem of stigmatization is not easily resolved, despite the rhetoric of many campaigns to ‘eradicate stigma’, since it is currently woven into the fabric of society. Positive persons may devise strategies, but as long as the problem of stigma is not tackled they will still not be wholly safe. It is the view of this study that focus should continue to be on the scale-up of services while accepting stigmatization for the time being as a hard fact. Policies should, in addition, be directed at improvements in the general level of knowledge of HIV/AIDS and its associated services (including VCT and ART). People in positions of leadership who are in the public eye should also become actively involved in encouraging counselling and testing services, and encouraging and supporting HIV positive people to openly own up to having the infection.

The minimization of stigma may end up being an important side effect of all these activities, even if it is not the explicit purpose of them, and the programmes will not have failed since they will have contributed to lower prevalence and incidence, higher counselling and testing rates, and an overall increase in HIV/AIDS knowledge. This study therefore recommends, among other things, improvement in information, education, and communication on HIV/AIDS, proper tackling of disclosure concerns (some of which are raised in this monograph), public actions from people in positions of leadership to test and disclose their status, and a great responsibility on the part of the untested and uninfected to test and find out their status, and then to be open about their status and avoid further spread of the infection.

#### *Information, education, and communication*

All of the stakeholders in the ‘follow-up workshop’ for this study (see Appendix 4) were of the view that stigma could be reduced through intensive education and campaigns on HIV/AIDS for members of the general public, people in the media, and health workers (especially those who do not provide VCT and ART). Even though awareness about the disease is nearly universal in Ghana (GDHS 2003), there is a need for intensive education about the causes and how it can be managed with ART. It was clear from the study that because the majority of people do not know about the availability or efficacy of antiretroviral medicines, the situation is similar to the pre-treatment era where people equated being HIV positive to having a signed death warrant. What is there to be gained from testing then? The lack of adequate information about the disease is one of the underlying causes for the stigmatization of PLHIV in their families and communities. Since improved levels of knowledge have not been achieved over the three decades of fighting this menace, this may not be such an easy task.

The HIV positive persons during the follow-up workshop specifically pointed out that people in the media – both electronic and print – lack information about the disease, which is evident in their reportage. “They often use bad language or dreadful words, such as ‘terrible illness that will result in death’ (*yadee kodi awuo*) to describe the disease and its sufferers,” said one participant. This feeds into the stigma associated with HIV/AIDS. “Besides, some [of the people in the media] do not even know the difference between HIV and AIDS. So, they are not able to explain to the listening public the difference between HIV infection and the AIDS disease,” another mentioned. AIDS Information Centres (AICs) could be set up. These could then not only store all information about the infection, but officials of the centres could be made responsible for all information, education, and communication tasks (IEC) in connection with their communities. As long as the predominant view about HIV is derogatory (such as that becoming infected

equals death or that HIV is a disease of promiscuity, etc.), interest in VCT, and eventually ART, will be low. This is because people base their decision about having the test on the balance of advantages and disadvantages of knowing their status, as shown in Chapter 4. Where the disadvantages outweigh the advantages, they will often refuse to pursue testing and thus treatment. This is largely the current situation. IEC materials and activities could be expected to help the general public to understand the disease better and also behave positively towards PLHIV, all of which would reduce stigmatization. New messages aimed at reorienting both the infected and uninfected away from fear must therefore be pursued.

#### *Disclosure concerns*

Most health policies and treatment facilities favour disclosure by PLHIV. However, it is clear from the study that not all disclosure brings positive results. In fact, the majority of disclosures by participants did not yield the intended results of bringing support in times of need. Currently, the main tools in Ghana for encouraging disclosure in the ART facilities include ‘partner notification’ through couple counselling and the ‘treatment monitor’ concept (see Dapaah 2012). However, research has shown that disclosure seems to have more advantages in settings where discrimination and stigma are low (see for instance MANET 2003 for Malawi, Sandelowski *et al.* 2004). Considering the high levels of stigmatization of PLHIV in Ghana, mandatory disclosure seems questionable. Why is the ‘treatment monitor’ concept compulsory? It is my view that disclosure should be encouraged as much as possible but must not be mandatory, because it also contributes to stigmatization and discrimination.

HIV/AIDS would be normalized when all the uniqueness about it – such as having to disclose before being put on treatment – is removed. Health workers, in addition, could propose testing and counselling to all patients to identify people infected with HIV who might therefore be eligible for treatment. However, counselling should not be taken as a given as it means more than it presumes. For instance, submitting to counselling before testing may be perceived by the testing person’s environment as an admission of promiscuity and thus the grounds for becoming the victim of social exclusion. When it is done after testing (as in provider initiated testing and counselling) counselling becomes a diagnostic tool enabling access to treatment (Hardon *et al.* 2011) and a return to health. The focus in the latter case would be to encourage more people to know their status rather than on the process of counselling (see also Hardon *et al.* 2011).

Social service professionals, such as those in the PLHIV associations and other NGOs in the field of providing care and support services to those associated with the infection, should be equipped to assist HIV positive persons in their

disclosure decisions, because they are key in providing the much needed social support for PLHIV. This study argues that, looking at the successes of the PLHIV associations and NGOs, more resources should be channelled there to encourage disclosure. It is in the PLHIV associations that cases such as Abrantee's – who became sick and was taken to places other than the ART facility for treatment because none of his caregivers knew about his infection (see Chapter 4) – are discussed. The sharing of life experiences in the association meetings and the subsequent lessons derived by all members go a very long way in convincing otherwise less likely groups and persons – such as asymptomatic members and more educated and affluent ones who do not need much socio-economic support – to rethink their decisions and perhaps disclose.

Unsurprisingly, given the risks of stigma and discrimination, the majority of PLHIV in this study did not disclose to significant others who could offer support in times of need. For others, who were tested quite far along their HIV trajectory when they were taken to the hospital with a severe illness, they may not have had a choice about whether to disclose and may thus be bearing the negative consequences of this. As Greeff *et al.* (2008: 323) note, citing Mill (2003), “encouraging disclosure within a trusting and supportive environment might be a strategy to attenuate [HIV-related] stigma.” However, disclosure should be decided upon on a case-by-case basis. Service providers should assist the client to weigh the therapeutic effects against the possible stresses and negative consequences before advocating for disclosure.

In the treatment of PLHIV, more should be done to ensure holistic treatment, in particular by considering psychological management. Many HIV positive people suffer from psychological problems. A substantial number of people in this study considered suicide, and a few actually went through it. Considering the highly negative perception of suicide in Ghana, the fact that people chose to do so tells of their desperate position. Some PLHIV were also found to opt for a concealed form of suicide by giving up the will to live and deciding to die slowly. Most felt lonely and became isolated. No assistance was offered in this regard in the two facilities studied.

### *Leadership*

There must be concerted efforts, especially from public persons in positions of leadership, to show the way forward. Most leaders in Ghanaian society have not tested their status. Those who have tested have not disclosed their status, likely for reasons discussed in this book.<sup>2</sup> It is not enough to talk about stigma; leader-

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<sup>2</sup> In the run up to the 2012 Presidential elections in Ghana, the Progressive People's Party's (PPP) presidential candidate, Paa Kwesi Nduom, underwent a series of medical exams to prove his fitness to Ghanaians. With concerns being raised regarding the health of public office holders, especially after the death of the former President John Mills, who was rumoured to have been unhealthy for a long

ship must be seen through action. A very good example in Africa is that of Mr. Festus Gontebanye Mogae, the former president of Botswana and chairman of the 'Champions for an HIV Free Generation'. He is credited internationally for his efforts to combat the HIV/AIDS epidemic in Botswana, and for being the first head of state in the world to publicly test for HIV. When leaders test and declare their status in public, it not only encourages testing, it also normalizes the testing procedure (and the infection in particular). It also demonstrates that one can continue to lead an active and useful life whatever their status. Although it is of course much easier when the result is negative, knowing one's positive status allows one to undergo appropriate treatment, adopt a healthier lifestyle, and avoid spreading the virus further.

During US President Barak Obama's visit to Kenya in 2006, he and his wife accessed HIV testing and publicly declared their status. This act, apart from making a statement about the importance of couples accessing counselling and testing services together and supporting each other during the process, was believed to have led to a remarkable increase in overall testing rates after the event. In the three months that followed the event, for instance, there was more than a fifty percent increase in all HIV testing activities across Kenya, compared to three months prior.<sup>3</sup> An appeal for a similar action<sup>4</sup> was made by the NGO 'Education and Health for All' in Ghana, calling on all Members of Parliament to test for HIV and declare their status as a means of lending their support to the campaign against the pandemic. Through this call, it was hoped that if Members of Parliament, like Mogae and Obama, got themselves publicly tested, it would encourage members of the public to do the same. More than a year later, the call remains unanswered. If such an example were replicated in Ghana, in the regions and districts, the present secrecy about HIV testing (discussed in Chapter 4), disclosure (in Chapter 5), and its consequences (Chapters 6 and 7) could be considerably diminished.

### *Responsibility of the infected*

Those who test HIV positive can play an even more important role in debunking stigma. The study has shown that some PLHIV publicly present themselves and their HIV positive status during sensitization campaigns. However, they only do this in communities where they are unknown or hardly known, because they are afraid that they will be found out and stigmatized. Unfortunately, this adds to the situation where the majority of Ghanaians do not know and therefore have no

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time prior to his death, it is strange that his call for thorough medical exams (including an HIV test) for all public office holders has yet to be responded to by the other aspirants.

<sup>3</sup> <http://www.lvct.org>. Accessed on 01 March 2008.

<sup>4</sup> <http://www.ghanaweb.com/GhanaHomePage/NewsArchive/artikel.php?ID=163542>. Accessed on 11 June 2009.

firsthand experience of someone living with the virus and therefore see it as an alien phenomenon affecting others.

Although in recent times (2012) several HIV positive people have owned up publicly to their status,<sup>5</sup> the truth is that many people do not believe them to be truly honest. This usually happens when the HIV positive person is not thin and physically emaciated. As also shown in this study, some HIV positive persons only agree to talk about their status during sensitization campaigns since they know people will not believe them, exemplified by the attitude: “Who in their right sense will go out and claim to be HIV positive if he really is?” In this regard, coming out publicly to share their story is a mechanism to cope with their HIV positive status, while remaining safe in the thought that people will not believe that they are actually infected. As a Malawian study shows, however, there is also a downside to this, as some people think that HIV positive persons who publicly disclose their status do so to deceive and trick donors and other well-wishers in order to benefit financially from their support (MANET 2003 cited in Greeff *et al.* 2008: 316).

This study proposes that there should be incentives for HIV positive people to become more involved in awareness raising campaigns and also in the treatment process itself. Though they may not be believed by everyone, the sharing of their experiences and firsthand expertise will be helpful for their fellow PLHIV and the general public as a whole. It would also improve their living standards by providing badly needed income while also giving them a life.

Throughout this monograph, HIV positive people’s ability to resist relations of domination, but more importantly their capacity for actions that recreate and enable specific relations of subordination, have been brought to the fore. With regards to counselling and testing, for instance, people may decide not to test for fear of the possible consequences of a positive result. However, the real crux of agency with regards to HIV begins after testing, where those found positive intensify strategies to avert the consequences and remain safe from the effects of stigmatization. Safety is tied to respect and honour. Everyday life is interpreted in this regard and PLHIV are cognisant of this fact. They want the respect of others in society. This study recognizes that for those infected with or affected by HIV/AIDS in Ghana, the need at the apex of their agenda is to live safely in the midst of stigma, and in order to achieve this they employ various strategies. However, as the study has also shown, living safely in the midst of stigma remains a complex challenge.

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<sup>5</sup> The Ghana AIDS Commission and its partners currently run a number of documentaries on several TV networks dubbed the ‘Heart to Heart Campaign’, where several PLHIV who act as ambassadors appear on television to talk about their experiences of stigma and discrimination with regards to their infection.