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

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Stigmatization of people associated with HIV can be devastating, even more so than the virus itself. It destroys the lives of HIV-positive people and their loved ones. All too often in Ghana, those with no direct HIV experience do not see the depth of the impact of stigma on individuals, households and communities. This monograph, the result of fifteen months of ethnographic fieldwork in two communities in Ghana, brings to the fore the lived experiences of people infected with and affected by HIV from their own perspectives. In particular, their negotiations between resignation to fate and the struggle for survival as they cope with stigma are presented. Significantly, this book shows that being infected with or affected by HIV is as much a social issue as a medical one, and those associated with HIV/AIDS require more than medical care and support. Concerted efforts by all stakeholders – social and political leadership, the untested, the uninfected, the infected, the affected, service providers and policy makers – would go a long way to reduce the main problem that persists with regard to HIV prevention and treatment in Ghana: stigma.

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Safety in the midst of stigma

Experiencing HIV/AIDS in two Ghanaian communities

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FACULTEIT DER MAATSCHAPPIJ- EN GEDRAGSWETENSCHAPPEN
Safety in the midst of stigma

Experiencing HIV/AIDS in two Ghanaian communities

Benjamin Kobina Kwansa
Dedication:

To my mum, Esi Arhinma
My sister, Aba Amoakoa
  My wife, Esenam and
  My daughter, EwuraEsi
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Preface

In this book, I have tried to present to the world what people infected with HIV, and their families and relations, go through amidst the very high levels of stigma related to HIV/AIDS that persist in Ghana. Stigmatization of people associated with HIV can be fatal, even more so than the virus itself. It kills hundreds of HIV positive people and sends the lives of thousands of others into chaos. All too often in Ghana, those who have no direct experience of HIV do not see the depth of the impact of stigma on individuals, households, and communities. This monograph brings to the fore the lived experiences of people infected with and affected by HIV from their own perspectives – in particular their negotiations between resignation to fate and the struggle for survival – as they cope with stigma. Their sentiments, extracted from their life stories, bring to the fore the urgency of dealing with this canker.

After providing a background to the HIV/AIDS situation in Ghana in Chapter One and the methodology of the research in Chapter Two, the subsequent chapters highlight the experiences of the respondents of HIV counselling, testing, and treatment, as well as the various strategies they deploy in order to live as normal people in society without the negative attributes associated with HIV. Their personal relationships before and after their encounter with HIV, including those with friends and family and society as a whole, are vividly presented, and their various negotiations, daily struggles, and dilemmas are emphasized. In all these accounts, I have tried to decipher emotions from reality, and exaggerations from details, both on my part and that of the respondents. Significantly, this book shows that being infected with or affected by HIV is as much (if not even more of) a social issue as a medical one, and those associated with HIV/AIDS require more than medical care and support. Concerted efforts from all stakeholders – social and political leadership, the untested, the uninfected, the infected, the affected, service providers, and policy makers – would go a long way to reduce the main problem that persists with regards to HIV prevention and treatment in Ghana – stigma.

Many of my friends and family have often asked about what motivated me to spend more than four years with people I am not related to, who may misunderstand my ambitions and intentions, and who may try to harm me by finding a way to infect me with the virus. After all, what better way to understand living with the infection than by being infected yourself? One of my friends once rhetorically asked. Indeed, there were times when I questioned my own motiva-
tions, especially when faced with shocking or deeply upsetting situations. Obviously, the process was sometimes depressing, but it was oftentimes deeply revealing and this, very much so, was my motivation. The PhD award aside, conversing with these friends who were HIV positive, with their concerned families and friends, and with the many others who felt lost and helpless when it came to understanding what their close friend or relative was going through, opened up more vividly the complexities of life itself. Life is complex, I kept saying. And the more I conversed with my friends the more complex I found life to be. It is my express desire that this study be an eye opener to many, including high level decision makers, as it was to me, and will bring about a radical shift in our perceptions and consequently a better health status and prospects for all Ghanaians.

In the conversations with my respondents, I sought to do just one thing: to understand and present the experiences of people living with HIV, and the many others affected one way or the other by the infection, from their own perspectives. What became clear to me was that as social animals, everyone wanted – and in fact demanded – love. If it was not given, it would be sought after. In the end, the complexities continued.

The complexities were, however, not limited to my respondents. My life as a researcher was also affected. During my early associations with my respondents, I must confess that I was not sure whether I was going to make it. I became involved in the everyday lives of HIV positive people for the very first time in my life. They became more than friends, and often we could eat and drink together, especially those who welcomed me into their homes. However, any time when I had a mild on-and-off headache, recurrent fevers, and mild insomnia, I became worried that I may have been infected. I tested myself for HIV several times while in the field using the rapid test kits I had obtained earlier from St. Patrick’s Hospital, initially with the aim of using them as presentation materials. In all cases the test showed that I was not infected, and yet I kept repeating the test until I left the field. Interestingly, I realized that by the time I left the field I had used more of the kits on myself than I had kept for the presentations.

The completion of this work has been made possible by the assistance and cooperation of many people, too numerous to mention each by name. Nevertheless, the efforts of some cannot be glossed over, so I use this space to acknowledge a few. First and foremost, I owe a debt of gratitude to Prof. Dr. Sjaak van der Geest, my promoter. His depth of knowledge and particular interest in Ghana placed me on a most valuable track of enquiry. He definitely retuned my mind to undertake this project in the very difficult moments and was always a source of encouragement to me. Dr. Rachel Spronk, my supervisor in Amsterdam, was also
always a present help, no doubt because of her in-depth knowledge on issues in Africa. I am indeed grateful to you both for your professional and personal guidance throughout the fieldwork and the period of write-up.

To my co-promoter Prof. Kojo Senah, of the Sociology Department at the University of Ghana, Legon, I am appreciative and grateful for your constant encouragement and counsel throughout the period of data collection and write-up. In addition, I extend my thanks to Prof. Frances Owusu-Daaku from the Clinical and Social Pharmacy Department of Kwame Nkrumah University of Science and Technology (KNUST) and Dr. Phyllis Antwi of the School of Public Health, University of Ghana, whose persistent expectation for the completion and success of this work kept me going. Your concern for the work even transcended academic lines, and for this I am sincerely grateful.

Beginning in September 2007 – the first phase of fieldwork – I met, lived, ate, conversed, worked, and became friends with hundreds of HIV positive persons, who opened up their lives and homes to me. They assured me and offered me comfort, even when they themselves were in turmoil. They are numerous, more than the approximately fifty whom I lived with and spent most of my time. Some have not survived to see the fruits of their conversations immortalized in this text. Unfortunately, I cannot mention any of your names, but I know that you will have the opportunity to see that I have mentioned you here, just as promised. To all of you who offered me accounts of your shocking yet rewarding experiences, whose names I cannot list here for obvious reasons, I owe you an enormous debt of gratitude. Throughout this book, the names of the respondents have been changed to protect their privacy, including most of those living with HIV and all the medical staff I worked with in Kumasi and Offinso. To all of you who so generously agreed to subject your lives and those of your families to my impertinent anthropological scrutiny, words cannot express my deepest and sincerest appreciation. The time spent with you has not only given me a new perspective on life, it has also produced this manuscript, which will hopefully lead readers to better understand the experiences of living under the shadow of the stigma associated with HIV/AIDS.

I am also very thankful to all those whom I interviewed and those who assisted me in the interviews. To the various informants, the research assistants for the survey, the four secondary schools, and the teachers who helped, I am indeed grateful. To Dr. Maxwell Kankam, Nurses Rose and Josephine (both pseudonyms), and all the workers of the ART centre in St. Patrick’s Hospital, the NGOs, peer educators, and various PLHIV associations in both Kumasi and Offinso, I have been privileged to know and work with you, and am eternally grateful. Your courage and perseverance will reap rewards one day, if not before your very eyes then certainly as your legacy in the future. To Mama Mercy at the
Offinso District Assembly, who graciously obliged my request and found me a comfortable place of residence in Offinso, and to Nana, my landlord at the Education House in Offinso, I thank you both for your assistance and the role you played in making my stay successful.

This research programme was commissioned and funded by the Netherlands Organisation for Scientific Research (NWO-WOTRO) and the Amsterdam Institute for Social Science Research (AISSR) at the University of Amsterdam. I am very grateful for the comprehensive support from both of these institutions. They generously funded the two stakeholder workshops in 2006 and 2009. The AISSR also provided a conducive academic atmosphere and facilities during the whole PhD study period, both in the Netherlands and Ghana. Special thanks to the entire staff of the AISSR Secretariat, including José Komen, Anneke Dammers, Teun Bijvoet, Miriam May, Hermance Mettrop, Michael Baas, and Roos de Jager. You were all very kind, helpful, and supportive. Each time I sought your assistance, you were ready to help and your role in facilitating my stay and work in Amsterdam cannot be overlooked.

I had the benefit of experiencing a number of groups and individuals who were more than generous with their time and read through several drafts of this monograph at various stages of the write-up process, and I am grateful for the useful comments offered that shaped and helped clarify my thoughts. To all the members of the ‘Body, Care and Health’ Cluster and the Post-Fieldworkers Reading Group of the Medical Anthropology unit of the AISSR, your friendship and collegiality, the interest you showed in the work and its progress, and your comments and criticisms on earlier drafts, need special mention. To the Ghanaian caucus at AISSR – my colleagues Dr. Jonathan Mensah Dapaah (KNUST) and Agnes Kotoh – as well as Dr. Erica van der Sijpt (AISSR), Dr. Danielle Konning (Vrije Universiteit, Amsterdam), and Sylvia Nsiah-Poodoh (Korle Bu Teaching Hospital, Accra), I am grateful for all your constructive comments, criticisms, and suggestions during the write-up of this monograph.

I also thank Zoe Goldstein, who thoroughly edited the manuscript, Janneke Verheijen who graciously accepted to translate the summary of this monograph into Dutch, and Emmanuel Obeng (Wesley Grammar Senior High School, Accra) and Victoria Sarfo (Amakom Abroutia School, Kumasi) who translated the summary into Twi.

I am grateful to friends in the Netherlands and Ghana who constantly supported and encouraged me throughout this period. I especially mention the church Pastor (Pr. Dr. Andrews Ewoo), the elders, and the entire congregation of the Amsterdam Ghanaian SDA Church in Amsterdam Zuid-Oost, who provided me with a family away from home during my stay in Amsterdam. Those worth noting here include the Essilfie family of Bodegraven, the Gyasi family, the
Adjei family, Selina Boamah, Manuel Fosu, Mabel Setsoafia, the Ofori-Atta family, Linda Afia Frimpong, and the youth group. You all blessed and shared fellowship with me and made my stay more comfortable. I wonder how it would have been without you. You may not have known it, but the familial atmosphere you provided even helped to improve my Twi, as this was the main language used in the church, and it went a long way to help me during the interviews I conducted for this study back in Ghana. May God bless you all.

Prof. Christine Oppong, Prof. Akosua Adomako Ampofo, Dr. Deborah Ato-brah, and Dr. Delali Badasu, all of the University of Ghana, and friends such as Ada Allotey (Zenith University College), deserve special mention for their encouragement. They showed keen interest in the progress of the study and promptly answered my oftentimes disturbing calls regarding this work.

I am also very grateful to my mothers (Julie and Millie), my fathers (Richard and Tony), and my siblings (Papa, Aba, Kudzo, and Seyram), as well as my extended family, for their support and prayers. Your constant moral support really kept my hopes alive. Finally, to my wife Esenam and our daughter EwuraEsi, who have endured years of neglect as the cost of my working on this book, and who nonetheless have been a source of encouragement and offered various contributions in different ways that made this work possible, I express my deepest gratitude.

Last but not least, as “all things were made by Him, and without Him was not anything made, that was made,” glory be to God.

Benjamin Kobina Kwansa
Accra, 30 November 2012
The study

_Feree 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 Ahoṣe 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’ (Ahoṣe).¹

Before Ahoṣe 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.

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\(^2\) 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 Ahofofe 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 etiology, 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 spiritual 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.

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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 underlie 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), 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

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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’ initiative\(^5\) 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, one mpanin-fos 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 woye no, nyansa nmim 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, wɔyi baako
"a na ebuo, se wokab'mu 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 though 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? 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.

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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

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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, 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

Explanatory models

HIV/AIDS

Hiding & disclosure

Agency

Reciprocity and care

Trust and mistrust

Respect & shame

Stigmatisation

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

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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/polycritical 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 (ommu adee). 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.
Ethnography in a highly sensitive setting

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

Getting clearance

Under the present regulations of the GHS, research that requires multiple interviews and prolonged observations must be subjected to scrutiny by the Ethics Committee of the GHS Health Research Unit (HRU). Established in 1990 by a policy of the Ministry of Health, and later incorporated into the GHS in 2002, the HRU has the mandate to coordinate and conduct research into health-related issues to facilitate policy formulation and programme implementation. The process of obtaining clearance from the HRU started in advance, before the
period for data collection was due to commence, with the sending of a letter of introduction from the Amsterdam Institute for Social Science Research (AISSR) along with the research proposal. After a series of reviews by the committee, permission was granted. However, additional clearance was needed for the institutional aspect of the project. The Internal Ethics Committees of Komfo Anokye and St. Patrick’s Hospitals also granted clearance after a series of reviews. A detailed description of the process of gaining access to the hospitals can be found in Dapaah (2012: 19-22).

**The respondents**

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

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

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

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

About half of the males and a quarter of the females had a level of formal education and were literate in English and/or Twi, the majority having a Middle School Leaving Certificate or a Junior High School equivalent of formal education. None of those followed had received a tertiary education. About ninety percent of respondents said that they came from southern Ghana, with the majority being Akan. The remainder came from northern Ghana, and two from the Volta Region. Only one person had not travelled outside of her current place of residence. The majority had lived in bigger cities, and a fifth had lived outside of Ghana: in Nigeria, Cote d’Ivoire, Benin, and Togo. Two had lived outside of Africa. Mobility therefore characterized their lives. Consequently, these HIV positive persons may have been exposed to other cultures and ways of life outside their milieu, and therefore may not have felt so subject to customary sanctions, especially those they considered archaic, arduous, or time consuming (see Kwansa 2005).
About half of the PLHIV followed were Christians, the other half being Moslem. A few said that they were either traditionalists or did not belong to any religion. Of the larger population of PLHIV, on the other hand, it seemed from the membership of the five PLHIV associations that I worked with in the Ashanti Region that the majority were Moslem. In their search for healing, however, they made pragmatic choices in their use of ‘spiritual therapy’, in order to give meaning to their predicament or extend their coping mechanisms (see Kwansa 2010). The term spiritual therapy is used here to indicate subscribing to the use of magico-religious concepts, acts, and symbolism in one’s bid to find relief and/or a solution to a health predicament. In Ghana, these include soliciting therapy from akɔmfo (traditional priests; kɔmfo, singular), aṣɔfo (mainly pastors from the Pentecostal Charismatic Churches; ɔṣfo, singular), adunsifo (traditional healers known to use spiritual therapy for diagnosis, treatment, and protection; odunsini, singular), and mallams (men learned in Quranic studies, including Islamic healers; mallam, singular).

Fieldwork methods

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

The physical setting

Offinso is located about thirty-six kilometres to the north of Kumasi. Maase Offinso is a rather small town with a population of about 100,000 people, but boasts the St. Patrick’s Hospital, which serves the local community and the numerous others in its over fifty kilometre catchment area. St. Patrick’s is a
Catholic Mission Hospital, and one of the few hospitals that is not government owned that provides VCT and ART services in the Ashanti Region. Offinso Newtown has a well planned layout. A concentration of buildings housing government offices and the palace of Nana Offinsohene, paramount chief of the Offinso traditional area, ushers one into the town. The secondary roads are still untailed. Most of the buildings in the central part of Offinso Newtown are cement block buildings of up to three storeys, while the majority of the buildings in the other suburbs are mainly mud houses, vulnerable to the frequent downpours of rain. Offinso, compared to the bigger cities such as Kumasi, is less noisy and represents a steadily expanding town due to the recent springing up of branches of government agencies and financial institutions there.

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

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

Housing is effectively controlled by the private sector, whether through private renting or individual construction on land obtained through the traditional land allocation system. In the residential areas in Kumasi, houses are built close together, and the streets are mainly paved, tarred, or gravelled, making more obvious its beautiful landmarks. Remarkably, many houses are clustered in such a way that you find one or two of the spacious homes of professionals or business people located in the midst of the small zinc roofed houses of the lower class. The majority, however, are compound houses inhabited by the extended families of locals and foreigners alike, with an average of five families living either in
single rooms or ‘chamber and halls’\textsuperscript{2} on one compound. A significant number of the homes visited in this study were those that the respondents had either built themselves or partly helped to build. More than half of the households consisted of members of the conjugal family and relatives who were somewhat permanent members of the household, such as in-laws, parents, and the children of siblings.

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

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

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

\textsuperscript{2} Chamber and hall are used in Ghana to refer to the bedroom and living room, respectively.
The practice of animal husbandry is not uncommon in other parts of the country; these animals may be sold or slaughtered and eaten to augment the family’s source of protein in their diet. Related to this are also backyard gardens where vegetables and other foodstuffs are grown to add to the family’s food basket.

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

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

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

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

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

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

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

Life in the localities

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

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

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

From Thursday to Sunday, one finds mourners at funerals, mostly gathered in school parks or sitting outside the house, under the shade of a large tarpaulin, accompanied by the blaring sounds of giant speakers. The numerous church organizations found in these localities announce their presence with their morning, afternoon, and evening prayer, healing, and deliverance sessions on specific days, and Saturday and Sunday worship sessions. Screaming, chanting, and
ecstatic singing and band ministrations characterize most of these homes and communities. Rich people are therefore socially adored since they are expected to grace these programmes and offer their donations.

My stage of re-socialization and selection of respondents

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

Gaining entrée into the Offinso communities

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

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

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

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

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

The selection of candidates for the project was based on considerations of the social setting and the area of study, as well as the relevant concepts, all of which outlined some criteria of interest. Selection of the respondents was primarily based not only on finding cases that were similar but also those that were considerably different from each other. In addition, cases were selected when the
potential to provide logical generalizations of the experiences being studied had been established. Very few of the cases were based on considerations of the various variables, chiefly religion and ethnicity.

Figure 2.1   Sources of recruitment of respondents from the two hospitals

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

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

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

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

Gaining entry to the Kumasi communities
Getting access to the respondents in Kumasi was very different compared to Offinso due to numerous factors, including the period required for obtaining internal clearance from the Komfo Anokye Teaching Hospital, the comparatively formal system of operation, the large number of staff, and the fact that home
visits were made by volunteer peer educators instead of staff nurses. In Kumasi, Dapaah linked me to Baba, the main man in charge of home visits, who is very devoted to his work and thus – after agreeing to work with me – made getting access to clients quite smooth.

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

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

One significant aspect of the Kumasi study was that I had access to a private laboratory that undertakes HIV tests (and at times counselling), which was identified earlier in the fieldwork process as a relevant site for recruiting clients who prefer private facilities to public ones. Generally, it was very difficult to get the identified clients to talk since the majority referred to the private laboratory did not know exactly what tests they were undergoing. I therefore resorted to observing the processes they went through and also the circumstances under which they came, whether voluntary or otherwise. These observations provided valuable data for analysis. Like the tests done in the hospitals, the majority were
diagnostic,\textsuperscript{5} though there were several cases where, unlike those in the hospital, the clients came voluntarily to the private laboratory. An older woman in her mid-fifties, for instance, came to the private laboratory with a request for five different tests. She complained that earlier she had done several tests, so she wanted to be told exactly what tests she had been asked to do this time round. The technician later confided to me that “[I] couldn’t let the cat out of the bag since that could discourage her from doing the [HIV] test so [I] managed to evade the question.” The woman was later found to be HIV positive. I also managed to get some people to talk to me informally as they sat and waited for their test results. These were people who were visibly worried and were willing to talk. The majority were very pleased to be advised by a stranger as to their next course of action. Mainly, people who had suspicions that they were infected because of persistent illnesses (either their own or those of a close partner) patronized this facility. For instance, one lady wanted to know her HIV status because her husband’s girlfriend had lost a baby soon after birth and had thereafter been frequently admitted to hospital for one illness or another. Though it was rumoured that this girlfriend had HIV, the lady became more alarmed when her husband also started feeling unwell. When the girlfriend eventually died, she came to the private laboratory to check her status. “Men are dangerous,” she kept whispering as she waited for the test result, which led me to start a conversation: “Hmmm, why do you say that, Madam?” We continued from there.

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

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

\textsuperscript{5} The majority had gone to the hospital with a problem other than HIV, but the health personnel used their discretion to recommend the test. Often, the clients did not know at the time the test was being conducted that they were in for an HIV test. More discussion of this can be found in Chapter 3.
responsibility for the mounts since it was obvious that he could not do it alone because of his deteriorating health. I could not fathom why he continued to farm when it was obvious that he was not fit enough. I had earlier linked his persistence solely to his non-disclosure and to the necessity to prove that he was still healthy. Later on, however, I gathered from discussions between his wife and her friends that he was in contention for a position as a sub-chief, and poor health – not to mention being infected with HIV – would be a reason for disqualification (though Daniel himself had never mentioned this to me). Daniel may therefore have been more concerned about disqualification from the race for sub-chief if he was seen to be unable to work on his own farm than he was about his deteriorating health and his farm per se.

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

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

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

After I had secured a room through my contacts in the district assembly, I required basic furniture. There was a man in his early thirties, married with three children, who had a carpentry shop two houses away. When I consulted him with the request, he gladly obliged to help the stranger who could pass for his twin in terms of age. Just like most Ghanaians may behave, he asked whether I needed other things (such as a shoe rack, wardrobe, sofas, etc.) in addition to the book-
shelf, trap door\(^6\), and study desk that I had asked for. I requested for him to pass by after work to see my room and then we could agree on what to fill it with. During that night we talked about family, education, societal norms, courtesy and respect, among other things. Subsequently, we met frequently, usually at night when he had finished work. Later interactions with the carpenter were mainly about the general beliefs, norms, practices, and traditions of the people in the community. His role waned as I became very busy and spent less time at home. Consciously, I also decided to cut down on our meetings because he became increasingly inquisitive, especially about the reason for my stay in Offinso.

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

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

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

\(^6\) ‘Trap door’ in Ghana refers to a netted door usually fixed onto the frame of the main door, to prevent mosquitoes from entering the room or allow for fresh air when the main door is open.
working in the field of care and support for HIV positive persons for the other functions.

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

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

Data collection

Over the period of fieldwork, I collected a lot of stories from both the print (newspapers) and electronic (television, radio, internet) media that were of relevance to the study. These secondary sources helped to see the fieldwork data in the wider context of Ghanaian society. The primary research, however, integrated a multiple mixed methods approach (Saunders et al. 2007), which made use of quantitative and qualitative research at the same time. According to Tashakkori & Teddlie (2003), the use of multiple methods provides better opportunities for the researcher to answer research questions set out for the study and allows for better evaluation of the research findings, which can be trusted and inferences made from them. The use of multiple methods of data collection is a form of triangulation that is central to ensuring quality research (Bailey 2007). During the early periods of fieldwork, all the HIV positive respondents
were told about how data would be collected in order to get to their experiences with HIV. They were told that I would live in the same community with them, visit them very often in their homes, converse, ask questions, participate in their daily chores where possible, and observe their everyday lives. All these techniques were used with the sole objective of distinguishing between cultural ideas and actual practices, public and private conduct, and prescribed and voluntary behaviour (see Parker et al. 2002). The following discusses in detail the various primary sources employed for data collection. These tools included observations, structured and unstructured interviews, in-depth interviews, conversations, and other methods such as focus group discussions and photography.

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

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

In most of the cases the observations were informal, focusing on what was deemed relevant as events unfolded – the respondents’ utterances and feelings and how these changed, the physical settings, activities happening in the setting, relationships and how they were activated and deactivated, among other things. There were cases, however, where specific themes were singled out to be observed amongst specific respondents. For instance, after I got to know that Kaakyire had informed his nephew Nsiah about his status, I observed their
relationship, especially during visits to their house, to see Nsiah’s reaction (see Chapter 7 for details of this case). During observations, non-verbal messages conveyed by the body language of respondents provided a lot of communication signals about the truthfulness of the interviews (cf. Hiltrop & Udall 1995). Both Nsiah’s speech and actions, for instance, provided backing for his uncle’s statement about trusting him not to disclose his positive status.

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

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

All in all, the objectives of the observations were, as Bailey (2007: 91) puts it, to “find out what people do, how they go about doing the things they do, why they are doing these things, how they feel about doing them,” and most especially how this explains why they do or do not access VCT and ART services.
Structured interviews
As part of the data collection, an interview schedule was used (see Kottak 2003). With this, I talked face to face with the interviewees, asked questions, and wrote down the responses. A structured interview guide was used. The essence was to probe for specific details on issues that the interviewee was competent and knowledgeable in. Specific questions in the specific order of my interest were asked. Though some follow-up questions were also prepared, I built up on issues that cropped up. This was mainly used for key actors and the significant relations of the HIV positive persons, church leaders, community leaders, technicians in private laboratories, and the heads of NGOs working in the field of care and support for people living with HIV.

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

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

Conversations
Most of the interactions I had with the participants were in the form of conversations, where the focus was not only to pursue my interest but also that of the participants. Though I had themes and guidelines for probing, the structure, procedure, and order of the conversations were flexible. Enough room was given for participants to sway and digress into other areas of interest, though the conversations did gradually veer back to subjects I was interested in, since those issues are largely private and they seldom had people to share those aspects of
their lives with. What was common among all the conversations was that they were not structured. On some occasions, I went to my respondents with my agenda, while they also had their own agenda. Usually, the clients got the upper hand. When I was not distracted, I began all the interviews on general health issues and with time drew the main study into the discussions, in order to ease the tensions often associated with talking about HIV.

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

In-depth interviews
This part constituted the longitudinal study that ensured that a particular group of respondents were followed during the fifteen month fieldwork phase (which took place unevenly for longer and shorter periods: from September 2007 to August 2008, and November 2009 to January 2010. These in-depth interviews were conducted with all forty-nine HIV positive persons in the two communities (twenty-three in Kumasi, and twenty-six in Offinso – refer to Figure 2.1 above); a number of the cases were followed up in the hospital setting. This aspect of data collection and the conversations were used to collect the life stories of respondents. The life stories undoubtedly added a deeper, thicker, and richer texture, not only to sustain the interview process in times of rising emotions, but also to divert the attention of other people present at the place of conversation from any suspicion of our discussion of HIV. The motivation for collecting these stories was to use these individuals’ stories, and other personal materials, to understand the individual lives of those associated with HIV within their social
context. Life stories as a method for eliciting data emphasizes the importance of the subjective experience within the social context (Roberts 2002: 3). Through life stories, it is recognized that what is captured is a mediation between the personal voice of the respondent and wider cultural imperatives (Goodson & Sikes 2001). These stories thus facilitated me to capture, probe, and render understandable the perspectives of the infected people and their close associates, while also making it possible for the reader to get as close as possible to their actual experiences (Denzin 1989: 69).

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

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

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

Other tools
Though not very consistently (since I spent most of my time away from home), I followed HIV discussions on the radio, in particular a recurrent discussion that talked about the link between witchcraft and HIV. In addition, discussions (related to HIV or otherwise) were also followed keenly in trotros and at drinking bars, where I took time to while the nights away in Offinso. These periods also provided valuable information for understanding the lives of PLHIV.
instance, during some of these discussions, it was found out that some people (mainly men) do consciously consider the physique of their sex partners before showing any interest. This was because slim and skinny people (women) were identified as potentially infected with HIV. Many young ladies, according to another discussion on the radio, take food supplements and blood tonics (such as cortisones, according to one respondent) to gain more flesh and body weight, since slimmer women do not find marriage (love) partners (see more discussion of this in Chapter 3). These conversations provided some insight into the public’s concerns regarding the issues under study.

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

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

Focus Group Discussions (FGDs): During the research period in Offinso, I managed to organize one FGD with a youth group, mainly young boys and girls aged between nineteen and twenty-two years, who had completed Senior High School and were currently unemployed. In addition, I held two FGDs in Kumasi
– one with a cross section of young professionals, and the other with a women’s group. The discussions mainly centred on the perceptions, beliefs, and practices related to, and their attitudes towards, HIV and PLHIV.

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

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

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

I acknowledge the possibility of my complicity in the deception of a number of family members (or significant others) of the HIV positive persons. This may have arisen because the majority of these positive persons had not disclosed the exact nature of their health problem to these people (see the discussion of ‘selling of sickness’ in Chapter 4). In order not to endanger the relationships of PLHIV
with their family members or significant others through revealing the former’s real identity, I agreed to the description given to me by the PLHIV as “a worker at the hospital where they were being treated.” This ‘health worker’ status was most convenient for both parties since it afforded me the opening to talk to these significant others about their beliefs and perceptions of different sicknesses, including HIV/AIDS, in order to fully understand the dynamics in related thoughts and acts. For the clients, it eroded the otherwise obvious curiosity that other people could have about my visits.

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

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

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

One of the ways of minimizing the effects of crudely disengaging from the participants, according to several experienced ethnographers such as Carol Bailey, is to discuss and plan the departure with participants, and if possible promise them future contacts. This helps to manage the often arising situation
where the researched feel used after the process, and also to ensure that if possible they have the opportunity to respond to the findings in the report. Notwithstanding all these advantages, I could only tell the respondents that I was leaving but not the fact that I was travelling outside the country for the next stage of the project – data analysis and write-up. This was because I was scared of the many more demands that might come with it because of the conventional association of being able to travel outside of the country with being rich. I felt that I would not be able to meet all their demands for maintaining regular contact and support, especially emotional and psychological, financial, and even physical. It made me feel limited and guilty.

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

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

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7 As planned, the period of fieldwork ended with a cross-sectional household survey in the specific communities sampled for in-depth study, using mainly closed-ended structured questions (see Appendix 3). In addition, the questionnaire was administered in four Senior High Schools (SHS) in the two communities. The purpose of the survey was to test the findings and see how representative the conclusions from the observation and in-depth interviews were. In all, about 1,700 questions were administered (about 150 in each SHS, and 550 in each sampled community). Four research assistants who were Senior High School graduates in Offinso Newtown (two males and two females) were recruited and trained to administer the questionnaires in the communities. It was relatively easier in the SHS after permission was sought from the headmasters and Social Studies teachers for each school. The students were also required to answer one of the three essay questions below, which were asked to gain more information about what they thought about particular areas in the research: (1) You may look strong and fit on the outside and still have HIV. Discuss. (2) Our understanding of the HIV disease is the main factor for the spread of this menace. Discuss. (3) Write a short story that ends with the saying "...so you see, we all need to go for an HIV test today"! Though some of the students were overtly disinterested in either administering the questionnaire or writing the essay, or both, the outcome, especially of the essays, was very interesting. Unfortunately, for lack of time to fully analyse the data from the essays and the survey, the data presented in this dissertation excludes this information.
be pitched against the quantitative ones to either confirm or contradict the results. However, it was not possible to include the analysis of survey and essay responses because of time limitations for the analysis. It is hoped that future work will allow for such comparative analysis.

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

Se ani anhunu a, enye tan
It is not nasty as long as the eyes have not seen
(Akan Proverb)

The HIV/AIDS team at St. Patrick’s Hospital had organized a sensitization campaign for residents in Namong, one of the communities in Offinso, where several of the people with HIV who were studied for this project lived. Many people in Offinso perceive Namong (which has a population of about one thousand) as one of the heaviest affected communities with regards to HIV incidence. “Every household has or knows someone who has died of HIV,” Eugene told me during our first encounter. Many residents and non-residents alike participated in the one-day sensitization campaign, which included several speeches from the health personnel in the municipality, and also songs and a drama performance, all to whet the appetite of the audience to undergo HIV testing. In all, more than 150 people volunteered to be tested. In December 2008, more than three months after the campaign, when I finally had access to the list of participants, I observed that (only) five people had tested positive. Cross-checking their names with the records of those undergoing antiretroviral therapy at the Special Clinic at St. Patrick’s Hospital, I found that none of them had yet come for treatment, at least at that centre. With permission from the doctor-in-

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1 The Special Clinic is the centre/facility responsible for ART, and other disease conditions such as tuberculosis, diabetes, and hypertension, at St. Patrick’s Hospital. According to the nurses at the centre, the name – Special Clinic – is one of the measures put in place to destigmatize HIV, thereby aiding access to the services.
charge at the centre, I decided to go, together with one of the nurses, to follow up on these five cases.

Only one of the five was reached by phone. For the others, the house numbers that they had provided either did not exist in the community or the calls did not go through. With the one successful call, the man reached said that he remembered taking the test and had expected the team to return after a week to give him the results, as promised. He indicated that, “Since they [the team] did not come back, I thought they were not serious [with their work], and that they did all these [campaigns] to enrich themselves and write more reports for more money.” The man was asked over the phone to come to the hospital (St. Patrick’s) for a discussion about the test, but he did not turn up on the appointed day and could not be reached again on his mobile phone. The doctor-in-charge at the Special Clinic explained that it was possible that he changed his mobile number since “He may have realized the ramifications of getting to the hospital and being told the worst,” i.e. that he is infected with HIV.

Counselling and testing facilities are the usual locations of the revelation of the unwanted news that one is HIV positive. The data gathered from the communities studied, however, suggests that there are several ways and locations through which HIV testing is conducted, including sensitization campaigns (as shown in the above case). This chapter introduces the reader to the available possibilities for finding out one’s HIV status in the Ashanti Region in Ghana. It shows how people get to know about their HIV status: the procedure for testing, the clients’ immediate reactions after getting the results, and their experiences of the testing facilities. As the case material will show, many people were unwilling to go for an HIV test unless it was mandatory. Using the narratives of HIV positive persons and others in the communities studied, this chapter will conclude by outlining the possible reasons for the widespread hesitation to know one’s HIV status.

Getting to know

As in most countries, voluntary counselling and testing (VCT) is the main entry point for accessing ART services in Ghana. VCT in Ghana first commenced with a pilot study conducted in June 2003 at Agomenya and Atua government hospitals in the Eastern Region. Other sites began in December 2003 and February 2004 in the two tertiary and teaching hospitals in Ghana: Korle-bu in Accra and Komfo Anokye in Kumasi respectively. As of 2009, there were 3,222 sites all over the country offering VCT services to the population of over twenty million. At the time of the study, almost 200,000 people in the Ashanti Region (about 3% of the population there) had undergone counselling and testing in the 466 sites offering these services (NACP/GHS 2010). Interactions with people
living with HIV, their families, and general community members showed that the majority of those who had undergone HIV testing did not go for the service voluntarily. The following sections therefore discuss the ways in which people found out about their HIV status in the two communities studied.

**Diagnostic testing**

The majority of the HIV positive people in this study recalled that they had found out about their positive status when they reported sick at the hospital with a ‘normal’ sickness, and just like any other patient went through the process of registering at the hospital and getting a patient’s card at the Out-Patient Department (OPD). They explained that they then went to the nurses who took their vital signs (blood pressure, body temperature, weight, and height), after which they joined the typically long queue to see the doctor. Some saw the doctor several times before their persistent condition warranted an HIV test; others were asked to do the test at their first appointment with the doctor. Abiba narrated how he came to be tested:

The doctor told me that I needed to do some more tests so he could find out exactly what was wrong with me. This time, he just asked me to go to that room over there and see Mr. Owusu [the counsellor in one of the hospitals]. Well, at first I didn’t think about anything … about this disease, so with the help of my mother I went. When we got there Mr. Owusu asked my mother to leave me, because he wanted to talk to me alone. It was then that he asked whether I knew why I was asked to come to him. When I replied in the negative, he told me that they wanted to check whether I have some of the worms/small animals that have recently been around(emmoa a, aba yi bì). My heart skipped a beat when he said that. Why will they have to test me for this? I haven’t messed up. And I am also not one who will meddle in the affairs of others, for them to want to hurt me. Why will anyone think about killing me? I just prayed that it should be a dream, and that I would wake up from it at that moment. Mr. Owusu, however, spoke to me at length and advised me to be calm. He then told me that I wasn’t going to die if I listened to him and obeyed whatever he and the doctors told me to do. Maybe you are not positive, he said. At that point, all that he was telling me was falling on deaf ears. I was just thinking about the consequences of a possible positive result. My mother would die if she hears about it … how about my father; already he doesn’t even want to see my face. He would just sack me from his house. At that point, I knew I was dead. I didn’t have any choice, so they did the test and I was positive, as I expected.

Unlike the case of Abiba, who was informed about the test before it was conducted, analysis of the life stories of those who were attending the two ART facilities in the study shows that the majority of clients were only told about the test after it had been conducted and the results were divulged during post-test counselling. This is especially the case for pregnant women. At maternity wards, HIV tests are routine unless one opts out; this constitutes an example of provider initiated testing and counselling (PITC). In many of the cases investigated, however, the pregnant women were not aware of the option to opt out, and the test was done without their knowledge. In cases where the test had not been done by the time of delivery or during a pregnancy-related complication, the woman
was usually tested without her consent. Prevention of mother-to-child transmission (PMTCT) was given as justification for this practice, and was explained as being for the sake of protecting the unborn child, as well as preventing re-infection of the client and/or infection of her partner.

**Private clinics and laboratories**

The circumstances leading up to getting to know one’s HIV status, as explained by the HIV positive informants and described above, was found to be similar in the Quality Care Clinic: a private clinic in Offinso, where a significant number of those who were on treatment at St. Patrick’s Hospital had been diagnosed. The majority of the cases from this private clinic were also provider initiated. Dapaah (2012) reports that it was in the ART clinic that the clients got to know their status after having undergone the dreaded test without their knowledge, let alone their consent.

The situation at the Quality Care Clinic was very different, however, from that of the private clinics and laboratories where people voluntarily walk in with the intention of testing for HIV. However, from observations in some of the private laboratories in the Ashanti Region, it was noted that counselling (both pre-test and post-test) was rarely performed. One technician in a private laboratory explained that there are two main groups that access the HIV testing services in their laboratory:

The first are the cases referred from the hospital. For this group we [the technicians] prefer to assume that they already know about the test to be conducted. If they don’t know, then we are not responsible for breaking the news. The majority of the cases are those that the clients initiate themselves. In these cases too, the clients already know what they are going in for and therefore did not need counselling.

Generally, although the private laboratories were found not to possess the right personnel to undertake counselling services, many people still preferred their services to those of the hospitals. According to informants, this was mainly because (and unlike most facilities in Ghana), “they are fast,” “there are no queues,” “they do what you ask them to do and not what they think you should do or what they want you to do,” and “they do not condemn you.”

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2 The Quality Care Clinic is one of the few private health facilities in Offinso. This clinic receives important mention in this monograph because of its unique role in referring clients infected with HIV to St. Patrick’s Hospital for treatment, care, and support. As observed among the clients at St. Patrick’s, a significant number were referred from the Quality Care Clinic.

3 This may be because of their own perception of personal risk, a demand by a church as a pre-requisite for marriage, job placement such as in the military, or to travel outside of the country – to the United States or China (until recently).
Sensitization campaigns and mobile testing facilities

There were cases, as outlined above, where some people walked into VCT facilities to use the services. These cases were found during interviews and focus group discussions (FGDs) with some members of the communities studied. In other cases, the services were brought closer to the people through sensitization campaigns followed by testing and/or use of mobile testing services. Tests conducted after sensitization campaigns (such as the case explained in the introduction to this chapter) and the use of mobile testing services ensure that a number of people are tested without having to go to VCT facilities. A number of the people in the communities studied, including some participants in the two FGDs, said that they had tested as a result of these services. Only one of the HIV positive persons, John, who was casually conversed with, said that he had made use of this means to get tested. None of the infected people studied extensively throughout the period of fieldwork belonged to this group, interestingly. John recounted his experience:

I like listening to such campaigns. In fact, on the said day, I was just taking a stroll when I passed by this group of nursing students who had come into our community to talk to us about HIV. I stood there and listened. After, they asked all those who want to know their status to come over and get tested. I went forward. It was about the fourth time I was doing something like this. Like I said, I like listening and participating in these programmes. But, my brother, that day was not good for me. I regret not walking away. I wouldn’t have been going through all these, if I had just walked away.

John was introduced to me by Nurse Josephine during one of my brief visits to St. Patrick’s Hospital to meet a respondent. John mentioned that he had experienced many psychological and emotional challenges in coming to terms with being infected. He was concerned with the cause of the infection, and asked why it had happened at the time it did, because he “had been doing this [having HIV tests] all the time and he had never been positive.” As with John, it was found that the few respondents who walked in or responded to calls from campaigns without any prior intention to test often felt sure that they would test negative.

Other ways of getting to know

Informal conversations with some members of the communities studied showed that people are wary of thin and consistently sick people, and that such individuals are easy suspects for carriers of the HIV infection. Gossip and insinuation are the main means by which these suspicions are channelled. These accusations made against thin people by community members were found to hold water after observations proved that these people’s physical changes (i.e. slimming, wasting) were sudden and prolonged, and were indeed also accompanied by ill health. Eugene explained:
We have been here for long and we know how AIDS treats people. When you get it, you will definitely waste away. How can you continue to defecate, vomit, and be unable to eat, and not grow lean? It is not possible. That is what they all go through. With time, they will start getting sick. They would not recover and then they will die. You don’t need a test to know. You already know.

In particular, people who are consistently sick, and especially when it is accompanied by an extreme form of diarrhoea, become suspects. In such cases, it was not uncommon to find community members tracking these sick people in order to find justifications for their suspicions.

The people in the communities also viewed certain behaviours as arousing suspicion regarding HIV infection, notably being rich and having multiple sexual partners. During an interview with Martha, the leader of the Single Parents Foundation, for instance, she narrated the story of a man who lived in one of the communities studied:

He opened a spot [drinking joint], which is still in existence. After he came back from Abidjan, he settled here, got married to a lady he came along with and they gave birth to two children, both of which died. He came with a lot of money. With his money he helped a lot of the boys in the area and he ran several businesses. He had money and helped so many people but he never went to school though he paid the school fees of many of the youths in the community. Due to that, and you know what money and illiteracy can do, he was chasing the girls indiscriminately. So when he finally came with the sickness, he settled with his wife right in the big house down the road where the truck is parked [pointing to the house]. By this time, he had slept and in fact lived with lots of the young girls around. Now he is dead. We are not doctors, but everyone in this village knows that he died of this disease [AIDS]. You can go round and ask everyone in the village and each will confirm what I am telling you.

The sexual partners of suspects are also targeted, especially after a suspect dies. Many people, especially thin young women, resort to the use of medicines to increase their weight. Below are excerpts from the interview with Martha, in which it was revealed that the partners of the rich man described by her above, who were thus also prime suspects of being infected, were rumoured to be taking medicines to keep their bodies plump.⁴

Kwansa: So are you saying that because you people saw that he used his money and influence to get so many women, he might have died of this infection?

Martha: Yes, we know the women he went out with. Apart from his wife, he married two more in the next town and lived about eight years and six years respectively with them. Because he had money too, he lived with some other girls intermittently; some even with the consent of their parents.

Kwansa: What happened to these ladies when he died?

Martha: They are still there. The two he married at the other village have re-married even though we all know the man died of HIV. They are looking more beautiful now because he had given them lots of money. And they are taking medicines too. The one that looked smallish like this is now as fat as this [using her hands to make the small and large gestures].

⁴ In Ghana, many medicines can be bought over the counter and without prescription from a doctor.
Kwansa: Medicines? What for?

Martha: Yes, medicines! I don’t know if it is for HIV. But there are medicines on the market to make one fat.

Kwansa: Do you mean blood tonic?

Martha: No! Not necessarily. There are a lot of medicines other than blood tonic on the market to make one fat. Even the ladies go to the extent of injecting themselves to be fat. Even when they give birth, they are given dexacortisone⁵ or something like that, that they take and become very fat. Even when you go to the spot now you will see the woman. Because he is no more, they are living with men. And because the man had money he only went in for beautiful ladies.

Kwansa: So do you think that even when you are infected with this disease and you take these medicines, such as the dexacortisone, you can still grow fat?

Martha: I think so. You see the virus in your system doesn’t work very fast, rather they spread little by little, so some people can live up to ten years with the virus without any medication. And for these people they start taking these medicines right after they get a hint of their state. And for these medicines, there are different types. Some ladies even use some injections to make their buttocks fat. So someone who gets the hint can just go and get these injections.

Remarkably, a heated discussion on the issue of thin people being prime suspects for HIV infection cropped up one day in a trotro, corroborating the perception that women these days use medicines to camouflage the virus. Some men were also said to be careful in choosing their sexual and marriage partners, based on this perception that thin women are more likely to be HIV positive. They consider a woman’s physique before making a move. In the trotro discussion, a middle aged man who was obviously the main speaker for the notion stated:

You marry a slim woman at your own peril. Unless you have known this woman for so many years and you know that she sits at one place (tena faako) then you can go ahead [and have her as a partner]. Otherwise, play it safe. Go for oboshie [a term for fat women based on a television advert where a very fat woman went by that name].

Eugene also noted that changes in the emotions of the suspect, and the loss of a baby during childbirth, are other clues about a person’s HIV status. He explained:

I can see a person infected when I look critically at her/him. You see, in my house, I have seen one of my mothers⁶ who became sick and was asked to go and buy some medicines. She has become reserved and emotionally worried this time round. And she didn’t get her baby when she went to deliver. She claims the hospital nurses said that she lost her baby because there was lot of water in her stomach. From her behaviour and speeches it seems to

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⁵ Dexacortisone is not the correct name for the medication. Checks from the chemical shops showed that prednisolone was the more common type that people bought for this purpose. The clients at these shops referred to it as ‘PP’. However, Martha may have been referring to dexamethazone, a type of cortisone used to treat inflammations and allergies, but purchased by clients for the purpose of becoming fat.

⁶ Most people in Ghana refer to their mother and father’s sisters also as their ‘mothers’. So depending on the age of the person in question, reference could be made to an older mother or a younger mother. In this particular case, Eugene was referring to the experience of one of his mother’s younger sisters.
me she does not know and yet she doesn’t trust herself. Or maybe she knows but doesn’t want anyone to know. When I look critically, I cannot tell where she got this disease. She already has a child. I know it is possible to have this disease and live normally but it can’t be so for the child. He wouldn’t stay longer on this earth.

Oftentimes, these suspicions and rumours about a person can go on for a long time without the suspect knowing about it. Some indeed may not have even thought about the possibility of being infected until they heard the rumours. Some of the people with HIV in this study noted that it was when they heard about these suspicions that they started fearing that they may be positive. Dorcas recalled that she was getting sick often, and though she is naturally thin, she was getting extremely thin, more so than normal. It became a worry to her when her niece came to tell her one day that, unbeknownst to her, people in the community thought that she had HIV on account of her physical appearance.

I hadn’t been well and I was seeking for help [at the hospital and healers], but no one had mentioned this sickness, and I had not thought about it either. All this while, they [the community members] were gossiping about me. Can you believe it? They had already condemned me, even without my knowledge.

After my niece told me, I could hear people talk and point fingers at me as I walk in the community. In fact, I felt bad, and finally stopped going out. But I wasn’t getting better, so my niece advised me to go for the test and seek proper help if that was the case. My husband will kill me if he finds out that I have HIV, but I gathered courage and I went. I am positive, but they don’t know.

Interestingly, it was found that these suspicions reduce and stop completely depending on the rate of recovery of the suspect. 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, was at the time of the study living normally with her HIV positive child without the usual suspicions because she no longer looked thin.

Another way that the respondents reported that they first found out about their infection was through the activities of traditional and other religious priests (mainly from the Pentecostal Charismatic Churches), who through various forms of divination and prophetic revelation had ‘diagnosed’ their infection. This group of HIV positive persons believed that their infection was caused by something supernatural (curses and other malicious powers), and therefore they made use of ‘spiritual therapy’ to complement medicines from the hospital (Kwansa 2010).

All these ways of getting to know about one’s HIV infection notwithstanding, having an HIV test at an official testing site continues to be the only sure way to know one’s HIV status, since all the other ways of getting to know one’s status have not been proven scientifically. Put differently, it is possible for a person to be suspected and maligned by their community for being HIV positive and nevertheless test negative. The following section discusses the counselling and testing procedure for finding out about one’s HIV status.
The counselling and testing procedure

Usually when a client walks in voluntarily or is referred to a counselling and testing facility for an HIV test at the hospital, he or she goes through a standard procedure. Counselling is a relatively new concept, known in the overall health care system in Ghana for around two decades. This is not different from other African countries (see Ego & Moran 1993, Lamptey & Coates 1994). Counselling in most parts of sub-Saharan Africa generally comes in the form of advice from ‘experts’ to patients and their relatives (Awusabo-Asare 1995), and counselling in everyday life is very different from what is found in the health care system. The following discusses the counselling and testing procedure as reported by HIV positive people and other users of such services, looking first at pre-test counselling, then the test itself, followed by post-test counselling.

Pre-test counselling

The pre-test counselling at the facilities is a form of counselling designed to help the client to decide whether s/he wants to have the HIV antibody test. This is usually the first of the procedures in all counselling and testing facilities. Within sensitization campaigns, counselling was also done, though it was not very extensive. Those who had gone for the service at the facilities explained that the counsellor had probed into why they had decided to come for counselling and about their personal history with regards to marriage, sex, risky behaviours, and general health problems. The counsellor had then asked about the clients’ level of knowledge about HIV and AIDS. After assessing this level of knowledge, the counsellor then gave additional information about HIV/AIDS, and enumerated the advantages and disadvantages of having the test. Some of the infected persons interviewed indicated that the counsellor had then explained the test procedure and how one can interpret the results. They also stated that the counsellor had talked about what to do after receiving the results of the test – whether positive or negative – in order to stay as healthy as possible for as long as possible. Abigail, a cashier at one of the banks in Kumasi, who participated in the FGD for young professionals in the town, mentioned:

> It was during the pre-test counselling that I felt afraid for the first time to take the test. I knew I hadn’t engaged in any risky behaviour, but it was during the counselling before the test that I felt, for once, that the result is fifty-fifty. That I could be positive! In fact, I wanted to back out at this stage, but it was too late.

She explained later that she had felt compelled to take the test after someone came to their church to give a talk on HIV and the importance of knowing your status. “But at that point, I asked myself whether it was really necessary that I do it. After all, I am not sick.”
Although pre-test counselling is aimed at helping the client to make an informed decision about whether or not to take the test, from the discussions (and exemplified by Abigail’s case above) most of the people who went through pre-test counselling felt that the counsellors did not present them with an option. Melissa added:

[It is] as if their only focus is to get you tested. Your feelings and emotions come second. They make it seem like you don’t have an option. You definitely have to do the test; [or] else they [the counsellors] may think that you are bad.

Oppong, a systems analyst, and also a member of the FGD for young professionals in Kumasi, said:

The counsellors focus too much on the effects of a positive result and that will definitely make you shake. I was asked what impact I thought a positive or indeterminate result would have on my life and how I was going to react to that. I had not given all these the slightest thought, so my heart started beating fast. If fright could cause one to be infected, I knew I was already positive [jokingly].

They even asked me whom I could disclose to, in the case of a positive result, and that really sunk me. I can’t tell anybody. I knew I was not positive, that’s why I went in for the test. Do you think if I were suspicious of not being negative I would go in for the test?

Most of the respondents did not remember exactly what was told to them at the pre-test counselling. They cited fright, shock, and thoughts of the effects of a possible positive result as preoccupying their minds when they realized that an HIV test was to be conducted. The accounts of the HIV positive persons in this study, and those of the young professionals, could be interpreted to mean that those who utilize pre-test counselling do not find the service very useful. However, Kojo (also a member of the FGD) insisted that as far as he was concerned it was very necessary to undergo counselling before the test. For him, he learnt a lot from the counsellor.

I learnt that a negative result does not necessarily mean that you don’t have any HIV antibodies, which should be confirmed some months later [if you had engaged in a risky venture], neither does a positive one show that you are positive since you may need a confirmation test to be sure. In addition, though I knew medicines were available for a positive result, I didn’t know much about it – where to get them, how to get them, the daily dosage, how long you will have to take them, whether there were different types or everybody takes the same, and even the problems associated with taking the medicines.

A few members of the FGD also shared this view that counselling before the test was very necessary, as they had gotten some new information during the process. Though some of the HIV positive people also said that they thought the pre-test counselling was useful, they could not enumerate the benefits they had derived from it.
The test
For those who walk in voluntarily for the test, and for those who go through the pre-test counselling in the hospitals and counselling and testing centres, a sample of blood is drawn in order to test for HIV antibodies. At the time of the research, two testing methods were available: the ELISA test and the rapid HIV test.

Enzyme-Linked Immunosorbent Assay (ELISA) test
From the time that HIV testing became available in Ghana, most of the facilities used the ELISA HIV antibody test. For this service, a sample of blood is taken from a vein in the client’s arm, and is sent away to a laboratory for the test to be conducted. The results take between one and three weeks. After the waiting period, the client goes for post-test counselling where the results are declared. If the blood sample tests negative, the counsellor informs the client that s/he has no antibodies for HIV in her/his blood. However, s/he may still be in the ‘window period’ so is advised to return for a repeat test, usually after three months. If the blood sample tests positive, a second blood test is done on the blood sample so that the result can be confirmed. This is usually called a confirmation test. If the second blood test is also positive, the counsellor will tell the client that there are HIV antibodies in the blood, but s/he is advised to return for another test in a few months’ time. If the second test is negative, s/he is told that the result is indeterminate or discordant. This means that it is not sure if s/he is HIV positive or negative. S/he will then be advised to come back to the facility in another few months’ time to be tested for a third time.

Some of those who used the ART facility in Komfo Anokye were diagnosed using the ELISA method. In their narratives, two main problems were mentioned. Firstly, due to the waiting period after the blood sample is taken, many people had the opportunity to refuse to go for the test results. Maakua, for instance, recalled that after her husband had died of AIDS she was taken by his family to the hospital for a test, but initially refused to go back for the results:

I worked with my husband in the other town [not too far from her husband’s hometown, where she currently resides]. His family was very rich and we [she and her husband] received substantial support from them. When my husband became very ill some few years ago, his uncle took him to several places for medical help until they finally got to ‘Gee’ [Komfo Anokye] where he was diagnosed as being [HIV] positive.

Probably because he thought no amount of money and/or medicines would help cure his nephew, the uncle immediately stopped all payments for his treatment and so he was subsequently discharged to come home and die. As if this was not enough, he summoned all the family members and announced to them the plight of their son. They subsequently took me back to ‘Gee’ to also check my status so they could help me if I was also positive. I refused to go in for the results, though it made no difference because the entire community had gotten the news. My husband’s family afterwards ejected my children and me from their house and subjected us to public scorn and disgrace. It became worse when my second daughter died some months later also after persistent illness. My first daughter also followed
with the persistent illness and soon it was my turn. That was when I went back for the test and found out I had this thing and started treatment with my daughter.

In particular, in diagnostic cases, where the persons were not certain but suspected that they were being tested for HIV, many refused to return to the hospital or clinic to get the test results.

In the case of sensitization campaigns (like the one described in the introduction), the same problem was found. People who undergo the test can change their mind and decide not to collect the results. On the other hand, they present people like Abigail and Oppong (participants in the FGD) and Maakua (in the case above), who initially had felt coerced into taking the test, with a second chance to decide whether they really wanted to know the results. This opportunity notwithstanding, sensitization campaigns may nevertheless present more public health questions, as people who test positive (as in the case of the five mentioned in the introduction) but who refuse to get their results may instead make use of other treatment options and miss the opportunity to be educated and inducted into treatment.

During data collection, one significant aim was to find and talk to members of the community who had undergone VCT and yet had not followed it up to get post-test counselling and care. A few were found through contacts with other infected people, but they all refused to talk to me. This particular problem of clients not returning to collect results, which arises from HIV testing practices that do not give on the spot results, are found globally. The Centre for Disease Control (CDC) in the United States, for instance, reported that out of the approximately 2.1 million HIV tests that are conducted annually in publicly funded counselling, testing, and referral (CTR) programs, in 2000 thirty percent of persons who tested HIV positive and thirty-nine percent of persons who tested HIV negative did not return to pick up their test results (CDC 2000).

There are also problems associated with negative, indeterminate, or discordant results. Those who test negative may initially go on with their lives unbothered, because in spite of their comparatively risky behaviour, when they find out that they are still negative this gives them a false sense of security. On the other hand, after an initial positive result, some may have lost hope in life and may have already been thinking about the consequences, only to be told later on that they are not positive. Once during a visit to the hospital I witnessed a case where a client was positive in the first test but the confirmation test proved negative. Her countenance obviously displayed how surprised and confused she was with this conflicting news. For greater detail on some of these experiences, see Dapaah (2012).
The rapid HIV test

In order to prevent the problems outlined above, where clients do not go back to the facility for their test results, most counselling and testing sites in Ghana currently use the rapid HIV test, where the test is conducted using blood, plasma, or oral fluid, and the results are ready almost immediately. For instance, if the test uses blood, the tip of a finger is pricked with a special kind of needle (lancet) and a drop of blood squeezed out. Using a thin plastic tube, the drop of blood is put into a small window in the test strip. Drops of special fluid (buffer) are added to this test window to help the blood move up the length of the strip. The test result is often ready in fifteen minutes. If the test shows that the client is positive for HIV antibodies, a second rapid HIV test is done, usually using the fluid around the gums of the teeth. If the second test is also positive, the counsellor informs the client that s/he is infected with HIV. If, however, the client’s test shows up negative for HIV antibodies, no further test is done. However, because s/he may still be in the window period, s/he will be advised to return for another test in a few weeks.

During the research period, the rapid HIV test was used in most hospitals, private clinics, private laboratories, and during sensitization campaigns due to the obvious advantages it has with regards to the waiting period for test results. However, it tends to limit the extent of client involvement in the decision to test, especially in the case of diagnostic testing, as the whole process can be over within twenty minutes, during which time the client may have to make a life changing decision.

CD4 T-cell count

Some of the people living with HIV in Offinso also mentioned that the CD4 T-cell count had been used to detect their HIV status. This is not an HIV test but rather a procedure where the number of CD4 T-cells in the blood is determined. A CD4 count does not show the presence of HIV in the system, but rather gives an indication of the HIV trajectory, and is used to monitor the immune system function in HIV positive people. Declining CD4 T-cell counts are considered to be a marker of the progression of the HIV infection, though several factors could account for a low CD4 count, including many viral infections, bacterial infections, parasitic infections, tuberculosis, malnutrition, psychological stress, and social isolation. In the two facilities, St. Patrick’s and Komfo Anokye, AIDS is officially diagnosed when the CD4 count drops below 300 cells. In the hospitals, Dapaah followed up on the assertion by HIV positive people that the CD4 T-cell count had been used to determine their HIV status. However, he discovered no confirmation of this among staff. Regular mention of the term in the facilities or during counselling may account for this erroneous assertion.
Post-test counselling

Post-test counselling, according to the HIV positive persons, is an occasion where clients are again asked to express their feelings about and expected reactions towards the possible results of the HIV test. Those who test voluntarily are then shown how to interpret the results on the rapid test kit, and are therefore able to tell the result just by looking at it. However, in the case of clients who take an HIV test as part of a diagnostic procedure, and who do not know that the test had been conducted, they are taken through some of the issues that should have been discussed during the pre-test counselling stage before the results are declared. Esther explained that even though she did not know that an HIV test had been conducted, when the counsellor started talking about and putting stress on managing physical and mental issues, better social relations, and safer sex practices, she feared the worst. It was still a surprise though when she was finally told that you have “some of the small animals/worms in your blood” (\textit{emmoa no bi wɔ wo mogya mu}).

The result is then declared and the various options available to the client discussed, whether they are HIV negative or positive. Counselling for those with HIV negative results was found to be used to (re)educate clients on HIV prevention, and clients with problematic high risk behaviours were referred to specialized organizations such as the Planned Parenthood Association of Ghana (PPAG) for ‘treatment’. For clients with a positive result, the counselling was used to educate them on issues including partner notification, and for referral for medical and psychosocial support and care. The facilities are also mandated to offer follow-up services to clients to enable them to access and utilize existing care and support services, including ART and home-based care services. Mapanyin expressed her feelings after the test:

For me, after the results were declared, I didn’t remember anything that the counsellor said again. I started feeling dizzy. I was confused. I knew that was it … I am done.

Some of the clients had issues with how their positive results were explained to them during post-test counselling. In almost all the cases investigated, the PLHIV said that they were told that “worms or small animals were in the blood/system” (\textit{emmoa wɔ me mogya mu or emmoa wɔ me mu}), as in Esther’s case above. This was probably considered the best way for counsellors to communicate the situation to the infected persons, since in the local language HIV/AIDS has no direct name. The logic is that the virus is like a small animal that gets into the blood and then works its way out. Other terms such as “extreme form of

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\footnote{The literal translation of the phrase commonly used to disclose test results – \textit{emmoa no bi wɔ wo mogya mu} – connotes (small) animals; however, the people I interviewed usually referred to them as ‘worms’. For in-depth discussion of this and its impact on the pursuance of alternative therapy, see Kwansa (forthcoming).}
gonorrhoea” (babaso wenfoa), “that sickness” (saa yadee no), “a sickness whose
name cannot be mentioned” (yadee a yennm.wordpress din), etc., were also used to identify
the virus. These latter phrases, however, bring up negative sentiments, especially
for people who are quite unwell. These latter phrases are therefore regarded as
being quite harsh, so people (including counsellors) prefer the much softer
‘worms’, which is often ambiguous and arouses less shock in reaction to the
news. Others, however, explained that such ambiguities as to whether it is “this
worm or that worm” lingered on in their minds, and so they did not fully grasp
the implications of the post-test counselling; it was not until they were referred to
the ART clinic for care and support that they actually realized the “magnitude of
these worms.” ‘AIDS’ was found to be more commonly used by community
members but less often by counsellors, probably to lessen the fears of those
found to be positive after the test.

“It better be hidden”: To test or not to test?

As noted earlier, the majority of people in the communities did not want to know
their HIV status. Statistics from UNAIDS some years ago suggest that despite the
enormous number of HIV infected people worldwide, less than ten percent are
aware of their HIV sero status, mainly because of fear of stigma and discrimina-
tion, fear that the test will be positive, and lack of access to treatment or testing
services (UNAIDS 2006). Some of those who test through the initiative of
hospitals decide to end their lives so as not to live knowing that they have the
disease. Rahim’s case brings this issue to the fore.

Though worn out because of the very long hours walking through the various
communities visiting the clients who accessed ART services at St. Patrick’s
Hospital, I was rejuvenated when the little boy we met at the entrance of the
house told us that his father was at home. Nurse Rose (with whom I was travel-
ling) had spoken a lot about Rahim, but we had not yet met him on any of our
home visits. Rahim had been to the hospital two months earlier and had been
diagnosed as HIV positive after referral for the test by the doctors. He was asked
to come back a week later for a confirmation test, but that was the last time he
was seen at the hospital. In retrospect, I reckon he did not accept the test result
because he was not bed ridden and could go on with his usual schedule unhin-
dered, though with difficulty because of his ill health.

Rose asked me to meet and talk with Rahim since by then she was too tired,
and wanted to relax under the huge neem tree just in front of the house. When I
sat with Rahim, he gave me one of the warmest receptions for a person who we
later found out had deliberately refused to go back to the hospital. He explained
to me that he did not know that he was supposed to have gone back to the
hospital, and since he was doing so well he did not presume it was necessary. I
asked him what test he had done, the results, and what he was asked to do next. He made clear to me that they never really explained anything to him, but that they had told him there were “worms in his system” and he was asked to come back later if he still felt unwell.

So when I came home I prepared an herbal concoction to de-worm. I later realized that what I was suffering from was spiritual since I have never had worms in my system so I resorted to prayers and it has worked tremendously. Can’t you see I’m doing very well now?

It was the first time that I had met Rahim, but to say that he was doing well in his current state meant that he was either exaggerating or had previously been seriously sick. He looked thin, dehydrated, and malnourished, and his skin was shining with the maps of shingles all over his body. I encouraged him to go back to the hospital on the next clinic day and promised to visit him (alone) very soon so that we could talk in-depth about his general health condition. I was very convinced – by his warm smile, candid nature, and unswerving commitment and promise to go back to the hospital – that he was going to get better. I went to see him two weeks later only to meet his little boy and the other members of the household, as well as some relations and friends, in black clothes. “Rahim is no more … he is dead!” It was rumoured, but later confirmed by his eldest son who I was earlier introduced to by Rahim as a worker in the hospital, that he had committed suicide.

Like Rahim’s case, the study found that the immediate reaction of people who had undergone testing, especially in diagnostic cases, was one of shock and an attempt to explain away the results. In Rahim’s case, he continued to live normally because he had killed the ‘worms’ that had led to him needing to do the test in the first place. As found in other cases, quite a number of those who had a choice – in particular, the cases where there was a longer waiting period – also refused to go in for the test result and continued to live without knowing that they were positive. Unfortunately, quite a number too, like Rahim, decided to ‘end it’ by committing suicide.

Until May 2003, when the Family Health International START programme, in partnership with the National AIDS Control Programme/Ministry of Health, started the first large scale delivery of ART services in St. Martin’s and Atua Government Hospitals in Manya Krobo District, HIV had been untreatable, and people had little to gain from knowing their status. The majority therefore did not see the need to get tested for HIV. However, HIV has turned out to be treatable in many cases, though access to testing facilities remains very poor. Those who do the test sometimes refuse to go for the results. In cases where they are told the result, some still refuse to accept it. “Getting to know what is actually wrong with you, as a patient, is already finding a solution to your problem,” one infected respondent told me. However, the case material suggests that oftentimes
people just do not want to know about their HIV status. “What will happen if I don’t see [or find out my status]?” (Se mann hunu a, na aye den?), one respondent in Namong asked. The following sections discuss the possible reasons why the majority of people do not want to find out their HIV status, and at times refuse to go for their test results.

**Public projection of HIV: The fear factor**
Travelling the major road from Offinso to Akomadan, I saw several Ghana AIDS Commission advertisement boards. These boards, placed at key vantage points and displaying the names of the community you are entering or leaving, all carry similar messages about HIV/AIDS. For instance, at Anyinasuso, the board had the inscription “Welcome to Anyinasuso, I fear AIDS, what about you?” (see pictures of some of the boards below). This message, in accordance with most HIV/AIDS slogans and campaign messages, is obviously meant to press home the idea of AIDS being a killer disease and thus something to be ‘feared’. A cursory look at most of the advertising boards about HIV/AIDS in Kumasi and Offinso reflected this stance. Over the years, HIV/AIDS has gained notoriety as a killer disease: it is dangerous, deadly, a menace, something which instils fear and revulsion in people. Also with public health personnel and other medical staff involved in HIV/AIDS information, education, and communication, there has been a conscious motif to emphasize the destructive abilities of the virus. The objective is to put ‘positive fear’ in people so that they flee from contracting this toxin. These messages are in contrast to those regarding other diseases, such as tuberculosis, though only a couple of decades ago they would have also given the same scare to the populace (see for instance a picture of a TB signpost below).

This fear of HIV/AIDS has led people to fear anything associated with the disease, thus leading to a very high level of stigmatization and discrimination of PLHIV. Communities look down on people who have HIV/AIDS. Some employers sack their employees, others are refused their rights to life chances, and children whose parents are known to have HIV/AIDS bear the scorn of their peers, at times encouraged by the latter’s parents. Awusabo-Asare et al. (1993) note that the fear and ignorance associated with HIV/AIDS have led to various reactions such as panic, scapegoating, stigmatization, and denial.

The fear of HIV/AIDS is also channelled to the fear of infected people, which influences the public’s reactions to people living with HIV/AIDS. Ephraim, for instance, was stopped from using the same facilities that he had hitherto used with his siblings when his family found out that he had HIV.

It was so pathetic. They [his family] treated me with disdain, as if I was no more a human being. I was not allowed to eat or drink from the same eating and drinking utensils. Rather my [step] mother bought plastic plates and cups similar to what we fed our dogs with for me to use. I was stopped from using our water closet, our bathroom, and was even moved from
the main house to the boys’ quarters. We did not have any WC and bathroom at the boys’ quarters so I had to make use of the public facilities outside the house. People [in the community] started asking questions. I couldn’t stand it anymore, so I moved to Kumasi.

It is not unusual at all to see families disown a member who is HIV positive, or to refuse to give the necessary help to her/him because “s/he has brought shame upon the family” or “s/he is going to die anyway,” but also for fear of becoming infected themselves. Due to the observed plight of PLHIV, many people do not want similar experiences to befall them and therefore do not want to know if they are themselves infected.

One fundamental issue in counselling and testing discourses is that of disclosure, and the fear that others will find out about one’s status, because of the fear of discrimination and marginalization of those infected and affected. According to the International Labour Organization (ILO), fear of losing employment often discourages individuals from using available testing services.

The fear of HIV/AIDS has thus led to the fear of knowing one’s status. More than ninety percent of respondents had taken the HIV test upon the initiative of the doctor or medical personnel looking after her/him. Others reasons for having the test, as far as the people in the community were concerned, included the test as a prerequisite for marriage, entry into the military, or for travelling outside the country. Generally, people felt reluctant to access counselling and testing services unless they were compelled to do so, and under such situations they still did whatever they could to avoid getting to know their status.

During the period of interaction with people in the two communities, it was not uncommon for me to receive a negative reaction when I asked whether a person may want to know her/his status if the opportunity was given. In response to the question of whether they would want to test and know their HIV status, a number of people in the communities, such as Abigail (a member of the FGD), replied by saying “I am not sick, so why would I want to know?” Massa, a teacher, predictably though philosophically linked having the test to writing an examination. He indicated:

Going for the [HIV] test is like going to sit for an exam. The result could be a pass or a fail. If you fail, your family would be disappointed in you. For this exam, however, you cannot re-sit and pass if you fail the first time. You fail once and you are doomed.

For others too, such as Eugene, “It is not nasty as long as the eyes have not seen” (Se ani anhunu a, enye tan). This is a popular proverb in the area that is used to explain situations where curiosity is found to be a vice. It is okay to be curious, but too much curiosity, or when it is pursued unduly or at the wrong time, brings problems to the prying eye. “Why do you have to go for a test to tell you whether you are sick or not, when you don’t feel sick?” my carpenter
Some HIV/AIDS and TB sign posts in the Ashanti region
informant also questioned. “If you pry too much into the eyes of a corpse, you see a ghost”(Se wo feeieefu ani a, wo ahunu saman), was another expression used to explain the irrelevance of going for the test if you do not feel sick.

Most striking was the association people drew between getting to know one’s status and “starting the dying process.” ‘Death’ talked about here was not limited to physical death, but also referred to emotional, psychological, and especially social death. Due to the fact that families and acquaintances alike discriminate heavily against people known to be HIV positive, just the thought of possibly being infected makes people start to waste away.

The fear of HIV/AIDS also leads to fear of certain groups known to be more likely to be infected. From 1986, when the first recorded case of HIV was found in Ghana, several linkages were drawn regarding the origin of the infection and higher risk populations. For instance, earlier reports of the disease, which linked HIV to migrants from neighbouring Cote d’Ivoire (Abidjan), brought about antagonistic behaviour towards migrants, especially those who had gone to Cote d’Ivoire and had come home sick. Due to the worsening economic and political state of Ghana in the early 1980s, a lot of people migrated to the neighbouring countries of Cote d’Ivoire, Benin, and Nigeria (Anarfi et al. 2000, Atobrah 2005). With male migrants who did not have their partners around, many had sex with sex workers, while some of the women migrants practiced sex work themselves. Many of these migrants made much wealth. However, when they came home around the mid to late 1980s, they were sick with what is now known as HIV/AIDS. Even today, since several migrants come home sick, it is not unusual for people to refer to AIDS as “those people’s sickness”(yaanom yadede) or “sickness for sleek people” (apremanfo yeade).

In public health campaigns, these high risk mobile populations are targeted and their behaviours discouraged. Going for the test and being diagnosed positive will therefore undoubtedly align the person to these groups, including the migrants who are feared. They will therefore refuse to find out their status. “AIDS is real” is currently the main campaign message in Ghana, with the intention that the general populace will come to know about HIV/AIDS and desist from risky behaviours. But how these messages impact upon and work for most Ghanaians remains unclear, though it is clear that people make their own interpretations. To a very large extent, people in the communities still associate the infection with these higher risk groups. In Offinso, for instance, there is the major association of the infection to travels to Cote d’Ivoire, Benin, and Nigeria, since the community has a very old history of travel. This was made clear in one of my interviews with an opinion leader, Eugene, in the community:

Kwansa: I remember the last time we talked you told me there are lots of people with HIV in this community.
Eugene: Yes that’s true!

Kwansa: How come this is the case?

Eugene: Hmmm, you see, we don’t have many people going to school in this community although we have a secondary school right here. And also it is very difficult to see a young guy, above twenty, who has not travelled.

Kwansa: Travelled? Where to?

Eugene: Oh, Benin, Nigeria, Abidjan, etc. If one has not travelled at all, at least, he may have been to these places. You wouldn’t get a fifteen, sixteen, or seventeen year old boy who hasn’t been to Accra in this community. In this community people make fun of you if you are of this age and have not travelled. They can even insult you with it. ‘Fool, have you ever travelled?’ (Kwasea, wo koraa watu kwan da?). And this can be from a fifteen or eighteen year old boy, because they travel a lot to Abidjan and all these other places. It is a very old system that is still in place. In time past, our mothers travelled and lived in Abidjan and some other places and they got this sickness. I say it is predominant here because they are often brought home when they are seriously sick.

Kwansa: So are you saying that no one gets infected here?

Eugene: Not at all [I am not saying that] … when these people come they spend a lot because they bring money. If you don’t go to school, what else will you do in this community? For a young girl, you will just take one of these boys in order to get twenty or thirty pesewas [about twenty or thirty US cents] to buy some food and also some needs. Those who stay together with these guys last for at most two months because the guys will have to leave for their next trip. He will have to go look for more money to come and spend, so they leave to Abidjan, Benin, and Nigeria. Today being Sunday, you will see a lot of them coming back to spend their monies – at least ten people will come to town today.

Other people in the community corroborated this story. HIV/AIDS was therefore linked to these migrants – both men and women. The females who had travelled and had money were, for instance, thought to be prostitutes and therefore carriers of the infection. Unsurprisingly, people in the surrounding towns and villages ‘know’ that this community has many infected people (see introduction).

Significantly, however, unlike earlier days of the epidemic when people attributed the origin and transmission of HIV in Ghana to witchcraft, an act of God, punishment, and insect bites (see Ametewe 1992, Anarfi & Antwi 1993, Radstake 2000), this study suggests that today there is direct competition between explanations related to behaviour and ‘spiritual’ causes (see Kwansa 2010). These HIV positive people considered the former (behavioural causes) as derogatory while the latter (spiritual causes) were used as a coping mechanism.

**Personal risk perception**

Available statistics show that the personal risk perception for HIV infection is low in Ghana; fifty-four percent of women and fifty-eight percent of men believe

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8 During the fieldwork period, one Ghana Cedi (100 Pesewas) – GHS (the Ghana currency) – was equivalent to one United States Dollar (100 Cents) – US$. 

that they have no chance of contracting HIV (GDHS 2008). These figures may be this low because of the low prevalence rate in the country (1.9% as of June 2008). The low risk perception may also be due to the fact that relatively few people (37% of men and 38% of women) personally knew of someone who had died of AIDS compared to other countries, especially those in East Africa. People who believe that they have no risk of contracting HIV are less likely to change their risky behaviours compared to those who believe that they have a moderate or greater risk of contracting HIV, and this belief may be channelled into their (un)willingness to go for HIV testing. This assertion was shared by most people in the communities studied, who thought that since they were not engaged in risky behaviours they were not at risk and thus did not need to go for an HIV test. A typical example was that of my very critical informant Eugene:

Kwansa: Do you know your HIV status?

Eugene: How do you mean?

Kwansa: I mean, have you checked whether you are positive or not?

Eugene: No, I haven’t! But I trust myself that I am not infected. My girlfriend claims that she checks hers at least quarterly because she is a final year nursing student in Kumasi.

Kwansa: Did you ask her how often she does the test?

Eugene: No! I didn’t but she always does it, I think it was only the first time when she started having clinical for her course that I suggested to her to do it, since she had access to it. But subsequent ones, she does it on her own volition.

Kwansa: So why don’t you do it too?

Eugene: Well, I don’t chase girls. I have been together with my girlfriend for not less than seven years so I think if she does it, it caters for us both. Or is it possible that she wouldn’t have it and I will?

Kwansa: I’m not implying so. I wanted to know why you haven’t tested. More generally, why do you think people do not want to know their status, and thus do not go for testing?

Eugene: I think it is lack of education. And come to think of it, when you go for the test and you find out that you are positive, I think you die earlier when you know it. So when you ask anybody around, her/his answer would be what happens if I don’t have the test (manyas a ebeye den)? You see, it is not nasty as long as the eyes have not seen. If he dies, that’s it.

Others who appear to have the knowledge and even sometimes the resources to prevent the infection do not protect themselves because they do not see themselves as at risk. These groups are the least probable candidates to go for HIV testing. Not surprisingly, therefore, and as discussed above, people refer to HIV/AIDS with phrases that do not include themselves, such as “that illness” (saa yadee no) and “those people’s illness” (enkrfo no yadee no). People do not want to be associated with the whole caboodle.

Others questioned available statistics. For instance, at a point in time during the late 1990s to early 2000s, the Ghana AIDS Commission had advertisements on radio and television that said, “Every day, there are 200 new HIV infections in...
Ghana.” One respondent asked how this can be true and yet most Ghanaians are still alive. He calculated that at least 70,000 new infections should be recorded every year, and for at least fifteen years about a million and half people should be infected. This is, however, not the case since as of the end of 2009 less than a third of this figure was estimated to be living with HIV. In 2000, the South African Ministry of Health estimated that roughly four million South Africans carried the HIV virus and about 1,700 people were becoming newly infected every day (Epstein 2007). If the purpose of these exaggerated figures in these campaigns is to scare people so that they become cautious not to infect themselves and thus become part of the statistics in the advertisements, the impact of this approach may be questioned. These messages may instead contribute to turning the fight against HIV/AIDS onto infected people, and, due to the fear factor, reinforcing the general communities’ reluctance to have anything to do with HIV/AIDS, even at the peril of their own lives. As noted by Epstein (Ibid.), these traditional prevention campaigns were too depressing: they tried to scare people into changing their behaviour, and this turned many people off.

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 product of the massive public education campaign aimed at prevention of the infection. Nevertheless, the reality is that since the majority have no firsthand experience of knowing an infected person (unlike in Eastern and Southern Africa), there is an apparent exhibition of ignorance and apathy, which is channelled into stigmatizing behaviours towards those infected and affected by HIV/AIDS. Many people in the communities still question the reality of the disease among the populace. In one instance, during the celebration of World AIDS Day 2007, a middle aged woman who stood at a distance to observe proceedings answered thus when I asked why she would not take a seat at the durbar grounds:

All this [the durbar] is a waste of time. Do you think if people are truly infected with HIV they would come around and give their testimony? It is not possible. These [the PLHIV who own up during such programmes] are all fake. They just come and say these things to scare us. No one in the right sense would truly come out and say … I have HIV. What for?

“What for?” remains a very pertinent question for the majority of Ghanaians. During our conversation this woman acknowledged that she did not know about the availability of medicines to manage the HIV infection, and did not know that the medicines were available at the local hospital (St. Patrick’s). Most pertinent, she did not know anybody who was infected, and did not think that those who claimed to be infected indeed were. Total lack or inadequate knowledge of HIV, in addition to the ‘fear factor’, therefore contribute to stigmatizing behaviour, which translates into the majority of people refusing to know their status.
Conclusion

This chapter was about the general public’s perceptions and experiences about HIV counselling and testing. Due to the levels of stigmatization of HIV, particularly directed towards those infected and affected with the virus, many people do not want to find out their status. There is a strong connection between not testing and stigma. On the one hand, if people are found to be HIV positive they will be stigmatized and lose their respect in society; so they resort to not finding out their status and to leading a normal life, even if they suspect that they may be infected. On the other hand, because of the shame associated with and the stigmatization of PLHIV, some do everything possible to conceal their status by going for the test early on and starting antiretroviral therapy, which will mean that their status will not be given away because they will appear ‘normal’. The case material suggests, however, that the majority of people chose the former option – of not finding out their status.

The belief is that it is better to suffer the disease quietly and hidden than to find out through HIV testing, because of the stigma associated with receiving a positive test result in addition to the feeling that “what you don’t know can’t harm you” (Skinner & Mfecane 2004: 160). What Skinner and Mfecane show is expressed in the proverb “It is not nasty as long as the eyes have not seen.” People do not want to be ‘harmed’ and they do not want to see anything ‘nasty’, so they do not go for the test. Even though this chapter discussed people not wanting to know their status – not wanting to lay their eyes on nasty things – the argument transcends the individual. Others are afraid that other eyes will see them. That is, in order for other people not to find out about their infection, they suffer the disease quietly.

The consequences of not wanting to know one’s status because of shame and fear of stigmatization are that by the time it becomes evident, most people are in a very advanced stage of the disease process, making it difficult for treatment to be successful. This poses a paradox. Many make it to an HIV treatment centre in a late stage of their disease. By this time, because of the noticeable wasting of the body, the situation would likely have become obvious to people in the community, those who made the person hide from testing in the first place. At this late stage, however, there is nothing to hide from anymore; neither the test nor the prying eyes. Many of the infected people followed in this study were, in retrospect, regretful of not having started ART earlier.

Knowledge about HIV/AIDS must generally be channelled into behaviours and behavioural change. People who get to know that ‘AIDS should be feared’ are supposed to change their behaviours in order not to become infected. They will therefore be wary in their sexual encounters, be careful not to be pricked or cut by infected objects, and pregnant mothers will be very cautious not to
become infected in order to protect their unborn child. The majority of people in the communities are aware of these preventive behaviours, and are in fact very alert regarding them. However, since education is inadequate and the fear of being stigmatized is great, people still question what will happen if they do not get to know their status.

There is a serious implication for HIV prevention efforts when people do not want to go for VCT owing to HIV/AIDS stigma (Greeff et al. 2008), in particular when it concerns people who are more likely to engage in high risk sexual behaviours. This has dramatic implications for the spread of HIV/AIDS (Gilmore & Somerville 1994, Duffy 2005). Educational messages may therefore have to shift from using scare tactics to spreading messages that the majority of people can relate to, such as informing people about the dangers of having long term concurrent relationships and how this sexual system puts all sexually active people at risk, even though most people may have few sexual partners (Epstein 2007). Most pertinent is the fact that those who go for testing and find out their positive status do not disclose their HIV status, not even to their sexual partners. Hiding behaviour therefore transcends the fact of going for an HIV test. It goes beyond people who do not want to know if they are infected. The following chapter explores the issues of disclosure among the infected people.
To sell or not to sell
the sickness

*Se wotɔn wɔ yadeε a na wonya ano aduro*

It is only when you sell your sickness that you get medicine
(Akan proverb)

On one of my many trips with one of the nurses to visit the people living with HIV in the communities studied, especially those who had not honoured their appointments at the hospital, we missed the only taxi going from town to the village. Since the other taxi that plied the same route had broken down, passengers in need of transport, including some taking their farm products between their house and the market, had to deal with the stress that comes along with such a situation. These taxis, so battered that they would not pass even the most lax test found in Ghana’s cities, are considered the passenger’s gods. People beg to hang unto them, preferring this to the over fifteen kilometre walk along the untarred pathway that will ensure that you get to your destination smothered in dust. On this day, the only other option was to wait for about an hour for the taxi to make a successful return, by which time the queue would have grown longer and tempers would flare, making it difficult for the weak to board the taxi in a battle of survival of the fittest. Passengers would also have to pray that the driver would not change his mind or become distracted by other things, including calls of nature, or familial or personal responsibilities.

The nurse and I decided to make the journey on foot since we were not sure whether the taxi was coming back, and even if it did, whether we could get on board. Along the way, as we discussed some of the difficulties in accessing treatment faced by HIV positive people, the nurse hushed me and pointed to a
village some few kilometres east across the route to the town we were visiting. “I had one client there,” she said, breaking the silence. “He was the chief of the village.” “A chief with HIV?” I asked. She continued:

Yes, you see, Nana [honorary title for a chief] became ill and after unsuccessfully treating it all by himself, he was brought to the hospital. His sickness became on and off, but after monitoring the situation for a while I suggested to him that we take his blood sample and test him for HIV. He agreed, though reluctantly, and the test was positive, so I decided to arrange counselling and treatment options for him. Later, after I had left and was preparing to go back to him, Nana called and told me it wasn’t necessary that I should come back. He said that since we have found the problem he was going to solve it.

I visited several times to explain to Nana that we could get him medicines that could reverse activities of the virus but he wouldn’t have any of it. He asked me to stop talking about this issue when I came to the palace. I resorted to calling him on phone to convince him to opt for the ART, but Nana stopped me from calling. He said he was sure people were watching him because of my frequent visits, and was sure they would end at nothing to find him out. He never agreed to undergo treatment. He said he preferred to die in dignity, without his people getting to know that he had HIV/AIDS. “Can you imagine how they would react knowing I have HIV/AIDS … ? Death is worthier,” he said.

So Nana died about a year ago. I was at the funeral but I continue to hate myself for not pushing harder. Maybe, just maybe, he would have changed his mind and [he] would have chosen to live, especially at the time he was dying.

The institution of chieftaincy is greatly revered, so the chief in this case tried to do everything in his control to hide the shame of being infected with HIV. On Valentine’s Day 2009, a paramount chief was alleged to have died after he went with his concubine to a beach resort. Some days after the report appeared in the media, the central regional house of chiefs “threatened to drag a section of the media to court to face the anger of the people of the region for daring to announce the death of one of the chiefs in a bizarre circumstance on St. Valentine’s Day in the Gomoa area.” Because of their position, chiefs in Ghana do everything to protect themselves, to maintain and project a good image, at least to the public. All HIV positive people are faced with this dilemma because HIV/AIDS is perceived as shameful and those who are found to be infected are seen differently; they lose face and respect.

Using the concept of ‘selling your sickness’, taken from the Akan proverb quoted above, this chapter reflects on issues of privacy and disclosure after people find out about their HIV positive status. The chapter also discusses how the people studied developed several strategies to live with the sickness and, to a large extent, get the support of friends and family. It shows how these strategies impact upon their access to ART services and their relationships with family and friends, and discusses their strategies in the context of the high level of stigmati-

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zation of infected people. In particular, the chapter highlights the issue of death being seen as an option for avoiding stigma and other problems associated with access and adherence to ART.

‘Selling the sickness’ as disclosure

Serovich (2001) notes that before the current millennium, the most common theory about HIV disclosure was the disease progression theory, which posits that individuals disclose their HIV diagnosis as they become ill, because when HIV progresses to AIDS they can no longer keep their status private (see also Hays et al. 1993, Kalichman 1995, Mansergh et al. 1995, Babcock 1998). Hays et al., for instance, found asymptomatic men less likely to disclose their HIV status to family and friends than symptomatic men. This theory has, however, not been found to be applicable to sexual partners, i.e. there is no significant relationship between the severity of physical symptoms and disclosure to sex partners (see for instance Perry et al. 1994 and Mansergh et al. 1995). Furthermore, as a consequence of the introduction of ART, and even in resource poor settings, people who enrol on time do not exhibit a standard pattern of declining health, so disease progression on its own does not constitute the prime component of the disclosure process.

More current is the consequence theory, which argues that individuals disclose their HIV status after anticipating the consequences of disclosure. After testing positive, therefore, as the disease progresses, stresses accumulate which result in the need to reveal one’s status to significant others (such as sexual partners), in particular once the rewards for disclosing outweigh the costs (Serovich 2001). The rewards are the positive consequences of disclosure, and may include “pleasures, satisfactions, and the gratifications the person enjoys” (Thibaut & Kelley 1959: 12), as well as social, physical, psychological, or emotional dividends that may please the HIV positive person (Serovich 2001). According to Serovich, these benefits may range from assistance with home-related chores and medical attention to social support and acceptance. Disclosure by HIV positive persons may be a crucial factor in reducing the further spread of HIV (Marks et al. 1991); may help PLHIV feel better emotionally (Greenberg & Stone 1992, Derlega et al. 1993); reduces stress-related problems (Pennebaker & Beall 1986, Pennebaker et al. 1990, Greenberg & Stone 1992); and could provide useful links to education, health care, and the social support needed to improve physical health (Serovich 2001). Serovich (Ibid.) further notes that disclosing to family members and close associates and getting their support greatly helps patients adhere to the medical regime. The costs of disclosure are the things of value that must be relinquished in preference for an alternative, equal or greater, reward, or something that would be punitive or distasteful that one would otherwise avoid
HIV positive persons, according to this theory, disclose to those who pose little risk, while avoiding those who could harm them.

The popular proverb that you must ‘sell your sickness’ literally means that a sick person has to communicate or disclose what is wrong with her/him, how s/he is feeling, and in effect reveal her/his innermost secrets about the suffering, in order to get medicine and other help. The medicine referred to here could range from diagnosis and prognosis to treatment. The person to whom the sickness is being sold may have experienced themselves or known someone who experienced a similar condition, so could ease the fears and frustrations of the sick person by diagnosing the illness, showing the probable course of the sickness (prognosis), or even the best way to treat the sickness. In theory, the more you talk about your problem, the more likely you are to get help. In reality, the sick person is more likely to selectively ‘sell the sickness’ to a person who can offer help – a doctor or a trusted family member – rather than to a stranger or a distrusted person, especially when the sickness is very serious and could stigmatize the individual or the family if an outsider were to know about it.

For the purpose of this chapter, the focus on ‘selling the sickness’ is not about diagnosis (which was dealt with in Chapter 3). Rather, the emphasis is on prognosis, especially treatment and care. The case material suggests that HIV/AIDS is not considered a sickness to be sold, because the ‘seller’ loses the support s/he may have had prior to the sale. Drawing from the consequences model for HIV disclosure, the cases presented here will show the various considerations – the cost-reward analyses – of PLHIV about whether to sell or not to sell their HIV sickness.

Strategies for selling

After going through the hassle of getting oneself tested (as discussed in the previous chapter), people living with HIV go through another complex stage in their lives – living with HIV/AIDS. Most significant are their thoughts of maintaining or regaining their social status and respect in society, mainly because of the ramifications within the communities of being infected with or affected by the disease (as discussed also in the previous chapter). Fearing what people will think, they employ strategies to conceal their status from those who should not know, and also tactfully deal with those who know so that they do not reveal it. They therefore choose one of four options: some prefer death to shame, others choose to live with the secret; some sell their sickness reluctantly, others willingly.
Not selling the sickness
As discussed in the introductory chapter, stigmatization of HIV positive people leads to labelling, stereotyping, separation, loss of status, and discrimination. The fear of these consequences causes some PLHIV to completely fail to disclose their status and to live in total secrecy. Usually, those who weigh the risks of the consequences of their infection – loss of respect, shame, the breakdown of relationships with friends and relations, etc. – consider not selling their sickness to be the best option. In the case of the late chief, discussed above, he considered the ramifications of his subjects knowing about his infection – which may have even included destoolment – and thought that the better option was to hide the infection and not to start therapy. Thus, in the case of Nana and some of the HIV positive people studied, as a consequence of their considerations of the negative ramifications of disclosure, they consciously decided not to let anyone know about their HIV positive status. Some settled on refusing to treat the infection with ART, perhaps resorting to other alternative therapies, while others accepted ART but were vigilant not to give away any clues about their infection. In the majority of the cases investigated, the choice they felt they were faced with was between ending it all or living with the secret; a choice that was, from their perspective, a rational one.

Preferring death to shame
Almost all of the HIV positive persons I met said that their first reaction after getting the result was to “end it.” After considering the possible reactions from family, friends, and the general public to their HIV status, they thought that death was “worthier,” as Nana put it, and thus a better option. During the course of the study, a number of the clients from the two facilities died by committing suicide, or were rumoured by fellow HIV positive persons to have killed themselves. An example is Rahim, discussed in Chapter Three. In the cases investigated, the means used to carry out these suicidal intentions were taking a poisonous concoction (mainly nkura aduro), starvation, and in one case hanging. Several also said that they did not carry out their intentions to commit suicide only because they did not have the means and/or the courage to do so. Mama Sôfô explained:

I know how Ama Donkor is a public disgrace in this community because she is infected with that illness (saayadee no). Even children do not respect her. So when I found out that I was also positive, I could not imagine myself in her position. I decided to end it. I decided to buy poison for rats(nkura aduro) and mix it in a bottle of Coca Cola. It was going to be fast. I know several people who had died using it. I just did not get the courage that time. You know I’m a Christian, and it is not good …

Kaakyire: I got some money from my sister and bought nkura aduro. I tried three times but I didn’t get the courage to drink it. I always thought about how my children would be ridiculed
because their father was not manly enough to live and look after them. That was the only reason why I did not end it.

By not selling the sickness and choosing to die, these HIV positive people on the one hand succeed in concealing their positive status. Nevertheless, death by suicide is detested. It is considered a bad death, and “normal funeral rites are not performed to honour the coward,” as Kaakyire put it. To those who opt for suicide, however, it is a choice between two evils – enduring the shame of HIV while still alive or going through the same while dead; the latter was deemed more suitable. Considerations of the effects of shame as a result of the suicide on family and children, however, made some of the HIV positive persons choose to live, as shown in Kaakyire’s quote above.

From observations and the accounts of some nurses and peer educators (who were part of the home-based care team) and some of the people living with HIV, it was clear that although some of those who refused ART did regain their health, the majority did not, and thus had to go back to the facility when they became seriously sick. Some of them, like Nana, died before they could go back. By choosing not to enrol in ART, to keep quiet about the infection, and/or to pursue other treatment options, some of the HIV positive persons did eventually kill themselves. In preferring death to shame, therefore, two forms were identified from the case material: the active form, which is death by suicide; or the passive form, which involves refusing to go for ART and resigning oneself to death in the long run.

Choosing to live with the secret
Among the HIV positive people in this study, those who chose to live but still keep their status secret were mainly those who were diagnosed while they were relatively healthy. A few had walked in voluntarily to do the test, others had tested because of offers made after sensitization campaigns. The fact that they were healthy and not in a critical or incapacitated state meant that their HIV test results were divulged personally and privately to them alone. The initial shock and confusion notwithstanding, these persons were in a better position to choose critically between the options available to them. The majority decided to follow the ART regimen and/or other options offered, which might help them to manage their situation while concealing their status from others. Due to the fact that they had no overt symptoms of the progression of the disease, little change occurred in their everyday lives after testing positive. They were therefore not compelled to sell their sickness in order to get medicines for it. For those who were married or in sexual relationships, especially the women, although they felt uncomfortable about not selling the sickness, the consequences of their partner knowing – such as divorce and loss of the relationship, loss of financial support, and further disclosure to others who they did not want to know – made them remain silent.
More than eighty percent of the HIV positive people followed, and a slightly higher percentage of the clients in the two ART facilities, had not disclosed their status to their family and/or friends. Instead they resorted to several schemes to keep their status private, chief among them being the pursuit of spiritual therapy. Kwagyei’s sister (who did not know the biomedical explanation for the continuous ill health of her brother), for instance, explained how she earnestly helped her brother in fasting and prayers. She also took him every Wednesday for prayers with one prophet, since “No one knew what [was] wrong with him, and only God can help out.” By not selling their sickness, Kwagyei and other PLHIV do not jeopardize the support of family and friends throughout their ill health.

Prior to becoming seriously sick, Kwagyei was very supportive of his family, so when he fell ill he moved to his hometown in order not only to get proper treatment but also to receive the support of his family. From conversations and observations, it was clear that his family believed that his predicament had supernatural underpinnings, and though comments from some people in the community suggested that he was suspected of having ‘that disease’, the family thought otherwise. Once Kwagyei’s niece told me that she had heard people saying that her uncle has AIDS, but she said “They don’t know what they are talking about. Can’t they see that he is getting better every day? We do everything with him, and then we should be infected too by now.” It was remarkable how clearly the treatment given to Kwagyei at home confirmed that his family did not suspect that he was infected with HIV. For example, they ate together with him, using the same plates, cups, and other household utensils, unlike what was seen in the majority of households where the PLHIV had sold their sickness. In choosing the alternative to selling the sickness, HIV positive persons could rely on the effects of the HIV infection conforming to people’s perception of a ‘spiritual’ attack, including the work of witches, curses, and other malicious powers (see below, and also Kwansa 2010).

Selling the sickness: The only option
The study also found some PLHIV whose family and friends knew about their positive status. These HIV positive persons did not choose to die, yet their secret was now in the open. In some of the cases, they explained that they had reluctantly sold their sickness because they had no other option. In a few cases, however, they had willingly confided in a few trusted people.

Selling reluctantly
As a consequence of people being reluctant to know their HIV status, those who test HIV positive often find this out at the end stage of their illness trajectory, when they are in the worst condition. They therefore need help to get to the facilities where they are then tested and their status determined. Most of the
people in the study for whom this was the case explained that, at this stage, they were compelled to inform their caregivers, at least those who were with them when the test results were given. Some of these caregivers were the first ones to be told about the result by the health care workers, because of the state of helplessness of the client.

In a case observed during the early part of the fieldwork in St. Patrick’s Hospital, Mary’s family had already suspected that she was infected when they brought her to the facility because of “how slim she had gotten” (na wafin dodo). I was shocked by her fragility when I assisted her brother and mother, who had brought her to the hospital, to get her into a wheelchair so that she could be aided to the Special Clinic. Her hands were very frail, and I was scared when I held onto her arm to get her seated. It felt like it was going to fall off. When we finally got her there, I could observe that she was in real pain. Her difficulty in breathing was obvious, and she was very unstable in the chair. When her HIV positive status was confirmed, her family refused to have her admitted. In fact, I later realized that they had been coerced by the nurse in the unit to get Mary to the hospital this time round after she (the nurse) had received messages that Mary had not responded well to the treatment given to her after her last visit to the hospital, and that she was dying.

The nurse at the hospital explained that since Mary’s family had suspected that her ill health was caused by ‘that sickness’, when it was confirmed they refused to “spend an extra penny since she was going to die anyway and the money would go [to] waste.” About three weeks later, I saw Mary’s ‘one week’ obituary notice all around the community. Mary had expired. A very grand funeral was held for her. They had rejected the living body infected with HIV and were celebrating the dead one. For Mary and some other infected people, they were not lucky enough to receive the test results directly and in private, so it was not possible for them to decide for themselves whether or not to sell the sickness. It had already been sold and they had to live with the ramifications.

Some of the PLHIV said that even though circumstances (mainly their ill health) at the hospital compelled them to disclose to someone – usually the caregiver who was present when the results were declared – they still expected that person to be very discreet about it. Osei explained that though his sisters and some of his uncles and aunties were present when he was asked to do the test, he was so sure that he was negative that he told them that they should not worry; he was going to come clean. He had earlier been rushed to Komfo Anokye on four

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2 Among the Akans, after the demise of a member, there is the gathering of close family and friends to discuss the aftermath and funeral arrangements. This is usually done exactly a week after the death of the member. Notices are usually posted, and this is the first information given to the general public regarding the member’s death. Currently, this practice is gradually spreading to other ethnic groups.

3 See in-depth discussions of funerals in De Witte (2003) and Van der Geest (2000).
occasions with severe stomachaches. He had grown so thin over a period of four months that all his family members were worried. The idea of having the test was suggested to his maternal uncle who worked at the hospital, and he openly discussed it with Osei in the presence of his other family members. Later, one of his sisters explained to me how scared she was of the test, though she had already thought that the nature of his suffering could be attributed to HIV.

No one said anything to me about the test. However, after about two weeks, I heard that the test was positive. Ei, I couldn’t believe it was true. My sister [a younger and relatively wealthy one and the major financier of Osei’s medical expenses] was telling someone on phone how Osei had been asked to do the test and how the positive result was given to him and his uncle. I suspected that she was talking to our sister in Europe. I eavesdropped and I was right. That was how I got to know. No one has said a word about it. And they think I don’t know anything.

Later, I heard our brother was complaining a lot that we were not visiting him as often as we did before the surgery that led to the diagnosis, so he inquired from our uncle whether he had mentioned anything about the results to us. I’m told that he confirmed that he had mentioned it to our younger sister. Since then he became so disturbed, he refused to eat anything. His health deteriorated very much, and he finally passed on.

I had spoken to Osei a few days before he died on one of my visits with a peer educator to his house. He had told us how disappointed he was in himself that he was going to leave behind his two children, the younger only eight months old. Though we tried to reignite his desire to live, it was clear that the thought that his sisters had got the news, that they had not bothered to care for him unlike before hearing of his positive status, and also that they would not be tight lipped about it, was too much to bear. He told us he wanted to drink poison and end it all, but did not have the strength to get it. His wife later told me that he starved himself to death.

In some other households that I visited, families who learned from the hospital that their relative had been diagnosed HIV positive began to maltreat them. Most families and friends tried not to broadcast the positive status of their relative or friend, probably because of the resulting shame that would be cast on the family, though they were nevertheless the major culprits in the maltreatment of the HIV positive person. In one case, a family kept their relative in a room and barred her from speaking to anyone. No one could visit her, not even her own children and the staff from St. Patrick’s Hospital. On one of our visits to the house, the nurse demanded to check the patient herself. Every time she came, the door to the room was slightly open, but she was told that her client was travelling. When the family vigorously refused, the nurse decided to make a scene by shouting and accusing them of preventing people from seeing their sick family member. Probably because of the fear of the consequences of the nurse’s action, they decided to shut her up by allowing us to go to the room and see for ourselves. They had lied. The woman was lying on the only mat in the virtually empty
room, with only a few cover cloths, two eating plates, a cup, a tablespoon, and a
chamber pot. She explained that she had seen us every time that we had come
there and had not travelled anywhere. She had been denied any visitors, and only
saw the world through the opened door. She sobbed:

They open the door in the morning when my sister co mes in with my food and to empty the
chamber pot. They don’t talk to me; they don’t even ask me about my health. I have run out
of medicines and when I told her she says what good is the medicine if I am going to die
anyway. They don’t care whether I take my medicines or not. They are waiting for me to die,
but even death would not come and visit me. I am tired.

Considering the possible consequences of selling the sickness, it was unusual
to find HIV positive persons who willingly did so, though there were some.

_Selling willingly_

As part of the requirements for enrolling in ART in the two facilities, the HIV
positive persons have to bring along another person, a treatment or adherence
monitor, who will also partake in the adherence counselling and help the sick
person at home when needed. The monitor should preferably be someone who
lives in the same household as the infected person. Josephine, one of the nurses
at St. Patrick’s Hospital, clarified:

…the main task of the monitor is to monitor the client and ensure that she follows the regi-
men religiously. In case the client is so unwell that she is unable to make it to the hospital, it
is the monitor’s duty to ensure that the client is not taken anywhere else for treatment but to
the ART centre.

The monitor must therefore know when the client has an appointment at the centre and
remind her. She must also know when the infected person takes her medicines, in order to
constantly remind her. In general, the monitor will have to know everything about the cli-
ent’s condition and what she does, in order to help her in times of need or when she forgets.

The person living with HIV must sell her/his sickness to the monitor in the
first place in order to get her/him to the hospital. This requirement chiefly
accounted for how other people got to know about the PLHIV’s ‘sickness’. Mr.
Nkansah explained:

… after getting to the hospital, I realized that if I am to live, I will have to tell someone else.
So I looked around … I cannot tell my parents. They are already old. They will die. They
will be disappointed in me. I cannot tell my sisters … they cannot be trusted. They may tell
their husbands and that would be it. My wife? Hmm! She will say that I went behind her. I
therefore confided in my friend at church. As for him, I know I can trust him.

Kaakyire, telling about how he decided to sell his sickness to a treatment mon-
itor, also recalled:

I remember when I was first asked to bring a monitor; I told the nurse categorically that I
won’t do it. If that is the only condition to get treated then I’ll go and die. So the doctor

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4 It must be noted here that based on the understanding of the proverb, the use of the word ‘willingly’
only means that the act of selling comes from the person with HIV him- or herself.
called and explained the need for a monitor to me. What convinced me was the fact that I may be bed ridden and still need the medicines, so the monitor would just have to be present and he could take them on my behalf. You could also fall sick suddenly and various people could give different suggestions but if the monitor is around, he would just take charge of the situation and get you where you can be treated, because he knows your condition. This could prevent the many people who rush you to the hospital in such critical conditions from finding out.

So after pondering on it for a while, I knew my sister [his main caregiver] could not be considered. However, there was no other person in mind, so I asked to be given more time to think about it and get someone. The next time I went alone but they [the nurses and the doctor] insisted that if I had no monitor, then there would be no medicine. So I went home and decided that between disgrace and death I rather choose death (Feree ne owuo de, anka fanyinam owuo).

However, one day I decided against all odds and called Nsiah, my nephew. I told him that, if God permits, I would want him to accompany me to the hospital to see the doctor. On the said day, he didn’t go out but rather asked that I let him know when I was ready. I told him that the appointment has been rescheduled to a later date so I would keep him informed. So when I went to the hospital I lied that I didn’t get to bring my nephew because he was busy, but I still wasn’t attended to. So the next week, I went with him. On our way to the hospital I told him exactly why I needed to take him with me. And I warned him that it should remain a secret between us … and that when a third person gets to hear, we would both end it there.

I know my nephew as someone who is discreet and thus capable of keeping such issues to himself. I told him I was placing my life in his hands, so if he wanted to kill me then he could go ahead and do that. So I told him that when I went to the hospital, the doctors said that I had TB, and that is the first one, the second is this disease. He was shocked and kept looking into my face, sheepishly. And I told him that the doctors have told me that they would give me medicines, and I would be fine. “If I had not told you about this, I’m sure you wouldn’t have had any idea about that, so I don’t expect that now that you know we will behave in ways other than we used to. If you would be infected, it would have been before now since we have been doing everything together. I therefore do not expect that you refuse to sit on the same seat I do, or avoid to be with me and touch me. When such things happen you will make me very sad (wo bema me were aho). So note that we can continue eating together and you won’t be infected. It is when we share blades and tooth brushes, etc. that we can transfer my contaminated blood that you can get infected. And that is why the doctors have asked that you come so that they can educate you on this, so if you come back and decide to tell everyone, then it’s up to you (ese wo ara) … I told him all that.

So he said he had understood the situation. You know, when I was working and he was in school I was providing a lot for his needs (na meye no fine). I was his only uncle and they are six [nephews] but I helped all of them.

Brothers sold it to sisters, wives to husbands, children to parents, nephews to uncles, and vice versa. However, the main criteria for divulging the information were trust and how safe the HIV positive person would be afterwards. Where there was no trust that the monitor would be discreet, and it was felt that they would act contrary to the expectation of the HIV positive person, the latter decided to not sell the sickness at all or waited until s/he had to sell reluctantly, as discussed in the earlier section.
The HIV positive persons in the study mentioned that for the first few days to weeks after they had ‘willingly’ sold their sickness, they watched out for the reactions of these trusted people and those they associated with to be sure that they had made the right choice. Kaakyire continued:

But after a week, I invited my nephew out to a popular joint where we used to eat and I bought some yams and palava sauce [kontomire stew] in separate bowls for us to eat together. I deliberately drew the sauce from the same bowl he did, to know his reaction. He seemed okay with it and we finished the meal. Another time I had just told him I was going to that joint to eat, when he offered to go, so when we got there I told him we should buy in separate bowls but he insisted we eat together. I tried this on about four different occasions and he passed the test. Even at home, he didn’t mind coming home to finish a meal I had started. So I realized I could trust him. If it were to be someone else, he would not tell anybody perhaps, but would try to protect himself by not touching things that I had touched or by not eating from the same plate.

Though a few were able to trust their monitors and could keep their status private (as Kaakyire’s case with his nephew shows), the fear of a possible negative attitude from people to whom the sickness is sold is not simply a worry over nothing, as the cases have shown so far. In other cases, the HIV positive people explained that their treatment monitors’ reactions had been a mixture of casting insinuations, suspicion, and at times blackmail. Many more of the people living with HIV who willingly told their trusted folks were shunned, rejected, and “some [confidants] even acted as vehicles for broadcasting the news.” Elizabeth, for instance, was tested through the PMTCT programme when she went to deliver her child. She informed her husband about the positive test result and encouraged him to go for the test as well. He tested negative and, as she explained, that “was the beginning of the end of our marriage”:

My husband was so loving until his test proved negative. For the first weeks he wouldn’t talk to me. He even didn’t want to hold our child. He said that I went behind him and that is why I had been punished with this illness. He later on stopped giving us money, even to the extent that at a point we had nothing to eat. When I complained he drove us away from the house and hasn’t bothered to look for us. It has been more than three months.

One category of infected persons who had relatively little difficulty in selling their sickness was the group who were ‘lucky’ to have had an earlier sickness – in the case of my study participants, tuberculosis (TB), leg pains, osseous meningitis (inflammation of the bone tissue), severe stomach aches, etc. – or various forms of surgeries, which later led to the HIV diagnosis. These people were therefore able to sell their sickness by proxy: they sold the non-stigmatizing sickness and thus were able to receive regular familial and collegial support. These people continued to claim that the ARV medications they were taking were for the earlier sicknesses. This was particularly so for those suffering from
TB prior to testing positive for HIV (note that about two out of three of all HIV cases in Ghana are co-infected with TB).  

Strategies for managing the sickness

For the HIV positive people – whether they sell their sickness or not – strategizing about whether to sell or not to sell is not the end of their bid to keep their HIV status hidden. Instead, it ushers in another level of strategic lifestyle, often more complex than that of the previous stage: strategizing to manage their private lives, including going to the ART facilities and also living comfortably at home.

*Strategizing to get to the ART facility*

Two factors accounted for the way in which these HIV positive people strategized in order to get to the ART facilities for treatment: communal and institutional.

*Communal factors*

For new clients, going to the ART facility is usually a very difficult undertaking. They fear that others will see them going there and thus give them away. They are careful about which routes they take and also literally watch their backs in order not to leave any trace. Especially in a rather small community such as Offinso, positive persons who enrol at the ART facility are most scared of the threat to their privacy. Amina, for instance, had gone to the hospital one morning for her ARVs. Some friends, hearing that she had not been well for some time, went to visit her at home. There they were told that she had gone to the hospital. The traditional care and support system in the community makes it imperative that they either follow her up at the hospital or come back later to make sure she is or will be fine. Amina’s friends chose the former. Amina got a hint of their arrival through a close relative who had gone ahead to inform her so that she could be ready to meet them. The visit, however, put Amina in a dilemma, because she could neither receive her visitors at the ART facility where she had gone to get her medicines nor get herself into another ward. She nonetheless managed to arrange with the nurse on duty to go to the main OPD, to create the impression that she had not yet been taken care of although she had already spent about four hours at the hospital. As part of the arrangement, when it was her turn for treatment she would be called personally by the nurse and would go with her

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5 The influence of HIV on TB has been increasing, such that while in 1989 about fourteen percent of TB cases could be attributed to AIDS, by the year 2009 about fifty-nine percent of the projected TB cases were attributed to the HIV/AIDS epidemic (GHS 2007).
to the Special Clinic (which is not close to the OPD), therefore avoiding being seen receiving ART by her visitors.

It was also observed that when people in the community are suspicious that a person is HIV positive, especially when there are overt bodily signs, they try to find proof in order to confirm these suspicions. This may include laying an ambush on the way to a known treatment centre to see whether the suspect will pass by. Some of the people I spoke with explained that they had to pretend every time that they are going to other units in the hospital, and then hang around (sometimes for very long periods) before they find their way to the ART clinic when the path is clear. Linda described how, at times, she hangs around for up to four hours in the hospital to be sure that the place is safe before going to the ART facility. She explained that on one occasion she had to leave for home without treatment because there were lots of people around she knew who she “didn’t want to know about me.” Others claimed that they stay outside when they see other community members at the hospital; some find ways to alert the nurses to their presence in order to make arrangements for them to see the doctor without going through the usual bureaucracies and the mainly long queues. Ellen, who is well known in the area because of the prominence of her late father, stated that she always had extreme difficulties going for her medicines:

The doctor and nurses even know about my situation, so when I get to the hospital, I call them and let them know I am around but monitoring the environment for a while. I only go there when all is clear. On one occasion, I had to wait the whole day because the place was never clear. I got there around 9:00am, and had to wait till it was 3:30pm when the nurse called to tell me all the patients were gone and the doctor was about to leave. They had to arrange for me to see the doctor at the theatre because my husband’s younger brother (me kunu ketewa) was at the hospital to meet with the Administrator.

The study also found that several of the clients who accessed ART treatment services at St. Patrick’s or Komfo Anokye came from very far away, including Accra, Tema, Obuasi, and Techiman, among others, ignoring the many other ART sites on the way to these facilities. Through links from my colleague in the hospital and also the people in charge of home visits, I managed to visit some of these clients (and talked to others on the phone) who had travelled all the way from the Greater Accra Region to access services in the Ashanti Region. Their reason for making such a long journey was mainly to remain anonymous. Ahofe, who was in her late twenties and not educated, ran a chain of stores in Kumasi, even though she lived about forty kilometres south of Kumasi. She explained that about eight months ago she thought she was pregnant and so reported to a private laboratory for a pregnancy test and later on decided to have an HIV test out of curiosity. She only proved positive for HIV. Later, she managed to locate an ART facility some fifteen kilometres north of Kumasi. She had not sold her sickness to anyone, not even her “serious boyfriend” who, she
said, intended to marry her very soon. In fact, she preferred to travel the long distance from her home (about fifty-five kilometres) or her business (about fifteen kilometres) to this facility so that no one would get a clue about what was happening to her. Her dilemma was not so much about how to disclose her status to her partner or another trusted person, but how to deal with the consequences of an open secret, because “a secret is only a secret as long as only one person knows about it.” For her upcoming marriage she said “I’m hesitating currently, but do not know what to do … what excuse can I give for backing out?”

In Kakra’s case, she stopped going to the ART facility altogether, thereby stopping her treatment, because a friend who is a nurse in the same hospital had given the hint of her status to people in their community. These people, therefore, wanting proof, “go to the hospital on clinic days, as if they are also patients, just to see me get to the place. When I realized that, I decided to stop going there.” Plans to get Kakra transferred to another treatment centre, after I prompted the ART staff, were not successful; at least by the time I left the field.

The strategies used by HIV positive persons to prevent inquisitive people from finding out about their status are not limited to hiding from those who are not infected. Some people on treatment hide or avoid some of their fellows who they already know are infected and are accessing treatment at the same centre. This, the ART clients explained, happens when specific clients known to each other, or living in the same community, do not want to meet at the facility. They try not to be enrolled at the same facility or arrange with their doctors (and nurses) to give them different days for appointments. In addition, newer clients make arrangements in order not to meet these people who they knew are infected and yet do not want them to find out about their own status. The problem with this arrangement is that clients in both facilities are asked to report to the facility when they experience any form of ill health, even when their appointments are not due. There is therefore no certainty of always being able to avoid specific people at the facility. When they get a hint of their presence, they rely on the nurses to make special arrangements, such as being called in (on the phone or sent for in person) as and when these specific people had left. Mama Sɔɔɛɛ mentioned that once, on her way for treatment, she did not get into the taxi as Ama Donkor (another PLHIV) was already on board. She had to call the nurses to make arrangements not to have appointments on the same day. She also refused to join the same PLHIV association as her. This is because Ama is already known to be infected in their community; Mama Sɔɔɛɛ explained that because “she had lost all respect, even from children (ŋkwɛdɔɔ ɛmpɔ mfa no nnyɛhwɛe), she would gladly reveal her new ‘partner’ if she found out.”

Some of the HIV positive persons also pretend to go to the market, visit friends, go for check-ups for previous sicknesses, and so forth, including dressing
appropriately for such trips or gatherings, in order to disguise the fact that they are going to the ART facility. This was particularly true for those who had not exactly sold their sickness. On one occasion, I met Serwaa in Kumasi in a black blouse and a matching pair of black trousers, on her way back from the facility in Offinso. Surprised, I asked why she was dressed this way – in black and also in trousers – since she had been suffering from shingles for about six months and it was not very healthy because of the heat of the sun at that time of the day (which averages about 38°C). She explained that there was a funeral in her family and she had to attend; this accounted for the black. That morning she also had to “dash to the hospital for her medicines,” and since she did not want anyone to know that she was that sick and was going to the hospital, she had to cover the shingles with the trousers. Others too claimed that they sometimes had to dress for the market or for work, since that was the only way they could disguise their visits to the facility.

**Institutional factors**

The location of the ART facilities and the days on which they receive clients both contribute to the strategies that clients adopt to hide their status. In Kumasi, the VCT facility is positioned at the polyclinic where some of the administrative offices and other units of the hospital, including the unit for postnatal care, are located. The ART centre is at the chest clinic where all chest infections, including TB, are treated. The idea for having the facility at the chest clinic, which used to be solely for the treatment of TB cases, was to de-stigmatize the location of the ART centre and also to more easily treat clients’ co-infections. In Ghana, approximately twenty-five to thirty percent of in-patient HIV cases have a co-infection with TB (GHS 2007). Since the percentage is much higher for cases in the sub-region (70%), HIV testing is mandatory for all TB patients.

During the period of fieldwork, a massive construction of new buildings to house the theatre, reconstructive surgery, and other departments of Komfo Anokye, including the mortuary, were being built just in front of the ART facility. The sheets demarcating the new site had therefore blocked off the activities of the facility from the curious eyes of the public. Previously, only a fenced wall with little openings (for fresh air, which also gave a view of the activities at the centre when watched closely) was the only demarcation from the public. Due to its positioning, PLHIV going for treatment usually want to escape the crowded places in Komfo Anokye, such as the polyclinic and the main wards. However, if using the D-block, the route to the ART facility requires passing the diabetes and hypertension units, which are right behind the facility and often very busy. The other option is to use the path for vehicles, which is right in front of the facility for hearing impairment and close to the public toilet. Those who
access the Komfo Anokye ART facility claimed to use both; the latter route was mainly used during peak hours at the hospital.

In Offinso, the VCT service is located beside the x-ray and injection rooms. As Dapaah (my colleague at the hospital) noted, it was therefore possible for other clients waiting for injection or x-ray services to see clients accessing counselling and testing services. ART is administered at the Special Clinic in St. Patrick’s Hospital, which is the very first building on the extreme left when entering the hospital gates. On the extreme right is the mortuary (see chart of SPH on p. 96). Once, one HIV positive person joked that the position of the centre just across from the mortuary was “to make it faster for the infected people who do not survive to be sent to the mortuary, since mortality levels are definitely high at the ART centres.” The name ‘Special Clinic’ was used for the unit, according to one of the nurses working there, to denote all the special cases, including hypertension, diabetes, TB, and HIV, with the main aim to de-stigmatize the latter group. “The public will therefore identify the facility with all the other cases which are deemed normal in society, therefore realizing that HIV is also normal,” she explained. Before 2009, there was a shed just in front of the main entrance where cooked food (including Kenkey and fried fish, beans, and red plantain), and fruits (including oranges, bananas, and apples) were sold. This same nurse clarified that the building that currently inhabits the Special Clinic did earlier accommodate these food vendors, but they were eventually relocated to make room for the medical activities.

The HIV positive people attending ART services gave both negative and positive opinions about the location of these ART facilities. One person explained that the location of the units is a contributing factor to the difficulty people experience in keeping their status private. Sandra, who goes to the Special Clinic for her medicines, explained that the building is too conspicuous, and no matter how crafty you are you will be found out. She stated:

... some people even hide or pretend to buy some food from the shed and rather sit there looking out for people who will be going to and from the building. They brand you as positive if you frequent the building. It is worse for those of us who use the back door of the building and thus walk past the shed for the food vendors [through a footpath]. One day, as I sat there to eat my bananas I heard them [the sellers] even gossip about us [the PLHIV] explaining our reason for going there to the others sitting with them. I felt so bad about what they were doing but I couldn’t say anything.

Kaakyire also confirmed such activities by the food vendors by saying that he “does not like them at all.” If it were his decision, he believed that “they should be relocated since they not only tell others about the infected people, they also accommodate the punks who just come there to make others out.”

It was observed that the hospital authorities at St. Patrick’s, after noting these concerns (since major issues were raised by the clients about it), ejected these
sellers, cleared the area of the debris, and built a seven foot wall to prevent intruders. Some of the HIV positive persons, however, mentioned that since the area has been laid bare after the ejection, prying people can now stand across the street (which is some feet higher) to watch the PLHIV as they collect their antiretroviral medicines from the pharmacist.

**Home strategies**

Though the PLHIV in this study were more likely to trust people in their own household with their private affairs, it was found that they were not enthusiastic or motivated to voluntarily inform them or leave clues with regards to their infection. They thus kept all medical records in their possession – hospital cards, prescription forms, and even their medicines – away from all (prying) eyes. Usually, the hospital cards for ART treatment are different from the ‘normal’ ones used to access general services at the OPD. In St. Patrick’s Hospital, the card is labelled ‘Special Clinic’, while at Komfo Anokye Hospital the numbers on the cards reveal the difference. So HIV positive persons feel that their cards could give them away. Some also thought that the prescription forms for medicines, and the medicines themselves, were not safe to be left in the open. They therefore hid all of these things from others.

Serwaa explained that she hid her medicines in her suitcase, under a number lock, to be sure that she was the only one who could access them. Kaakyire hid his under the family’s sofa and claimed that he was sure that nobody would consider looking for them there. According to Linda, she previously kept her prescriptions and medicines, including those for Adu-Poku, her five-year-old son, together in a polythene bag and placed it on top of their television set in her living room. This was because, since they were “alone in the house with her younger sister, who is not troublesome and inquisitive, there was nothing to be afraid of.” She had to relocate these materials, however, when she realized that her neighbours had grown suspicious about Adu-Poku’s problem since he, unlike his older brother, was always sick and had to be sent to the hospital. They had repeatedly asked him (and his older brother) to get them his medications so that they could find out what was wrong with him. Linda therefore put the medicines under a lock in her wardrobe and asked her sons to refer anybody who asked them about the medicines to speak to her directly. “That ended the story since they cannot talk to me directly about their suspicions,” she stated.

During visits to both hospitals (and the accounts of my colleague in the hospitals corroborated this), it was clear that some of the PLHIV disposed of their ARV packages and leaflets even before they left the hospital premises. The main place for disposing of them in Komfo Anokye, for instance, was along the
Picture 7-8  Directional signs/chart of the St. Patrick’s Hospital
footpath that linked the medical students’ hostel with the major road to the treatment centre. This path was used often by clients who went to the main bus station, Kejetia, after treatment. Another strategy was to scratch off the writings on the containers of the ARVs or pour the contents into a different container altogether. The main motivation for all these activities was to do away with any indication – be it on the container or in the leaflet – that would show that the person was taking ‘AIDS medicines’. Serwaa had scratched off all the writings on one of the containers, and for the other medicines she poured them into a polythene sack which she hid among her clothes. She explained:

… they [her family] know that I take medicines every day, but what exactly I take no one knows. My small sister is the reason why I hide the medicines. She is the only one who has attained higher education. She is inquisitive. She reads everything. I know she will read everything about my medicines if she gets them. That’s why I try not to make them available to her.

Interestingly, Aba gives some of her medicines (mainly co-trimoxazole, an antibiotic used mainly as a secondary prophylaxis) to other people in the household when they are not well:

Often when someone [in the compound house] is not well, they come to me because they know I take lots of medicines, and also know much about how to get relief from pains because of what I have been through. Usually, I give them two tablets of septrin [co-trimoxazole] and it always helps. They therefore come to me every time someone is not well for advice and also for the ‘magic’ pills.

Due to her previous experiences with battling several illnesses, the others in her housing compound felt that she was the best person to ask for help during their sicknesses. She also made use of the situation to normalize her status by offering them some of the medicines she was taking. Aba explained that they probably do not know that the medicine she gives them is septrin; rather, they may take it for “a different or more potent type of paracetamol,” which is more common for relieving pains. “Amazingly, they all reported improvements in their health after taking the medicines, so they keep on coming. I had to plead with them not to abuse the medicine or else it will cease to perform the magic,” she explained.

This practice of giving one’s medicine to others in order to normalize the situation or to keep one’s HIV status private was found amongst a number of the clients visited. This is in line with the usual pattern of most people first resorting to self-medication in times of ill health. The ill person or an aide may go to a chemist or drug store to explain the symptoms and get advice for the right medicine, or they may simply buy the medicines known to be good for the condition. It is also not unusual to ask a neighbour for a pill or two. These HIV positive persons thus capitalized on this existing practice to normalize their infection.
**Spiritual strategies**

Several of the PLHIV in the study resorted to spiritual therapy, partly as a strategy to conceal their sickness. Since the HIV infection conforms to people’s perceptions about spiritual attack, including the work of witches, curses, and other malicious powers, HIV positive people can get the sympathy of friends and relations and also draw attention away from themselves when they consult for spiritual help (see Kwansa 2010). A variety of health care-related practices occur within the medical set-up of Ghanaian society. These include the activities of herbalists, bonesetters, traditional midwives, Moslem scholar-healers such as *mallams* and *marabouts*, possession priests (such as *trɔnu* among the Ewe, *akɔmfɔɔ* among the Akan), *Tigare* and *Mami Wata* shrines, and a variety of Christian healers and prophets. However, use of these different methods is not mutually exclusive, and people may combine a variety in their quest for health and healing (Krause 2006). For HIV positive persons, four main options are used for this strategy: *akɔmfɔɔ* (traditional priests; *ɔkɔmfɔɔ* singular), *asɔfo* (mainly pastors from Pentecostal and Charismatic Churches [PCC]; *ɔsɔfo* singular), *adunsifo* (traditional healers known to use spiritual therapy for diagnosis, treatment, and protection; *odunsini* singular), and *mallams* (Islamic healers; *mallam* singular). A cursory stroll through communities in the Ashanti Region leads one to the various locations of the shrines, cults, traditional healers, mosques, and churches, via meticulous directions posted on decorated signposts of different sizes.

Depending on the extent to which some PLHIV had sold their sickness, they would embark on the search for spiritual therapy alone or accompanied by a friend or kin, similar to what was described long ago by Field (1960) in her study among the Ashanti concerning visits to shrines by the sick. Where sick persons depend wholly on family, it was found that the PLHIV were more likely to reluctantly agree to their proposal to visit a healer. They went to particular healers and churches, either because they had met other people who had been there personally or because of the recommendation of others, who sometimes based their testimonies on hearsay. The usual pattern followed was to discuss various options (traditional healers, spiritual churches, *mallams*, etc.) until the PLHIV or their accomplice arrived at one or more that they hoped would ensure the betterment of the sick person. Most whom I met had gone (or were going) through several regimens, although they were also on ART (see Kwansa 2010). Due to the many options in terms of spiritual therapy, and the relatively religious

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6 For more on how the HIV positive people’s behaviours of negotiating between denominations and religions are guided more by proximate, seemingly pragmatic decisions, rather than by decisions guided by the principles of a pluralistic medical system, see Kwansa (2010).
nature of most persons in Ghana\(^7\) (and in the study area in particular), many people negotiated between the various systems. However, these negotiations oftentimes resulted in the PLHIV compromising strict religious doctrines or practices, and at times led them to partake in altogether new doctrines. Accordingly, there is a frequent crossing of religious and denominational boundaries in people’s search for therapy (Kwansa 2010); all these negotiations being primarily strategies to hide the infection.

To sell or not to sell? Cost-benefit analysis

In their quest to keep their status to themselves, HIV positive people often miss out on opportunities that could ensure a comparatively better life. In the first place, several positive persons refuse either to start ART or to continue treatment because it could lead to others finding out about their status. Obayaa, for instance, was diagnosed as HIV positive at St. Patrick’s Hospital about a year before fieldwork commenced, but she had refused all attempts by the hospital staff to get her to the ART facility to access treatment and care. Although all attempts to have her talk to me failed, Sis Akua, another HIV positive person and a close neighbour of Obayaa, explained that Obayaa refused to go for treatment because she felt that it would expose her. She had been feeling unwell intermittently but preferred to go to the Quality Care Clinic (QCC), a private hospital in Offinso, where the opportunistic infections were being treated, rather than to St. Patrick’s, because she “felt safer there,” probably because of the anonymity. However, a few months into the study Sis Akua told me that Obayaa had begun attending a private hospital in Kumasi to continue treatment for her prevailing ill health, since she suspected that the doctor at the QCC “may also be suspecting that” (that she may be infected with HIV).

Obayaa’s case epitomizes that of several others, who would keep looking for alternatives for help – biomedical, folk and spiritual, self-therapy, and also substitutes within these alternatives – because they either did not want to know their HIV status, or did not want to accept the reality of their positive status and start ART, for fear of being discovered. In the process, some had to spend substantial costs in terms of money, time, and deteriorating health, which could all have been avoided if they had chosen to confront the possible consequences of selling their sickness.

Some of the clients also failed or were unwilling to join support groups for PLHIV, which would offer them collegial, financial, and emotional support to fight off the socio-economic concerns surrounding being infected.\(^8\) Most of the

\(^7\) According to the 2000 government census, approximately 69% of the population of Ghana is Christian, 15.6% is Moslem, and 15.4% adheres to traditional indigenous religions or other faiths.

\(^8\) In-depth discussion of the activities of PLHIV associations follows in Chapter 6.
PLHIV associations provided financial support of GHS 8 (about US$ 8) monthly to their members to help defray the cost of ARVs and also transportation to meetings and to the hospital. Members also received food support, in the form of cooking oil, *Tom Brown*\(^9\), yellow corn flour, and occasionally rice, which went a long way to augmenting the family’s diet in most of the poverty stricken homes of these HIV positive people. Because of their attempts to hide their sero positive identity, the HIV positive persons who did not make it to the PLHIV associations or other meetings where these supports could be obtained missed out on these potentially lifesaving opportunities.

Others joined these associations but chose at will which programs to commit to and which to stay away from. Kaakyire, for instance, lived close to an animal project run by one of the PLHIV associations – the Christ our Hope Foundation. He was therefore frequently unable to participate in the project’s activities. When the group launched the project, for instance, I observed that he was unusually quiet and stayed very much in the background. In fact, at a certain point I realized that he had vanished from sight. I later found that he had gone into hiding behind the caretaker’s single room apartment on the site. He explained that one of the guests at the launch was a very good friend of his brother-in-law who he was currently living with. Since only his nephew knew that he was positive, he was sure that the man would be extremely surprised to see him there, and would eventually inform his sister and the family, since the launch was being done for PLHIV.

In addition, those who had not sold their sickness at all or who had sold it by proxy were inhibited from taking an active role in the work of these associations, as well as other, mainly public, advocacy responsibilities. These public campaigns – which include PLHIV giving speeches and talks during HIV/AIDS sensitization events, discussing their experiences at public gatherings or with the media, and attending workshops and training programs – were all found not only to be a very significant way for those who had sold their sickness to gain invaluable knowledge about their current situation and also psycho-social support, but they also received (sometimes) huge financial compensation. This is because of the limited number of people ready to defy the consequences of publicly and openly revealing their HIV status, even amongst those who had sold their sickness. During the 2007 World AIDS Day celebration in Offinso, for instance, I identified only one of the HIV positive people in attendance during the whole programme; he was the video cameraman and was therefore not recognized as a PLHIV.

\(^9\) *Tom Brown* is ground lightly toasted corn flour, used for several Ghanaian delicacies including porridge (also called Tom Brown) and *aprapransa* (a palm soup dish with toasted corn flour).
When invitations to such programmes and other financially rewarding trainings and conferences become available, many a time the leaders of these associations go through the routine of trying to convince their members of their importance, not only to the individual but also to the group. This notwithstanding, only a few people were ready to take up these invitations. Though illiteracy and the associated lack of confidence were found to be the reasons for the reluctance of many, the primary reason was the positive persons’ attempt to hide their identity. Frequently, Chief Appiah\textsuperscript{10}, head of the Christ our Hope Foundation, would talk about how he wished he had members who were ready to defy the public shame, like he had done, to take up these challenges, since he was fed up of being the main focus of the group and having so much on his hands. On one occasion, probably because I was a regular attendee at the meetings, Chief Appiah was bent on nothing else but convincing me to represent their association at a conference.

It wouldn’t cost you anything … all expenses are fully paid. They will cover your accommodation and meals for the whole one-week period and in addition you will pocket not less than GHS 200 [about US$ 200] in per diem by the time all is over.

His decision to convince me may have been based on the thought that I was better able to represent the association, and give them a voice at the conference. He was obviously disappointed when I could not take on that responsibility. But the fact that he could not get anyone to attend explains how very daunting a task it was for members to go out with the “HIV infected person tag” hanging on them, as Esther phrased it. For the majority of PLHIV, who struggle to have at most two square meals a day, who literally rush at the end of the month to these meetings to get the GHS 8\textsuperscript{11} and some few grains, and who almost always have outstanding medical bills to settle, the fact that they allow around GHS 250 to slip through their fingers explains the enormous cost they bear for not wanting to publicly sell their sickness.

Esther, a very astute young lady who said that she had found out about her infection after she had worked at St. Patrick’s Hospital, and thus was “very careful to come out since she was relatively known,” explained how she always counted the cost of not taking such responsibilities.

My brother! Those who go there do not know anything and when they come, they mess up in the reportage(\textit{na wototo paapa so}). Hence, we don’t get anything substantial and beneficial from those meetings. What hurts me most is that they have pocketed these huge sums of money for virtually doing no work. No work, my brother. No work. I can’t explain to you how much time I spend in bed thinking about these. I could be so much wealthier if I can get

\textsuperscript{10} Chief Appiah is not a chief, but his personality commanded the title given to him by his peers.

\textsuperscript{11} By the middle of 2008, many of the associations did not have their proposals accepted and thus their funding was not renewed. They therefore could not sustain the monthly money given to their members. Read more about this in Chapter 6.
the confidence to come out. And the group will benefit too. Ei! But I can’t imagine the consequences … my mother will die when she hears about it … she will die. And for my little girl, I don’t want to think about it. I can’t do it … no, I can’t.

Others also missed out on very promising favours from friends and relatives since accepting them could expose their secret. These opportunities would obviously be beneficial, not only to them but to their families in general. They would not have thought twice about grabbing these opportunities with both hands prior to their discovery of their HIV positive status. For instance, Serwaa, who has several siblings living in Europe and the United States, refused to travel abroad to see them even though she was staying at home “doing nothing.” Her siblings had earlier promised to resettle her abroad when things went well for them, only for Serwaa to constantly refuse when the time came. She feared that she would be found out, because “technology is so high abroad and I cannot hide it.” Esther also explained that she missed the opportunity to get married to a very rich and noble professional because of her current predicament, and because she did not want to infect him.

He is innocent, and does not know anything. It is not right to do that. Previously, I was taking a lot of money and presents from him but I have stopped that. I don’t want to further disappoint him. I have told him on countless occasions that it can’t happen, not because I don’t love him but it just can’t happen. He doesn’t want to back out. You know, he is flooding my mother with gifts here and there, thinking that she can make a case for him [to me]. She [the mother] is therefore putting so much pressure. ‘You don’t work,’ meaning I don’t earn much, and ‘you are always in debt. Your child will have a father and the man will take good care of you,’ she always says. In fact, I know it is true. And that is why I can’t tell her the whole truth [about the infection]. She will die.

People living with HIV take into account not only the costs to themselves, but also those of others, including care givers and dependants, such as Esther’s mother in the above case. One drastic cost of either selling your sickness or not selling at all is death. Some of the HIV positive people died because their families did not know exactly what was wrong with them, so they were taking them for treatment – often to several different places and healers – but not of course to the ART facility. Abranteé, for instance, whom I met at a PLHIV association in Kumasi, became terribly sick close to the end of the fieldwork period. After I had not seen him at two consecutive meetings, I went to his house only to find him bed ridden. He had not been at the ART facility since he ran short of ARVs because the sickness had started and he felt too weak to make the journey. At that point, his treatment monitor, who was also HIV positive, had travelled with his six months’ supply of medication to a neighbouring country, so Abranteé could only hope to get better and go there himself or get lucky to have a visit from someone who knew about his condition. Neither had happened until I arrived. He could not sit, talk, eat, or even turn around as he lay on his mat. His family members had taken him from one traditional healer to another, and as he
lay down pitiably he still had some concoctions beside him that he was intermit-
tently forced to take. But “he will vomit them all few minutes after taking them,”
his older sister explained. I made arrangements for some peer educators in the
hospital to visit Abrantee at his home, and he was later taken to the hospital.

A week after fieldwork, when I had left the country, I was told that Abrantee
had passed away. The peer educator who gave me this information said that he
was sure that Abrantee would still be around if he had heeded their advice and
confided in at least one family member, or had called any one of them during the
critical period. I also think that his physical and mental condition might have
contributed to his indecision, although the extent of his fear of being stigmatized,
culminating in his preference for silently taking concoctions rather than divulg-
ing his secret, cannot be ruled out. In order to be safe from the stigma of living
with HIV, Abrantee refused to disclose even to the point of death. On the other
extreme, however, is the situation of HIV positive persons who did confide in
some trusted family members, only to be rejected, quarantined, and discriminated
against, also to the point of death, as discussed above.

Conclusion

Studies have shown that many people in sub-Saharan Africa are reluctant to
disclose their HIV positive status; moreover, those who do disclose are selective
in choosing their audience (Greeff et al. 2008, Campbell et al. 2007, Miller &
Rubin 2007). This study has shown that the majority of people in the Ashanti
communities living with HIV continue to keep their status secret, even when the
disease progresses and the symptoms become obvious. They also continue to
remain silent up until the point when they are extremely ill and weak and are
taken to hospital by relatives, where the staff sell their sickness to their relatives
instead of directly to them. This disclosure route is contrary to the disease
progression argument. Their incapacitation warrants the sale of the sickness to
others. Regarding disclosure to sexual partners, the study did not find any
significant link between the progression of the disease and its sale. Rather, it
corroborates the argument of the consequence model of HIV disclosure, where
PLHIV anticipate the reactions of those in their environment. When there is an
anticipated positive reaction, the sale is transacted. In a situation where a person
anticipates a negative reaction, s/he chooses not to sell, or to sell by proxy.

This anticipation of a positive reaction is the main consideration for disclo-
sure, and is not limited to spouses. 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. Though some PLHIV
expected great rewards for selling their sickness, the majority feared that the
reactions from the sale would be negative. They therefore resorted to decisions
that may seem illogical, such as rejecting testing and treatment, resorting to alternative healers, refusing to attend workshops and seminars, and thus either waiting for death or actively hastening it through suicide. Others who were ‘lucky’ to have a co-infection (with TB, for example) disclosed by proxy, selling their unstigmatized sickness. The majority did not disclose at all, however, even to their spouses, for fear of repercussions such as social exclusion.

Selling or not selling one’s sickness is tied to the experience of shame or respect, coming not only from individuals but in the broader context of one’s kinship relations. To uphold their good name and restrict the shame of HIV as much as possible, families go to the extent of hiding HIV positive members. The material also shows cases where some families broadcast the news of an infected member as a way of distancing themselves from the individual’s predicament. In all these cases, the family’s respect was deemed paramount and the individual’s stained identity was not allowed to affect the whole family. This must be understood within the context that some sicknesses can take on a family dimension, as the status and respect of a family can be jeopardized by an individual’s problems; an entire family can be categorized as having a particular disease. Such sicknesses – mainly leprosy and epilepsy – can be taboo in terms of social mixing, so that members of a family where this sickness is present may have difficulty in marrying persons from other families. In the case of HIV/AIDS, this taboo is exacerbated because of the shame brought about as a result of ‘courtesy stigma’. Sick people may be quarantined, or families may disown members for having such sicknesses. Another study carried out in Ghana has also shown that even though people living with HIV may regain their strength with ART and that the physically devastating effects of HIV/AIDS is tempered, they still face psychological isolation and condemnation from their family, friends, and society because people around them are aware of their HIV status (Blackstock 2005).

In exercising their agency not to disclose, or to disclose either partially or fully, the majority of PLHIV do not necessarily toe the line when it comes to the Akan proverb “It is only when you sell your sickness that you get medicine.” When HIV is concerned, selling the sickness does not necessarily get you medicine, and you can get medicine without necessarily selling your sickness. As the case material suggests, the majority of those who sold their sickness were instead isolated, lost their status, and lived in fear, while the majority of those who got help were those who either did not sell their sickness or sold it by proxy. For each selling strategy, amidst the high levels of fear of stigma, people developed several coping strategies, which included schemes to deal with the infection in their homes, households, communities, and even for trips to the ART facilities for treatment. These involved disposing of the boxes and leaflets of the antiretroviral medications before getting home, keeping medicines away from others in
their homes, giving some of their medicines to other ill people in their homes, disguising their trips to the hospitals, and resorting to alternative – mainly spiritual – therapy.\textsuperscript{12}

Also related to the issue of disclosure is consideration of the extent to which a PLHIV may be treated differently after s/he discloses. Disclosure could, for instance, lead others to be more careful in relating to the infected person, for example by refraining from having unprotected sex with them, while in other cases the infected person may face the possibility of others avoiding all contact with them, from avoiding touching to shunning even causal interaction.

For those who test positive for HIV, in deciding to sell or not to sell their HIV status, they must adjust to the shock of their diagnosis, consider the possibility of living in total secrecy while still getting the support of family and friends, consider the probable recipients of the sale, consider what aspects of the sickness can be sold, and anticipate the reactions of the recipients of the sale. After these considerations, and weighing the rewards and costs of selling the sickness, the infected person will decide to sell or not to sell.

Interestingly, the benefits of selling were often found among other people with HIV, who became quasi relatives bearing one another’s secrets. Their associations and activities became avenues to de-stress and to get the social, physical, psychological, familial, and emotional dividends that would otherwise be the motivation to disclose to family and friends. HIV positive persons are likely to disclose only to persons they trust. Nurses and other medical personnel play a central role in this new ‘family’ of trusted people. As discussed in this chapter, several infected people used them as accomplices in the hospitals and at times in their homes. These networks and the activities of the PLHIV associations are discussed in the next chapter.

\textsuperscript{12} Even though the healing of an HIV positive person through spiritual therapy never occurred during the course of this research, its significance as a coping mechanism and way of escaping stigma should not be underestimated (Kwansa 2010).
Friends and siblings:
About trust and mistrust

Some friends are better than siblings
(Akan saying)

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

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

The current predicament of PLHIV in Ghana makes them vulnerable to being stigmatized by friends, family, work colleagues, and others whom they relate to. As can be seen from Serwaa’s case, they therefore develop new relationships,
while some of the old ones fade out or are severed completely. Due to the indifference that can arise in relationships with family and friends after PLHIV sell their sickness and/or the limitations imposed by non-disclosure, this chapter explores three other types of social encounters that the PLHIV experience: those with hospital staff, with other HIV positive people, and with home care professionals (including NGOs and PLHIV associations working in the field of treatment, care, and support). All of these three categories include people who are aware of the status of the HIV positive person and who should, for that reason, be trusted. These new relationships are, however, not without problems, and not all people can be trusted.¹

**Care for the sick**

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

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

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

¹ Similar developments are described in Chapter 7 in Dapaah (2012: 125-140).
his/her personal relations, the task of caring for someone who is seriously sick may be assumed by many other community members (Manuh & Quashigah 2009). Friends and other community members may provide food, shelter, and clothing, or with their visits keep the sick person company and give him/her reassurance. Janzen (1987) calls this the ‘therapy management group’. He notes that the family members of the sick person may also act as intermediaries and are involved as advocates between the sufferer and the various medical specialists. They lend assistance to the physicians and assume responsibility for both diagnosis and therapy, mainly in the home. On the whole, when it comes to serious disorders such as cancer, physicians in Africa share the diagnosis and other relevant information with family members, and may rely on them to ably care for the patient at home. These informal home care practices are mainly put in place in order to avert frequent and long hospital stays so as not to aggravate the declining health condition of the patient (Carter 2007, Van Dyk 2001). Family relationships thus play a significant role in ensuring that patients obtain humane care at home (Chimwaza & Watkins 2004) and also help the sick person to access medical treatment (Thomas et al. 2002).

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

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

The first encounter: The medical staff

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

Befriending the staff

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

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

Through these interactions, the nurses get to know the HIV positive people. On several occasions, the nurses even realized that they were related somehow to the clients – through blood or through a mutual acquaintance, such as former schoolmates or other relations. These links usually begin the relationship, where these PLHIV risk their innermost secrets – which may not be known even by their close relations (including spouses, siblings, and parents) – to these medical staff whom they may hitherto not have known, talked to, or even associated with. They thereby develop a level of trust in these medical personnel and expect them
to be discreet as well as helpful in giving care and support; something which means the world to most of them. They also take the medical personnel by their word, not just regarding the fact that they (the staff) will keep their status secret, but also in terms of following their prescriptions and counsel without question.

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

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

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

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

The nurses are very good since they remember everything you tell them about yourself. On every visit, as they take your details [vital signs – blood pressure, weight, temperature, and
[85x772]110

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

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

**Reassurance and assistance**

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

From the interactions and bodily gestures of the respondents, it was clear that, due to the fact that the doctors examine them to understand their problems and give medical explanations, they are seen as the main persons in their treatment process. As Miriam outlined the care she was receiving from the ART centre, the smile she revealed as she mentioned the name of the doctor treating her was enough to explain how grateful and content she was with him. Miriam, like most of the clients at the ART centre in Offinso, had a distended stomach from being on ARVs. Hers was, however, unique and abnormal, according to her account of what the doctors had told her. Her stomach was not only bloated but also hard, and she felt extreme pains during the night. She told me that each time the doctor touched her stomach, and gave explanations for her problem and prescribed medicines, she instantly became well. She went home very okay, only for the condition to recur after a few days. Although the problem grew worse and Miriam eventually died, she never stopped talking about her encounters with the doctors.
Some of the clients, especially those who were illiterate, also mentioned that the nurses were kind and helpful in telling them how to take their medications and when to come back for their next appointment. For these clients, the nurses wrote the dosage diagrammatically on pieces of paper or on the boxes containing the ARVs. Sandra described the process that led to use of this strategy by the nurses in Offinso.

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

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

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

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

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

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

After the nurse took my BP and temperature [and other vital signs], she asked me to sit at a particular place. I misunderstood her, so I joined the queue because I didn’t know that my treatment [for a first timer] was going to be different. After some few minutes, another nurse came angrily shouting my name and I might have responded after about the third or fourth shout, to which she started raining insults on me. She kept saying that I was not the only person there to take all their time. She even asked me to go home if I wasn’t prepared for
treatment. She wouldn’t listen to any explanation. I had to keep quiet and listen to them insulting me … as if I am foolish. If I had given birth early, my child would be of their age, but they reduced me to nothing.

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

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

The PLHIV noted that very few of their fellow HIV positive persons managed to talk about their reservations when they felt bad about the services provided, and usually they were only able to voice them when they were very angry. In their bid to express their misgivings, they often had to face the displeasure of the medical staff, mainly the nurses, who then tended to be very critical when attending to them. They often felt upset by this. Furthermore, some people felt
that due to their HIV positive status they were treated less cordially by medical staff, and this was a source of anguish and displeasure. Abiba, who said that she had many a time incurred the displeasure of the nurses because she speaks out, argued that “anybody can get sick so sickness does not make you less of a human being. It must not give people the leeway to just behave anyhow to you.” She alleged that once she confronted a nurse at the ART centre who was showing disrespect and sheer arrogance towards another client:

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

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

The PLHIV further noted that some of the health workers fail to understand what they go through in order to get to the centre for treatment. “If they know, they will be glad that we manage to be present every time we are asked to,” Serwaa remarked. Many explained that the nurses in particular insulted and maltreated them when they were late or missed an appointment. Serwaa: “Can you believe that they tell us if we don’t come on time, we will not be attended to?” Massa also mentioned several cases where people had come late for treatment and the nurses refused to attend to them so they had to come back another time. “That’s inhuman, insensitivity at its best,” he noted. Since the majority of the PLHIV in this study had not sold their sickness, it was noted that they must adopt several schemes in order to prevent others from knowing that they are going for ART (as described in the previous chapter), and this often makes them arrive at the facility late or at times miss their appointments entirely.
Another point of friction between medical staff and the HIV positive clients is over correct ARV adherence. As Aisha stated, “when they count your medicines and realize that you have more medicines than you are supposed to, meaning that you didn’t take the medicines correctly, they don’t spare you.” A number of the PLHIV confirmed this. To prevent these reactions and avoid the fury of the medical staff, especially the nurses, most counted their available medicines before attending the clinic and removed the excess. Ephraim explained, however, that on one occasion the plan backfired when he removed too many of the pills. He was found out, but the nurse rather joked about it:

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

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

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

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

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

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

From observations, it was clear that some of the accusations of preferential and ill treatment were true, though some of the HIV positive people seemed overly sensitive and critical when it came to finding faults in the system. Mama
Sofa admitted that there were sometimes cases when it is rather they, the HIV positive clients, who misplaced their aggression onto the medical staff by getting angry over little or at times no provocation from the medical staff.

The home visits

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

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

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

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\(^2\) Several peer educators were working in the ART centre in Kumasi. Peer educators are HIV positive people who have been trained extensively in counselling and care for their fellow HIV positive persons. Some are also responsible for the home visits. In-depth discussion on the role of peer educators in Komfo Anokye Hospital can be found in Dapaah (2012). Other aspects of their role in treatment, care, and support of PLHIV are discussed in Chapter 7 of this monograph.
clients and their various problems. The clients in turn had introduced him to their families as someone who worked at the Komfo Anokye Hospital and who was responsible for following up on all the people who had been to the hospital in that area/neighbourhood. Since he was very active and looked professional, no one suspected that he was HIV positive, which made it easier for the clients to welcome him into their homes. Another peer educator whom I identified later on during the fieldwork had undergone special training on providing care for HIV positive people who were bed ridden; he was sponsored to go round and support this specific group. In Offinso, however, the main nurse in charge of the home visits – Nurse Rose – was a native to the area, and because of its comparatively rural nature, members of the community seemed to know her and the work she did at the ART centre. According to Nurse Rose, St. Patrick’s Hospital had received funds from the National AIDS Control Programme (NACP) in 2007 to provide money and especially food aid to its clients on ART through the home-based care programme. Within this period the food was distributed to the people in their homes using the hospital van. The team that was responsible for these visits also used the van to provide food to other community members in need.

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

Unwanted visits
Most of the PLHIV who had not sold their sickness to other members of their household were very hesitant about allowing the home-based care team to visit. This came to light when I was arranging with the nurse-on-duty in Offinso and the peer educators in Kumasi to find out the homes of those receiving the services from the two centres. In Kumasi, it was not uncommon at all to pass by a house and hear a comment from the peer educator to the effect that “there is one gentleman/lady here … but s/he doesn’t want to be visited, so we cannot go there.” The nurse-on-duty in Offinso also told of a case where a man, Daniel, had threatened to chase the team that had gone to visit him without his permission with a machete. “They were lucky not to have met me at home when they came,” Daniel later told me. He explained that no one apart from his wife, who also receives treatment in Offinso, knows about his HIV status, so he did not want to
“loosen [his] guard. What do they want in my house? If they have anything to do or tell me, can’t it wait till we come on our next appointment?” Daniel had accepted to host me in his house “anytime I wanted to come,” so I was curious to find out why he would want to host me but not those from the hospital. He explained:

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

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

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

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

I managed to explain the situation to the nurse, who for her part said that she did not know all this about the client and that there could be a way for her to arrange to meet Maakua’s daughter and still disguise it. She felt, however, that Maakua “was too defensive of her child to the extent that she was being too aggressive. It was because of her attitude that I threatened to go there. She is not
doing her child any good.” Luckily, several of the PLHIV did mention that when they had informed the home-based care officers that their presence in their homes would wreak havoc, they had managed to plan together ways to disguise the visits.

**Disguised visits**

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

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

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

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

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

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To ‘flash’ is a popular term used in Ghana to indicate when a person calls (or is called on) a mobile phone but the call is cut after only a few seconds of ringing. This is a popular way of alerting others, since it comes at no cost because the receiver does not pick up the call.
In effect, though the PLHIV said that they understood the importance of the home visits, their inability to offer something to the home visitor in return, an act which they explained as a necessity, led to them rather escaping from the visit and thus avoiding the obligation altogether.

**Agreed visits**

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

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

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

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

> You hear them talk about their own difficulties, at home and even at the hospital. You then ask yourself whether they are the same people you meet at the hospital. They also have family problems and problems with their relationships. If you get to know all these, then you know you have someone to talk to. One who will truly understand you and offer you help.
During these home visits, they reveal their problems to the visitors, who do their best to offer help. Ruth described a situation when the peer educator who visited her found her very hungry:

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

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

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

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

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

When you get to the hospital on the same day [every month] with a particular group, you meet them often during subsequent visits. If on a particular occasion you don’t see one, you ask about them. The next time you see them, you ask why they missed their appointment. If they tell you of any problem and you can help, you offer your help since it is difficult to
discuss this sickness with just anybody. Through that you develop some friendship. In fact, you just miss people if you don’t see them around.

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

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

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

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

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

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

These warm relations among the PLHIV continue even after the death of a group member. Usually, it is those members who are in close contact who hear about the death, and in turn inform the other members at the hospital. The details
of the funeral rites are made known to the members and arrangements are made to attend. When the deceased is a client of a particular ART centre, it is not unusual to see some of the other clients travel to the funeral to pay their last respects. During some of the funerals attended during data collection, these PLHIV were found to be very active, just like families and friends. These observations show how close these PLHIV felt to the deceased.

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

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

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

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4 Many of the PLHIV in these associations use the acronym PLWAs (people living with AIDS), pronounced plawas, probably because of their encounters with the various policy makers and NGO workers in the field.
various associations were under one national umbrella, the National Association of People Living with AIDS (NAP+).

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

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

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

*Yɛda  w’ase a ɛfata*  
If we give you thanks, you deserve it

*Yeyi w’aye a ɛfata*  
If we give you praises, you deserve it

*W’ayi yen afiri owuo mu*  
You have delivered us from death

*W’ama yen nkwa enni awiee*  
And have given us everlasting life

*Ni yɛda w’ase a ɛfata*  
So if we thank you, you deserve it

Martha (profiled in the case study below), the leader of two PLHIV associations – Life Assurance and Hope for the Best – explained that there is a conscious effort in her group to encourage members to sing good songs since it is a way of providing comfort, and the words are chosen carefully to send a particular
message. She explained that the song above is always sung to make the members focus on the purpose of existence and not on their suffering. She explained:

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

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

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

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

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

Osofo Maame concluded by telling the members that there is hope (anidaso wo hɔ), and asked them to repeat the phrase “there is hope.” As can be seen above, repetition of words of hope are often used to uplift the souls of members. In an interview with Pastor Hagan, who visited the Christ our Hope Foundation, he explained that when the members pronounce these words of hope, “they claim these promises and it goes a long way to ginger their withering spirits and pep them up to face life. They may not know at the instance the effects of the repetitions but it works.”
All of the members spoke highly of these words of encouragement that they hear monthly. Abiba, who belonged to the Hope for the Best association, said that she finds great delight in listening to the words of advice and encouragement. Although a Moslem, she travels a long distance from another region where she lives to attend the meeting. She indicated that the words of encouragement from the association “are very helpful and keep [her] going through the month,” and that it makes her “long for meeting days.” In fact, she explained that “I am always the first to be there and I don’t think it is going against my religion. A little from here and a little from there will keep us going.” She reckons, however, that but for her current ill health she would never have been open to the Christian teachings. She finds more solace in it now. Generally, the spiritual lives of these HIV positive people were characterized by the crossing of denominational and religious boundaries through compromise, reorientation, and sometimes conversion (see Kwansa 2010).

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

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

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

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

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

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

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

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

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

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

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

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5 For a list of all the associations in the Ashanti Region (as of 2008), see Appendix 5.
tered at the meetings. The members were also encouraged to talk about the infection with others when the opportunity arises. Mr. Nkansah contributed the following during a discussion in one of the associations:

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

Baba also chipped in that:

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

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

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

Member question: Can we marry or not?6

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

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

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

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6 Marriage seemed to be a real and passionate concern of most of the HIV positive people, especially the younger ones of childbearing age. In-depth discussion on this can be found in Chapter 7.
Massa noted that these interactions, “apart from making them [PLHIV] part of the whole process, show that they are still human beings who have something to contribute somewhere, unlike what the other world seem to think about people infected with this sickness.” These associations seem to be the only places where PLHIV see themselves as normal human beings again. They were seen to be very happy singing, praying, sharing jokes, making fun of one another, and most importantly to them, contributing to the furtherance of the association.

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

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

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

It was obvious during these meetings that the members were also highly suspicious of people whom they did not know to be one of them. Oftentimes the
leaders thus had to draw a link between the resource persons and the association members when introducing them, to eradicate this mistrust. Strenuous efforts were made by the leaders to let the members feel that the resource persons were one of them. For instance, once, when Baba was introducing a resource person who is a pastor, he explained:

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

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

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

Below is an in-depth case study of Martha Osei, founder of the Hope for the Best and Life Assurance associations. The Hope for the Best and Life Assurance PLHIV associations both came out of the Single Parent Foundation (SPF), an NGO focused on single mothers and their children, and all three organizations were founded by one woman, Martha Osei. Martha began by teaching in a disabled school opened by her husband, where blind, deaf, and physically challenged people were given vocational training. SPF was originally founded on humanitarian grounds, because children in the community were often hanging around the disabled school, at times from morning until evening, in order to partake of the food offered to the students. Below is Martha’s description of how she set up the various groups, services, and forms of assistance they offer, as well as the challenges they face.
I got to know that their parents died of HIV/AIDS and their plight was just representative of that of a wider segment of children in the community. I adopted these children, starting from seven in number to forty in the next year, and now about four hundred. After screening these orphans and vulnerable children (OVC) I realized that the majority of them were orphaned by HIV/AIDS. The parents of the children we had first in the group were traced to have contracted the illness from their stint in Cote d’Ivoire. Most of them too had spouses who had gone to Abidjan. Apart from looking after the kids, we also gave the parents some skills to live leading to the formation of the SPF.

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

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

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

I don’t really know why families continue to stigmatize their members. They still consider it as akohwie yadee [a disease for hopeless people], so you don’t have to waste your time on them. One client who had support from a sister
because she thought she had shingles received all her love and support, but when her sister suspected she had AIDS she started giving excuses, such as by the time she dies she may have lost all her possessions. The reason why they refuse to care for them [HIV positive people] is that such people are seen as *egwamanbofoo* [immoral people], or people who have been cursed. In the past, we heard that there is a river in Cote d’Ivoire that you are cursed with. They say the god is so powerful that even if you keep someone’s change, it can give you this disease. Also some make use of prostitutes and get an STI, which they linked to curses.

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

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

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

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

Some of the members who feel unsecured about a particular difficulty are addressed. For instance, one lady who met our resource person who knew the group was for the SPF asked us to relocate her, but that wasn’t possible since we
don’t have enough funds to pay her transportation. So she was advised to answer when queried by the resource person that she lived with someone who had lost his parents so she is representing them. That helped since the resource person was related to her husband.

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

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

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

Some people too say on radio that they have a cure, that appeals more than the ART, which only manages. They don’t advise them to take herbal preparations. We tell them that ART is not compatible with herbal treatment. We realized that herbs are not good for them because of the strength of their lungs and kidneys. It was found in the homes that they still take it at home. They make use of spiritualists. Due to these ideas that they have, we study the word and pray because we believe that whatever medicines you use can only be potent with God. And the worries too are taken care of.
Also, funds are not forthcoming, even from GAC, making us struggle to keep our programmes running. We cannot pay for the right personnel to even write proposals for more funds. The introduction of the health insurance has helped not just the clients but we the NGOs too. People infected with HIV get sick very often. We decided to pay for all their medications but it has become problematic with increase in members. We had so much arrears to pay. The NHIS [national health insurance scheme] has been helpful. NHIS does not cover everything, though only a small fraction is not covered. For the GHS 17 premium per member, we use monies received from ANCP [Australian NGO Cooperation Programme] to pay for that. We all agreed to cut down the allowance on meetings and use the difference for health insurance. Those who have already used their monies to register, we refund for them.

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

Conclusion

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

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

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

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

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

As this chapter has shown, the main consideration for accepting new friendships amidst the high levels of stigma associated with HIV is trust. The PLHIV may have internalized the stigma, and therefore as a reaction they easily mistrust other people’s behaviours. Several scholars, including Sarpong (2009), have noted that in order to support a person with a serious sickness, it is important for care givers to establish trust. Trust is engendered by confidentiality and expected, consistent, and predictable reactions. This trust forms the basis of a continuous and consistent relationship (Meize-Grochowski 1984), rests on feelings of inner satisfaction that are an offshoot of the relationship (Topalis & Aguilera 1978),
and develops based on the experiences in the relationship (Erickson 1963). Only with those whom the PLHIV trust, therefore, do they share their secrets. Families were least trusted by the HIV positive persons in this study because they either did not want to be stigmatized by them or they did not want their families to experience the courtesy stigma due to their infection.

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

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

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

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

The next chapter discusses the financial experiences of people living with HIV. It shows that money is one of the main challenges in living with the infection, and highlights the fact that money (or the lack thereof) in some cases leads to vulnerability for PLHIV, while in other cases it protects them. It kills some, and keeps others alive.
Agyeiwaa lay moaning helplessly on the mat, her family clearly bemused as to the next course of action and feeling powerlessness to act. Her mother, Mama, told how the coffers of the family were empty and consequently their “precious jewel” was dying. Agyeiwaa had been relatively well-to-do prior to becoming sick. She had lived in Accra and looked after the family very well by regularly sending remittances to her parents and other siblings in the village, and also by taking care of the school fees of a number of her nephews and nieces. As a result of her sickness, however, she had sold everything she had – several pieces of cloth, clothes, jewellery, cooking utensils, and even the piece of land she had bought for the family to work on – in order to “get treatment for this inexplicable and strange illness” that no one in the family (but her mother) knew the exact details of. “All the sources of funds ran dry yet her condition kept deteriorating,” Mama explained.

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

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

**HIV, blood, and money**

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

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

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

\(^2\) HIV infection does not necessarily incapacitate the infected. However, due to the fact that the majority of people in this study only got to the testing and treatment facilities at the end-stage of their HIV trajectory, by then most were suffering from several opportunistic infections, leading to their incapacitation.
save a dying person. However, for some people blood transfusion can be used to make money. Informal conversations with colleagues in Accra showed that some young men position themselves around the Korle Bu Teaching Hospital where they donate blood, for a fee, to desperate patients. For them, their blood is literally money; for the recipients, their blood is life (sika ye mogya). Speaking more generally, money is life.

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

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

The economic situation

Available funding to support Ghana’s response to the HIV/AIDS epidemic includes about US$ 6.7 million from the Global Fund to fight AIDS, Tuberculosis and Malaria (Global Fund); about US$ 12 million from multilateral partners,
including the World Bank; about US$ 8 million from bilateral donors; and fifteen percent of the Government of Ghana’s annual health budget (UNAIDS 2005). The fact that these funds are being channelled towards HIV/AIDS interventions in Ghana notwithstanding, the economic situation of the majority of HIV positive persons in this study was dire and worrying. The majority were not working, and were thereby reliant on the benevolence of family, friends, and other support groups. A few still received wages and salaries from their labour, either by continuing with the same jobs as before they discovered their infection or in newer ones. This section is devoted to the economic situation of PLHIV, both the unemployed and the employed.  

**Infected and unemployed**

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

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

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3 Employed and unemployed are used here to refer to the person being engaged (or not) in a venture that provides an income. Thus it does not refer only to formal employment. People working on their farms, or in the informal sector such as in the quarries or selling along the streets, for instance, were all classified as employed. In fact, the majority of the employed persons discussed in this study were earning their money in the informal sector. Being unemployed meant that the person did not do anything to earn money.
continuous assistance. I had visited several of my respondents and I knew how hard pressed they were financially, but never imagined that US$ 2 deserved all this praise – after all, it was not even meant for her – until I heard the whole story.

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

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

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

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

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

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

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

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

5 Buruli Ulcer is an infectious disease caused by mycobacterium ulcerans. The early stage of infection is characterized by a painless nodule, with non-pyroscopic necrotizing lesions developing in the skin and occasionally in the adjacent bone as the disease progresses. Buruli Ulcer is currently endemic in Benin, Cote d’Ivoire, Ghana, Guinea, Liberia, Nigeria, Sierra Leone, and Togo. In Ghana, Buruli Ulcer is more prevalent in the northern parts of the country. Data from 1999 put the prevalence rate of the disease in the Ga West District (in southern Ghana) as 87.7 per 100,000, higher than the estimated national prevalence rate of 20.7 per 100,000, though lower than in the most disease-endemic districts, where it can be as high as 150.8 per 100,000.
the other looking for a cure. By the time I got to the hospital, it was so serious my arm was amputated. In fact, it was a battle for my life, which I only won because God was on my part.

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

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

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

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

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

7 Though no rigorous efforts were made to establish the validity of these grace-to-grass claims, some substantial evidence was found to support them; for instance, Konama’s pictures, and the respect shown by family members to Agyeiwaa, among others.
curious since that too was very unusual for her – generally she had a calm
disposition and did not argue. I gathered from one of the nurses later that Konama had brought some pieces of cloth to sell to the nurse, who had offered a rather ridiculously low price, which set off the argument. Konama explained later that she preferred to sell to the nurses because they offer better prices compared to others in her community and they also offered ready cash. However, on this particular day she needed some money to buy food and medicines,

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

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

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

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

Due to the fact that many had sold their properties and belongings – for some this included the tools for their vocation, lands for farming, and other implements – some of the HIV positive persons in this study were not able to return to work
again even after getting better. They did not have the money to buy back the tools they needed for work. Others were found to be too weak to engage in the usually labour-intensive vocations of the majority of people in the communities. They were thus rendered financially dependent on friends and family for sustenance and survival. However, some families found it extremely difficult to cope (as seen in the case of Agyeiwaa) since the HIV positive person had hitherto been their main source of income.

**Infected and working**

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

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

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

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

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

They all mentioned, however, that the frequency with which they go to the hospital these days is much greater than before the infection. The fact that they
are able to earn money to buy food, medicines, and cater for other necessities could be said to motivate them greatly.

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

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

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

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

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

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

\(^9\) The activities of the peer educators in the hospital are discussed extensively in Chapter 6 in Dapaah (2012).
receive large sums of money that they use for the associations’ activities and their remuneration as officers. At times, the invitations for workshops and conferences are extended to these associations; the leaders of these groups, who have sold their sickness, often grab these opportunities to attend and to receive the remuneration.

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

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

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

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

The financial needs

After enrolling on ART, the HIV positive persons are mandated to go to the treatment centre at least once a month. During these monthly appointments they generally have a physical check-up and receive their monthly stock of medicines. For those who have been on ART for around three years or longer, they have longer periods between appointments. In Komfo Anokye, for instance, some have six-month intervals between appointments. Due to the resources available to the PLHIV to purchase medicines, however, it was observed that some clients have to go to the hospital (the pharmacy and not necessarily for treatment) in order to collect their medicines more than once within this six-month period. They are also advised by the facility to come to the centre whenever they feel unwell, even if this falls in between appointments. In these cases, some people
may got the hospital more than once a month, depending on their health condition. Since the majority of PLHIV in this study had financial difficulties, every trip to the hospital required a lot of strategizing in order to balance the cost of accessing therapy with their other pressing needs, all of which must compete for their limited resources. The sections below discuss the financial needs of HIV positive people, focusing mainly on transportation, hospital expenses, food, and other costs including family care and various life expenses, and how they manage the situation.

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

Those who were fairly weak and/or did not want to be traced going to the ART centre (see discussions in Chapter 5) used either the public trotros/taxis or chartered taxis. In Offinso, taxis are the most common and convenient way of travelling within the town, since trotros do not run within the Offinso municipality. Transport costs to and from the facility ranged between GHS 0.60 and GHS 3 (US$ 0.60 and US$ 3) depending on the distance and whether it was chartered. In Kumasi, though trotros are a more common means of transport for middle-lower class people because they are relatively cheap, taxis were found to be more convenient and comfortable for people going to and from the hospital. In trotros it is not uncommon to see passengers getting off occasionally in order for others sitting behind them to alight, so for people who are sick, such experiences may be draining. Transport costs in Kumasi were found to be slightly higher than those in Offinso, depending on the distance and the choice of transport means. In both Kumasi and Offinso, however, when going to the hospital for treatment most of the HIV positive people were compelled to evaluate how they could get there, depending on the amount of money they had to spend on transportation, meaning that sometimes they would either have to walk or miss their appointment altogether.
Picture 9-10  Trotros and taxis at the Kejetia main station
For the significant numbers that travelled several kilometres to the treatment centres, their transportation costs were comparatively high. Some used either trotros or taxis for the journey, while most often people had to use both. They would therefore spend between GHS 2 and 8 on transport to and from the ART centre for each visit.

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

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

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

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

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10 Ruth is one of the many people who routinely carried their daily stock of antiretroviral medicines in order not to miss the time to take the medicines.
health workers did not take it kindly. A number of the clients complained about such maltreatment, mainly from the nurses, when they missed appointments, ranging from insults to making them wait longer for treatment. In some situations, the PLHIV mentioned that they had seen their peers being turned away.

**Hospital expenditure and medicines**

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

At the ART centres in this study, the patient folders and hospital cards were free for all HIV positive persons. This was not the case for the general OPD, however, where some of the PLHIV with other problematic health conditions went, and they therefore had to pay for these additional services. Furthermore, although the antiretroviral medicines were highly subsidized, the PLHIV were supposed to pay an equivalent of US$ 5 per month, no matter what combination they were taking (this is instead of the roughly US$ 500\(^{11}\) market value of the antiretrovirals). In addition, all the HIV positive persons took co-trimoxazole, and depending on their health condition were given other medicines including painkillers, blood tonics, nutritional supplements, etc. The minimum amount an HIV positive person might spend monthly in the hospital was thus GHS 5 (for the antiretroviral medicines), though this figure could rise to about GHS 20 for some. For those with specific problems – for instance Nana Adjoa, who had an eye problem – they could spend up to GHS 100 weekly. Nana Adjoa explained:

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

\(^{11}\) Prior to the use of antiretroviral medicines in Offinso, Martha reported that HIV positive persons were given a magnesium dietary supplement product – V-1 – costing an equivalent of US$ 150, which was available through donor support to her NGO.
Nana Adjoa had become temporarily blind in one eye, and as she explained she was “losing the other eye too.” Temporary blindness is not a known side effect of any antiretroviral drug. Blindness, however, can occur among PLHIV as a result of opportunistic infections\(^\text{12}\) (Epstein 2007). Nana Adjoa was relatively well-to-do; she had a large provision store and a ready market for her products, since it was strategically located close to a public facility. Unfortunately, however, since the NHIS does not cover the medicine for her ailment – even though the package is said to cover about ninety-five percent of diseases in Ghana, including malaria, diarrhoea, hypertension, diabetes, and asthma\(^\text{13}\) – the amount needed “just for the eye” was more than she could support. She was therefore resigned to her fate and only “hoping for a miracle” to save her sight – and life. Since, unlike Nana Adjoa, most of the PLHIV were not working, had no income, and lived on the benevolence of friends and/or family, they had to go through the monthly ordeal of ‘begging’ for money and support in order to meet these hospital expenses and thus to live.

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

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

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

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

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

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

Food

After managing to get their antiretroviral medicines, and taking them for some time, HIV positive people face another challenge: meeting the pressing need for food as a result of taking the medicines. Food is an important element in the therapy for HIV positive persons. Mr. Nkansah, an auto mechanic, equated the role of food in the human body to that of oil in a car:
as food is like oil in the human body so is blood like petrol in a car. Your system can be very okay, having everything intact, but you need enough lubrication, which is performed in the body by the food you eat, to go about your daily tasks. Without it, the whole system will be weakened.

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

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

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

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

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

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

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

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

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

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

These cheaper alternatives notwithstanding, the situation on the ground – lack of funds and the consequent inadequate food supplies – ensured that getting a balanced meal every day was a luxury. In the homes of most of the HIV positive people in this study, it was observed that when it comes to what to eat, it was more about finding something to eat to survive rather than having a balanced diet, a somewhat ‘survival first’ issue. Most of them therefore took their medications on an empty stomach while strategizing how to get the day’s meal. On one occasion when I arrived at the home of Memunatu in a distant suburb in Kumasi at around 11am, she and her three-and-a-half year old daughter were visibly hungry but were waiting to take the day’s only meal at 3pm, drinking water all morning in order to survive the day. Some of the employed HIV positive persons
who were not in a position to afford meals throughout the day were also found to work on an empty stomach for long hours and to ration their limited stocks. Earlier cases in the chapter, such as that of Konama resorting to the cheaper alternative of eating gari to survive, show some extra dimensions to these strategies.

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

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

**Kin and communal responsibilities**

The descent group-based kinship system that still prevails in most Ghanaian societies ensures that relatives are tied together both in times of joy and sorrow. Apart from fixing lineage affiliations and the citizenship of members of kin (Fortes 1950, Nukunya 1992), it also redistributes resources and ensures communal solidarity among members of the community. This system therefore allows both human and material resources to be redistributed to all members of the kin group. These responsibilities are most pronounced during rites of passage – birth, marriage, and funeral ceremonies – and other ceremonial and leisure activities such as festivals, parties, etc. By custom, in most societies in Ghana, such as the Ashanti, Ewe, and Ga, during child naming, marriage, and funeral ceremonies both families and friends alike are expected to grace the occasion with their presence and presents. In addition, for mothers, since combining the care of a
young child with their own income generating activities or other unpaid services can be daunting, friends and kin members, particularly the females, often go to the home of a new-born to help out. This assistance also extends to meeting household expenditures, as well as possibly accommodating and paying or helping to pay for the education of a member of kin and affines and some community members too. This was the norm in the respondents’ communities. Most of these HIV positive persons (the majority of whom had not disclosed their sickness) had benefited significantly by receiving help (including financial support) from kinfolk, friends, and other members of the community.

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

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

Sarfo was now living in the family house in his village with one of his sisters, whose children he had supported. He showed that it was now very difficult to send the children on errands since they knew that they would not get any tip or reward for it. The norms and ideals, described earlier, which demand that children respect adults and that good deeds are reciprocated may not always relate to actual practice. Sarfo explained that “Yesterday, I had to go and fetch
water with a bucket from the next house because none of the children I asked wanted to go.” Subsequent explanation by Sarfo’s sister brought to the fore the fact that PLHIV often do not have their expectations met because of these norms. She explained that although Sarfo had asked for the children to be with him, even prior to his illness he was stingy and did not treat the children well. “He deserves no sympathy from anyone,” his sister indicated. There is therefore a thin line when it comes to cultural norms and practices.

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

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

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

Sources of funds for people on ART

As the majority of the people on ART in this study either did not have the strength or lacked the capital to engage in income generating activities, lack of money was one of the main challenges they battled with. They were unanimous in the belief that having money goes a long way in terms of positively impacting on one’s life before, during, and after becoming infected, as the case materials discussed above have also proven. With money, too, it is easier to maintain one’s social position and be independent, as evident in the life stories of those HIV positive persons who were still working. The stories of the peer educators and other PLHIV who were engaged in income generating activities, such as selling at the treatment facilities, running the activities of the PLHIV associations,
farming, stone quarrying, and petty trading, are examples of those who maintained their social esteem and position through money (see also Dapaah 2012). It was also rumoured that some of the HIV positive people, especially the females, maintained sexual relationships with richer partners as a survival strategy in order to get regular financial assistance (see in-depth discussion in Chapter 7).

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

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

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

Others had to live on money they received monthly from participating in the activities of the PLHIV associations (outlined above). Occasionally, they received food and medical aid from other donors, mainly foreign philanthropists, who sometimes visit the associations and participate in their activities. On one such occasion, an American philanthropist visited the Life Assurance association
and donated quantities of assorted food supplements and immunity boosters. Martha, the leader of the association, indicated that they receive these donations occasionally, though she thought that the majority of the donated goods were very close to their expiration date when they are delivered. “We are therefore forced to use all of them immediately we receive them since we do not know the consequences of giving it to them after they expire. It may worsen their condition.” She hoped that one day they “will receive a lot of these medicines that [they] can use continuously for at least six months in order to benefit fully from it.” Indeed, a look at the expiration date of the items brought by this American showed that the majority had to be used within one month.

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

Conclusion

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

Money impacts on every aspect of the lives of a person infected with HIV. It is like blood. If you do not have it, you have no life. Epstein (2007: 27) captures this impact among people in Uganda when she notes there are two types of AIDS – one that affects the poor, making “them slimmer and slimmer and slimmer until they finally disappear, and one that afflicts doctors, bureaucrats, and foreign-aid consultants with enormous grants and salaries; they fly around the world to
exotic places and get fatter and fatter and fatter.” The majority of the respondents in this study were poor and they got slimmer and slimmer and slimmer until they finally disappeared (as in the case of Konama); though a lucky few were still engaged in occupations that ensured that they managed to meet their treatment expenses and therefore maintained a normal weight and could live normal lives.

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

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

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

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

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

AIDS has been described as a disease of poverty, but it might be more accurate to describe it as a disease of inequality, which settles in the ever deepening chasm between rich and poor (Farmer 1999). In Ghana this inequality between the rich and the poor is further reproduced within families in terms of personal wealth and attitudes towards sick members, gender roles, and most especially
occupational status. These factors show that the poor suffer more. As mentioned earlier, it was a common sight to see some of the HIV positive people take their medications on an empty stomach, which to some extent had an effect on their health. Others skipped their ART appointments because they did not have money for transport costs to the facility, or had not eaten so did not have enough strength to walk the distance, while others may have resorted to cheaper alternatives including local medicines (see for instance Kwansa 2010). Like Agyeiwaa, some of the clients died during the course of the study, when it was obvious that if they had had sufficient food and money to buy medicines they would not have expired.

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

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

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

The study proposes – and this was unanimously agreed upon at the follow-up workshop in Kumasi (see Appendix 4) – that since HIV positive persons provide a unique perspective on living with HIV, they should be incorporated more
formally into the medical system, where they can act as resource persons for the various forms of counselling – especially adherence counselling. This process was started but was not continued at the Komfo Anokye Hospital (see also Dapaah 2012). Such a move will achieve two main goals – provide a badly needed income to some HIV positive persons while also giving them a life, and it would allow them to put their hands-on expertise at the disposal of their fellow HIV positive people in need. Extra training could be given to them in this regard. It must be noted that although Dapaah indicates that such an initiative was not supported enthusiastically by the medical personnel of the hospitals and ART facilities, because the few PLHIV who were involved in peer education were thought of by the medical staff to have abused the opportunity, such initiatives have been tried and proven successful in other countries (see Salomon et al. 2005).

In summary, the HIV positive people in this study who had money were living better lives. They were more likely to eat well, buy their medicines, renew their health insurance, honour their appointments at the facilities, and therefore fared better on ART. Most importantly, they looked happier because they could continue to maintain their familial relationships (and, as will be seen in the next chapter, their sexual relationships), and continue to enjoy the respect of society since they were not suspected to be infected. These wealthier PLHIV nonetheless posed a greater risk of the further spread of HIV within society, since some hid under the cloak of being ‘normal’ and engaged in unprotected sexual activities and other risky behaviours, which in the long run pose a significant threat to others. The next chapter discusses the irony of the ‘new hope’ provided by antiretroviral medicines; issues of being normal on the one hand and abnormal on the other.
Sometime during fieldwork Nsiah called me for an urgent meeting to discuss an issue that had cropped up with his HIV positive uncle Kaakyire. Nsiah had agreed to Kaakyire’s request to be his treatment monitor in order for him to receive treatment with ARVs as well as for his co-infection with tuberculosis. When Kaakyire had first fallen sick, he was so ill that all his family and friends thought that he was going to die. His wife, who did not know that he was infected with HIV, left him since she could not “continue living with someone who was going to eventually die.” In view of the fact that Kaakyire could not care for them, his two children had also been sent out to relatives to be cared for, and therefore the family was scattered. His sister had decided to shelter and provide for him, at least until the worst happened. The decision to bring Kaakyire to her house reunited his relationship with her son Nsiah. Though they were not living together prior to his infection, Kaakyire had supported the schooling of his nephew and supplemented the provisions by his sister. They were thus very close, though living apart.

Nsiah was the only one who was aware of Kaakyire’s HIV positive status (see full case in Chapter 4 under ‘Selling willingly’). Nsiah had explained earlier that he agreed to the request because he “felt privileged that [his] uncle could confide such serious information” to him:
I understand why he [Kaakyire] trusts me among all his relatives and friends because we do everything together at home … We eat together from the same plate, at times sleep on the same bed, and we bathe together … You see, we are the only males left in the family [all the males had died, most mysteriously] so we are very close and therefore talk about everything. But, some of these things when someone is able to tell you, you know the person has so much faith in you.

When we met on the appointed day, Nsiah was visibly angry and disgusted. He narrated how Kaakyire had many ladies around him. He explained that when Kaakyire had originally confronted him with his predicament, he felt that he was the only person in the world who could assist his uncle and therefore did not waste time in accepting the request. However, he felt disappointed about what was happening now. He explained:

I respected him and knew that he would respect himself by taking good care of himself. However, just after about nine months on the medicines when everything seems normal in his life, look, he has started misbehaving. Every time, I see different women coming to him and the way they behave in the house, I suspect that there is something going on. There is one lady who has been sleeping overnight in his room and I presume they may be sleeping together [having sex]. I am very angry about the whole situation. Why does my uncle want to be so wicked … ? To intentionally spread this deadly disease?

In another case, Sis Ellen had called me “to meet her urgently for an important discussion.” When we met, she mentioned that she was in a dilemma. She told me about how, before finding out about her seropositive status, she had led a very independent lifestyle and could choose with whom she had (sexual) relationships. She mentioned, however, that after finding out about her status she “did not have a sexual life” anymore, and fought hard to discourage all the men who came to her.

When I found out about it [the infection], it made me sick. I grew so lean because I felt bad that this had happened. But I decided to live. So I went for the medicines. When I came back fit and healthy, I decided to devote all my time and efforts to the work. Now, because the men know that I’m not going to die, they don’t stop asking me to marry them. I tell them that my mind is not on relationships but on my business, just to put them off.

But this was until Mr. Sam came into the picture, and that was Sis Ellen’s problem warranting the call for the meeting. Mr. Sam, according to her, had proposed to marry her even before she found out about the infection, “and he is still waiting for an answer.”

He would not leave even when I became unattractive (myee tantanntan). He told me that I was sick because there was no man in my life. All this time, I put him off like I did to the rest, but he would not go. This time, he is serious. He has brought drinks to my family asking my hand in marriage. You know what, I love him too. I wish I could marry him. I cannot live like this forever. I don’t know what to do.
That same night, while lying on my bed reflecting on the day’s trip to Sis Ellen’s house, Maame Amponsah ‘flushed’ me. I called her, and as if to add insult to injury, she lamented about how her husband Daniel was “misbehaving – he had taken to some bad habits,” and when she complained, he asked her whether “he should not sleep because of death?” I return to this issue involving Maame Amponsah and Daniel later, but suffice it to note here that all these encounters – with Nsiah, Sis Ellen, Maame Amponsah, and Daniel – highlight some of the complexities in the lives of people taking antiretroviral medications, which is the focus of this chapter.

After between one and six months of being on ARVs, HIV positive people experience drastic changes in their health. A few experience deteriorating health, some of whom eventually die. Most, however, regain their lost weight, their appetite for food, and return to their normal routines prior to the infection. Some are even able to win back friends and loved ones who had rejected them because they suspected them of being HIV positive. They are able to win back their respect in society and its associated feelings of emotional and psychological satisfaction, as discussed in previous chapters. They feel human again since everything seems normal with them, thanks chiefly to the medicines. These improvements notwithstanding, being on antiretroviral medication brings about another phase of the complexities – physical, emotional, and social – associated with living with HIV/AIDS. First, these HIV positive people must battle with their bodies adjusting to the introduction of the medicines, and such difficulties may include side effects, treatment failure, and drug resistance. Secondly, some grapple with the numerous dos and don’ts associated with being on the medicines, for instance regarding their sexual lives, as seen in the cases above. Finally, people on ART can become involved in a series of contentions with members of their households and communities – with their associated accusations and counter-accusations – as shown in Nsiah’s case.

This chapter discusses the HIV positive persons’ intimate experiences while on antiretroviral medicines. Specifically, it explores their experiences of normality (responding well to treatment) and abnormality (being unable to do everything normal people do). One area that the chapter highlights is that of the sexual relationships and reproductive ambitions of people on the medicines, and their relationship with death. These concepts of feeling normal and yet abnormal, of sleeping and dying, are discussed using the local saying: Should we not sleep because we will die (Se yebewuo nti yenna)? The reactions of those in their environment that make HIV positive people feel normal, abnormal, or both are also examined in this chapter.

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1 See footnote 3 in Chapter 5.
Sleeping and dying

“Se yebewuo nti yenna?” is a rhetorical question meaning that there is no point in worrying about the inevitable. The ‘question’ is usually asked when the speaker wants to defy norms or logical expectations in pursuit of individual gain or pleasure. For instance, if student A wants to party with friends when examinations are due instead of studying, he may use this question as an excuse to continue partying. In another instance, if a patient who has been prohibited from eating meat has found herself at a party with friends where everyone is eating meat, she may also question whether because of death she should not sleep, and will proceed to eat the meat.

In other cases, the one asking the question (se yebewuo nti yenna?) may want to approve of or recommend a particular action to another that defies norms or logical expectations. For instance, other students who may not be writing the said examination may use this statement to encourage student A to act against what is logically required of him. In the patient’s case too, her friends may also use the saying to tempt her to eat the meat.

Se yebewuo nti yenna? may therefore be quoted under different circumstances. In the context of this chapter, to ‘sleep’ is used to refer to the ‘don’ts’ or prohibitions given to HIV positive people on ART. It is nonetheless used chiefly to refer to enna2 (sexual intercourse). Death, on the other hand, is used to refer to the process of dying as a result of the infection and/or non-adherence to the treatment principles, including “doing the don’ts.” Death, as it is used here, is a process and not necessarily a one-time event, and may include both physical and social death.

This view is epitomized in Ayettey (2009: 14):

Life and death indeed co-exist … Daily, and indeed every second, parts of us go through the process of death, ahead of the final event of death. Parts of us become ‘terminally ill’ and others ‘die.’ We lose our hair, teeth, and epithelial cells in a programmed cell death. This process continues throughout life with the rate of dying increasing and rate of living decreasing. We continually face decay and degeneration, obeying the second law of thermodynamics.

The case material suggests that some of the people on the antiretroviral medicines suffered severely from their side effects and felt that they were therefore “dying but not dying,” as formulated by Abrante. For some of the others who respond fairly well to ART, they theorized that death (the final stage) would come when it should, so it should not prevent them from sleeping (i.e. enjoying themselves). This chapter discusses in detail these particular ramifications of being on antiretroviral medications.

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2 Da in Akan is a verb which means to lie down or sleep. Enna (the noun form), just as it is used in English (‘to sleep with’) can also mean sexual intercourse.
Dying but not dying

A few people in this study who took ARV treatment did not respond favourably to the medicines. For some people, these reactions to the ARVs lead to death. Others exhibited various signs of side effects and viral resistance, including symptoms ranging from dizziness, persistent headaches, abdominal pains, insomnia, anaemia, and diarrhoea, to hallucinations, nightmares, migraines, sexual dysfunction, and changes in taste perception. In a case in point, I was informed by a respondent that my “good friend Agyei is going mad since the past week. He has been taken to a prayer camp and been admitted.” I had met Agyei the week before and he had expressed his happiness about having finally been put on ARVs after about six months of undergoing therapy. He explained that he was “looking forward to ending the petty aches and pains, and sleepless nights” he suffered due to his ailing health. I went to his house a week later because we had made an appointment to discuss his experiences with the medicines. When I arrived I received the information about his having been taken to the prayer camp. When I enquired further, his mother (who knew about his appointments at the hospital but not about his infection) explained that:

It all began when he started talking to himself. You would find him talking but when you go to see whom he is talking to, you realize that he is alone. I am worried because he seems to be talking to strange people. He picks petty quarrels and wants to fight everyone. He’s grown so aggressive within this short period. At night he gets bad dreams. He shouts a lot … and sweats throughout. He has gone wild and no one has managed to tame him. So he was chained and sent to the prophet.

Another time, during a visit to St. Patrick’s Hospital, I encountered another person on ARVs behaving in a similar way. He was wild, agitated, sweating profusely, talking dirty, and looking visibly unkempt. He had to be held in order to sit still and arrangements were made for him to see the doctor before his appointment was due because he was causing pandemonium at the centre. Josephine, one of the nurses at the hospital, matter-of-factly stated that suffering from hallucinations was “a normal reaction to the change in the [body] system due to the medicines. It will stop after about a week. If it doesn’t we may have to change the drug combinations.”

Unfortunately for some, intake of ARVs did not correspond with any improvements in health. Some recounted that on the contrary it rather hastened their dying process. Asantewaa noted how she found herself not getting healthy, and

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3 Agyei’s mother later told me in confidence that she feared that her son was dying, because it is believed that some people die before their physical death. During this liminal stage – of being neither fully alive nor fully dead – the person concerned is believed to have the ability to talk to “residents of the other world,” exhibited in the overt action of talking to oneself. This action, of talking to the spirits, immediately precedes death proper. This was therefore the concern and worry of the woman, that her son was almost dead.
yet not dying: “They [the health workers] say I will get better. I was hoping so but now I want to die. I don’t like the state I find myself. If I will die, let me die. And if I will live, let me live. Now, I am dying but not dying.” Asantewaa’s condition of health was poor when she started taking the medicines, but later she developed some “serious stomach and abdominal aches.” She could not eat because she vomited everything that “falls into the stomach.” She continued to grow thin and emaciated. Her hopes when she started taking the medicines – to get back on her feet again and live like she used to – were quashed, and she now prayed for death. For Asantewaa, and others like her, the medicines were keeping her alive though her condition was not improving. “It’s like slowing down your dying,” she noted. Various persons were found to have resigned themselves to their fate because of the effects of the medicines.

The symptoms of the HIV infection and of the ARVs, many of which were glaring, resulted in suspicions among family, close associates, and community members about HIV being the possible cause of the person’s suffering. These HIV positive people therefore suffered a degree of social death (as described in Chapter 3), including loss of status and respect, while they waited for the end-stage of death, the physical death.

Between normalcy and abnormality

The majority of PLHIV who responded well to the medicines mentioned that they hovered between normalcy and abnormality, since through ART they had become “normal and yet were not quite normal.” Although in some ways their lives returned to normal, something had changed fundamentally due to the infection and the therapy, culminating in their inability to do everything that they used to do or wanted to do. Firstly, the prime reason they gave for this was the continuous physiological, psychological, and clinical discomfort, mainly brought about due to the effects of the medicines (as discussed above). They experienced feelings of uneasiness and reacted negatively to the medicines, especially during the very early periods. Within a week or up to eight weeks or longer the ill body gets used to the medicines, but not without associated feelings ranging from mood swings and headaches, to overt symptoms such as skin rashes, diarrhoea, and frequent nightmares, or in some cases death. Other serious sicknesses found in the field, such as asthenia, insomnia, and hallucinations, could be linked to the side effects of the medicines, though all could also be attributed to opportunistic infections as a result of the deficiencies of their immune systems.

Secondly, for the majority who were not displaying these overt symptoms of being HIV positive, this feeling of being “normal yet abnormal” came about because of some of the rules and regulations given to them as part of the therapy. They are normal because “the infection is not written all over [us] as it used to”
and they are “able to live without any [health] hindrances,” and yet abnormal because “[we] do not have the freedom to do all the [social] things [we] used to do.”

Thirdly, they also noted that societal antagonism against people suspected to be infected – looking down on them and in most cases shunning their company – also emphasized the fact that they were normal and yet abnormal. The following therefore discusses how HIV positive persons who were responding well to antiretroviral medicines experienced the treatment. It considers their experiences: with the side effects of the medicines; of being “normal but still fighting on;” of the rules and regulations, with special emphasis on ‘sleeping’; of normalcy as a sense of security; and finally of the negative responses from others to (i.e. the societal backlash against) asymptomatic HIV positive persons.

**Normal but still fighting on**

Even for those who responded very well to the medicines, it was not uncommon to see or hear them complain about one ailment or another. Muscle aches, skin rashes, and loss of appetite were most prominent in the complaints, though it was also observed amongst those who were relatively new to the antiretroviral regimen that they suffered from nausea, vomiting, and diarrhoea. A critical observation notes that all of these may be side effects of specific drugs or drug combinations, and rightly so some of the PLHIV were told that their ailments would subside over time. Those who had all manner of ailments felt disappointed since the medicines “lacked the ability to make them illness-free.” They reckoned, however, that their present condition was still better than prior to starting the medicines. Ruth explained:

> I am feeling much better than I was four months ago. I am not fully fit as you can see, but I thank God for how far He has brought me. My major problem now is that I cannot eat well. One, I don’t have appetite. And [two] when I force myself to eat, then I will vomit everything. When the food falls into my stomach then I will run diarrhoea till there is nothing more in my stomach. At times, I feel like I am shitting my intestines out. I have complained to them [at the hospital]. They keep giving me some medicines and telling me that it will be fine with time. In fact, it is much better, but I am still not as normal as I would want to (me ho nto me sedea mepe no).

The PLHIV did also express a level of hope for better health conditions. Musa, who had been taking the medicines for a little over a year and had had serious problems with skin rashes (shingles), also mentioned that “I hope things will get perfect very soon since I have come a long way up till this point and the journey left is but a little more. I never believed I can stand again on my feet so I will keep fighting on.”

For all the respondents followed extensively, the intake of the medicines was like a daily ritual. Even though they considered the daily intake of the medicines very arduous, most of them were motivated by the fact that they saw an im-
provement in their health situation, as Musa’s case above illustrates. They therefore made every effort to continue taking the medicines. Kaakyire also noted that taking the medicines had made him more conscious about time, and he had bought a watch for the first time to adhere to the strict regime.

Because of the medicines, I bought a watch with an alarm so that it reminds me when it is 7am and 7pm. That is when I take my medicines. Even when I have to leave home before that time in the morning, I put my medicines in my pocket and when the alarm rings, I buy ‘pure water’ and swallow it. Now, when it is time to take the medicine, my body feels it and when I look at the watch, I will realize that it is two or three minutes to time.

Due to the exact times at which they have to take their medicines, as seen in Kaakyire’s case above, the PLHIV claimed that their bodies had gotten used to taking the medicines, to the extent that some reported that when they did not take them on time they felt “uneasy” and “restless.” Achiaa narrated her experiences:

I have to eat and take my medicines on time. If I have not eaten by 8am, I have to take my medicines before I will feel okay. Otherwise, when you see me, you will think that I am a little girl who cannot control her hunger. I sweat a lot, and I can neither sit nor stand. I just have to eat or take my medicine to be okay.

The major fight that all the HIV positive persons mentioned – and some complained about – was the fact that they must take the medicines for the rest of their lives. “So, will I be sick for the rest of my life?” “Won’t there ever be a time that we will have to stop taking these medicines?” “Is that all the doctors can do for us?” were some of the nagging questions that the people on medicines kept asking. This problem was even more severe for the children taking the medicines. They cannot comprehend fully the situation they find themselves in, but nevertheless they will have to be on antiretroviral medications for the rest of their lives (as long as there is no cure). Linda, who had a five-year-old son who had been on the medicine for about a year, was always worried about him:

At times, he protests that he will not take the medicines again, and I wonder what he will do when he grows a little older. I feel sorry for him that he must take all these medicines, unlike the other children he plays with, but what can I do?

Normalcy: Sense of security?
Interestingly, some of the PLHIV expressed the thought that being on the medicines and getting back on their feet also secured them from infecting others. These feelings were based mainly on rationalizing the information they heard during the sessions at the ART centres. Abiba noted that she was told that:

HIV was more potent during the early stages of the infection and therefore an infected person has to be careful even when practicing safer sex. However, being on medicines reduce the viral load to a minimum depending on how positively one reacts to the medicines, and also the person’s nutritional intake. … if you want to get pregnant, then there is a particular level your viral load has to drop to, and as you continue taking your medicines, the probability of transmitting the infection [both to the partner and the baby] would be minimal. If all these are true, then I 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?

Egya also explained that:

After being on the medicines for some time, everything feels normal. You can do whatever you wish to do because you are again very healthy. It is at this point that you tend to doubt whether you were really infected in the first place. For me, I don’t stop taking my medicines. Because I don’t get sick anymore and I am able to do everything again, I feel it is very unlikely that I can transmit this thing. I may still have them [the virus] in me, but it is not that much and [not] powerful enough to be able to get into others.

The implication of these ideas, as expressed by the HIV positive people, is that after becoming well again due to ART they may not need to ‘sell their sickness’, since they no longer feel sick and may even doubt the continued presence of the virus in their system. Several scholars have shown the link between early use of ARVs and a decline in transmission rates. For instance, Granich et al. (2009) used a mathematical model to show how once receiving antiretroviral medicines, the infectiousness of HIV positive persons falls to one percent of their value before treatment. As a result of such information and ideas, HIV positive persons may knowingly engage in unsafe sexual practices, although not with the specific intention of spreading the virus, and such ideas may have implications for adherence to treatment and in terms of drug resistance.

During an informal discussion on the side effects of the medicines and associated ailments, some nurses in Offinso mentioned that most of the people taking ARVs were not adhering strictly to the rules. Clients at the facilities are advised about ‘healthy practices’ including 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 advice (such as regularly taking the medicines, and abstaining from alcohol intake and unprotected sex). Non-adherence to any or all of these prescriptions, according to the nurses, comes about when the PLHIV regain their health through ART after battling with various opportunistic infections. Nurse Rose explained:

This [state of feeling normal] makes them complacent. It makes them forget all the toils and distress they endured. Indeed, good living brings forgetfulness (Eye ampa, asetena pa ma awerefire). If you had seen them on their dying bed, you wouldn’t believe what you see now … that they don’t want to listen to common instructions.

Specifically, the nurses also mentioned that some of the PLHIV drink alcohol, take the medicines on an empty stomach, and most especially miss doses.

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4 This calculation was made on the basis of the relationship between plasma viral load and antiretroviral medicines, and estimated decreases in viral load for people receiving the medicines.
When you do these things, the medicines do not work well. They rather cripple you. The viruses behave in extremely different ways and the effects are what you see in the clients. When they come here we advise them, but they go home and do other things. It’s unfortunate but a lot of them are dying just because they don’t listen.

These behaviours, that may result from the false sense of security brought about by improved health as a result of the ARVs, were so widespread that Nurse Josephine once retorted that she was no longer interested in working with these clients, because “they end up bringing all our toils to Cos 90 [zero]. It just becomes a waste of time.” A visibly frustrated and angry Josephine explained:

In this work, you are encouraged when you see that, through your efforts and the grace of God, someone who came in almost dead is now back to his [or her] feet. You know how most of these people came in. You put in all efforts. You spend extra time and money. You try to let them feel like living again. You talk to them. You visit them at home. Some do not welcome you and chase you away. You do all these to let them live. And then, they choose to die. They don’t listen to you anymore. It’s very sad and unfortunate. The more it happens, the more you ask yourself whether this whole work is worth it.

In the homes of these HIV positive people, these problems mentioned by the nurses were very obvious. Especially among the men, when they became ‘normal’ again it was not uncommon to see that they resumed their drinking sessions with friends. It was found that they did so as a means to debunk earlier suspicions of their infection, to show that whatever people thought about them earlier when they were sick was not true, and that they were still “normal as they used to be.” Maame Amponsah, in the same conversation as cited in the introduction, narrated how her husband Daniel (who was also taking antiretroviral medicines) had changed all of a sudden and was now “misbehaving” and “taking to his old habits of drinking and chasing women.”

He gets so drunk that he at times forgets to take his medicines. When I confront him, he gets angry and at times violent, so I am scared to do that again. He is killing himself because he wants his friends to think that everything is well with him … but that is killing him.

Maame Amponsah further explained that she could not discuss the issue with anyone since neither family nor friends knew anything about Daniel’s (and also her) infection, and she did not want to talk to the medical personnel as Daniel might think that she had reported him. Armed with this information, I asked Daniel about his behaviour and its relationship to his compounding ill health, but he avoided all attempts to delve into these habits. Even at a later stage of the research when I often found him tipsy, he only confided to me that “I go out with friends and also drink a little.” He knew that “the alcohol may be contributing to my random ill health,” though he still maintained that he did “not miss taking his medicines.” Others were found to have missed their appointments at the ART centres due to drunkenness. Their concern was mainly to live without the societal or health constraints linked to HIV, just like other (HIV negative) persons.
Although, together with their families and friends, the PLHIV were extremely delighted about their improved health as a result of ARVs, they still wished that things would improve further. They desired to be like they used to be. They hoped for a time when they could enjoy life without any limitations and that their activities and behaviours would not be scrutinized by family, friends, and the general public. Being normal as a result of the ART, however, can be said to give some PLHIV a false sense of security that all is well, leading to non-adherence to the advice of the medical personnel. This eventually caused some of the people on medicines to die.

**Sleeping in spite of death**

Another area of concern for those who were responding fairly well to the therapy was their sex life. A significant percentage of the men were very concerned about their apparent loss of sexual drive after they had begun taking the antiretroviral medicines. They expressed worry about how they had lost all feelings for engaging in sex, particularly during the early periods of being on the medicines. Once, a worried HIV positive man asked whether it was a deliberate attempt by the whites (i.e. the producers of the medicines) to stop them from having sex. Observations, information from gossip, and other complaints received from close associates of HIV positive people, however, showed that those who had been on the medicines for some time (at least six months) and had regained their health did engage in sex like they used to.

In contrast to the earlier periods, where those on medicines felt that they had lost their sex drive, this return of their sex drive and the desire to have children was linked not only to their intention to continue their lives as they used to, but probably to test their newly achieved ‘normality’ when the opportunity arose. A number of those on antiretroviral medicines were found to have made their partners pregnant, without any serious pressure from those in their environment to do so. For instance, Anokyewaa (a mother of five and on antiretroviral medicines) became pregnant to Opoku’s eighth child after “he was able to have sex again even though [they] had agreed they would not have children again.” I did not obtain Opoku’s opinion on this matter since he could not honour the several appointments we had made. However, his wife Anokyewaa indicated that:

> Ever since he was able to do it [have sex] again, he wouldn’t let go. He demands it more than before. Even when I tell him I am not safe, he does it. He thought I was using it as an excuse because we had decided not to have any more children. And he is not worried that I am pregnant. In fact, he is rather happy (Sé me mmoa, meka se n’anigye mom).

As discussed in the following sections, the reasons given for ‘doing the don’ts’ were mainly the desire to fit (back) into society, to feel human again, to achieve personal aspirations for life, and to a lesser extent to test their normality. Signifi-
cantly, the case material also suggests that HIV positive persons taking ARVs do these things, including having (unsafe) sex, as a coping mechanism to withstand societal pressure.

It is often reiterated to clients during pre- and post-test counselling sessions how they should practice safe sex, mainly by way of abstinence and condom use, in order not to infect others and/or re-infect themselves. To the clients, however, it was a huge challenge to abstain when people in society expect otherwise. Similarly, condom use is also difficult because of its association with promiscuity and spoilt morals (Bosompra 2001, Anarfi 2003). Kaakyire, for instance, had to live at variance with his sister’s wishes, who felt that he was “recuperating and so must re-live [his] life to the fullest, including getting married and possibly having more children.” Since his sister was not aware of what was actually wrong with Kaakyire – because he had not disclosed his HIV status to her – she and some other family members mounted incredible pressure on him to get a woman to live with.

She started inviting some of her friends to our house and [virtually] forcing them to come to my room and get to know me … you know what I mean? Initially, I would just sack them by telling them I was busy or sleeping or something else, but they wouldn’t stop coming. Later they started coming home when I was alone but I tried to put them off. Can you believe they misinterpreted my actions to the extent that one day my sister told me they were asking whether the sickness I had and the medicines I was taking had made me lose my manhood?

To Kaakyire – and this epitomizes the possible reactions of many men – challenging his manhood “was the worst thing any woman, whether your friend or relation, could ever think of for a man.” He could not stand it. To prove his manhood he started living with one of the ladies, “with the hope of eventually marrying her.” Kaakyire’s case is not an isolated one, and many other cases corroborate his story; it shows how people have to navigate between social norms and expectations and their own conditions. Oftentimes, they do not have much success in having their own way and follow societal expectations instead, even though these actions may consequently affect both the individual and society as a whole.

At the time of fieldwork, Kaakyire had a farm and was growing assorted vegetables, including carrots, spring onions, lettuce, and cauliflower. As a result, he was thought to be capable of catering for the needs of a partner and children. It was therefore not surprising that a lot of women, especially the unmarried ones, wanted him after his recovery from his serious ailment and “delivery from the hands of death” (they had all seen him go to the hospital having been paralysed by the HIV infection). For young men like Kaakyire, living with a woman was meaningful to them. It meant that they were responsible, which came with a higher status and respect in society. For the young women living with HIV,
getting a stable partner showed even more that they were decent and good for marriage, since being single was usually associated with prostitution.

From the communities studied, it was found that societal norms and expectations had a way of putting pressure on individuals – who were good looking, or who had stable jobs and were therefore independent – to take on a partner. From Kaakyire’s case, for instance, three ways come to the fore: family and friends constantly echoed the idea of him getting married; he received recommendations of women who were deemed good for marriage; and the women themselves took the initiative to let him know that they were available.

The fact that the majority of the PLHIV in this study were in the prime of their lives, combined with the expectations from society, could explain why these currently healthy persons chose to remain normal by hanging out with friends, having (sexual) partners, and having (more) children. According to Ghanaian tradition, marriage is a sacred duty and every adult is expected to marry in order to extend the lineage. Anarfi (2006: 170) notes that in Ashanti communities, marriage is “accorded much respect, mainly because it confers respect upon the people who enter into it.” Gyekeye (1996: 76), in his essay on African (in fact Ghanaian) cultural values, and writing on the subject of marriage, also observed that:

… an unmarried woman [in African societies] is almost an anomaly. Marriage is a requirement of the society, an obligation every man and woman must fulfil, a drama of life in which every man and woman must participate. Traditionally in many African societies, a young man who has a gainful employment of any kind and earns some income is expected, in fact, to marry. Any undue delay on the part of the young man to marry will cause his parents or the elders in the lineage to worry and even interfere in his private life in order to advise and encourage him to marry.

Gyekeye further notes that among the Akan, if a man has reached the age at which he is expected to marry but does not do so, or is not seen as making attempts to do so, he will be regarded as *ckwasea*⁵ (a fool). One of my informants, Eugene (not HIV positive), even said that among people in the communities in the Ashanti Region, such a person would be regarded as highly irresponsible (*ckwaseampanin* – ‘elder of fools’). This expectation puts pressure on the youth to get married when they are of age, although it is observed that increasingly many women and men do not marry until later and there is evidence of an increase in single mothers because of the absence of men, since the latter may not be financially ready to settle with the women.

These pressures to marry notwithstanding, it was evident from the lives of the PLHIV in the study that although they wanted to abide by the counsel of the

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⁵ According to Gyekeye, the term *ckwasea* has a moral rather than an intellectual connotation. It means one who is irresponsible, worthless, good-for-nothing, and contemptible, rather than one who is simply unwise.
medical personnel (to abstain from unsafe sex, for instance), it was difficult for their families to understand – why would a ‘normal’ person decide not to get married and have babies? These conflicts between norms and realities are rooted in traditions. Societal expectations force some HIV positive men and women to navigate between these traditions and the counsel from the medical staff, which oftentimes are in opposition. For example, as described above, people in society expect every young person to get married and have children, and if they do not they will be classified as irresponsible or a fool, while the medical staff’s advice is that they should abstain from sexual relations or at least use a condom (thus seriously curtailing the possibilities for marriage and children). Making the decision to not get married and have children is often considered highly unacceptable by a person’s family and members of the community. Like Kaakyire, the majority of PLHIV had to consider what was ‘safe’ under the circumstances. Some went ahead and followed the medical counsel, while many engaged in sexual activities and made babies.

Especially for the youthful, unmarried or recently married, and industrious HIV positive persons, being unable to disclose their sickness brought untold pressure from family and friends for them to live normal lives by having partners and/or children. They were therefore caught in a dilemma: whether to live normally while being abnormal, or to be normal through and through. Oftentimes, they were found to have succumbed to external pressures and to have opted for the latter. On one occasion, Ahofo (as mentioned in the introduction of this dissertation) confessed to me while conversing on the phone that she would not mind having a baby, even if it meant that the baby would also be infected. She explained that “If I give birth today and the baby dies tomorrow, I don’t mind. I’d be very happy. After all, everyone will know that I also gave birth but s/he died (Anye kora no, obiara behunu se menso mewoo ba ma no wui).”

The HIV positive people were under a great deal of pressure to live up to societal expectations, and often this pressure posed a great challenge to them. During my visits to PLHIV, and at PLHIV association meetings, many women were found to be pregnant or carrying babies. Most had not disclosed their positive status to their husbands. Some did not even know about their pregnancy until it was quite late in its term. Dapaah (2012), who was my colleague researcher in the hospital, reported for instance that Patricia only realized that she was pregnant during the early period of her last trimester. She had frequently complained about problems in her abdomen and a distended stomach, but brushed away all suggestions by the medical staff to have a pregnancy test. One of the side effects reported with HAART\(^6\) combinations, especially the protease

\[^{6}\] When several antiretroviral medicines, typically three or four, are taken in combination, the approach is known as Highly Active Antiretroviral Therapy, or HAART. HAART decreases the amount of the
inhibitors, is the uneven absorption of body fat and other nutrients, known as lipodystrophy. The symptoms may include high levels of cholesterol and other fats known as triglycerides, which may make the HIV positive person feel very tired and generally ill. Other symptoms are a swollen belly, enlarged breasts, loss of weight in the face and loss of muscle in the arms and legs (so that the person looks very thin). Most of the HIV positive people in Offinso had distended tummies as a consequence of the medicines, and Patricia felt that hers was also the same. She was only proven wrong after a pregnancy test was finally conducted.

The affairs of the female PLHIV were more glaring because of the visibility of carrying a pregnancy, though the men were also found to be engaging in (unprotected) sexual relationships. From listening to gossip among the PLHIV, some of the men taking ARVs were said to have impregnated their spouses. During the latter stages of fieldwork, for instance, Ahmed’s wife was found to be pregnant. I later came to understand that because Ahmed had not disclosed his status to his wife, he was hoping that when she went for antenatal care “she would be found out” (through the PMTCT programme). He explained that “since there are medicines to manage the situation, when they catch her too [diagnose her as HIV positive], she will also be put on the medicines, and they [mother and baby] will both be okay.” In Ahmed’s case, he was not found to be under any (societal) pressure to have more children since he and his wife already had four (three sons and a daughter). From the above quote, however, it may be interpreted that the action of getting his wife pregnant may have been his way of disclosing to her. A significant number of the HIV positive persons were also found to be engaging in such ‘normal’ behaviours, but with little social pressure.

This desire to be normal in society – just like everyone else – ensured that most HIV positive people chose not to reveal their sickness to others (see Chapter 4). Oftentimes, I came to understand that the partners of the PLHIV in the study did not know about the latter’s HIV status. It was therefore unsurprising that many of the HIV positive people who were relatively healthy became pregnant or made their partners pregnant. Most of the clients were bewildered as to why they could be ‘normal’ again in most areas of life, but when it came to their sexual relations they “would have to always think twice” and “use condoms when having sex with even your spouse,” as Mr. Nkansah put it. As seen in this section too, some of these HIV positive persons succumbed to societal expectations and resorted to ‘sleeping’ in order to be found ‘normal’ again by society at large. The case material also suggests that some of them were ‘sleeping’ in order

active virus and rebuilds the immune system. If an HIV infection becomes resistant to standard HAART, there are limited options. One option is to take larger combinations of antiretroviral drugs, an approach known as mega-HAART.
to experience the ‘normal’ human feelings and emotions of being a man or a woman – being in relationships, having (unprotected) sexual relationships, getting (someone) pregnant, and having babies (as seen in the case of Aho below, who wanted to have a child even if the child would die the next day). Sis Ellen (whose case is outlined in the introduction) also displayed these feelings when she lamented that “if all is well with me, at least overtly, why can’t I get a partner, and have my own family?” Remarkably, the material further suggests that some of the PLHIV used their current status as ‘normal’ to resist society’s pressure. The following sections are dedicated to the HIV positive persons’ encounters with society at large.

The cost of being ‘normal’: A struggle within society

A significant number of the HIV positive persons in this study claimed that they refused sexual interactions, marriage, and other promising opportunities because they did not want to infect others. Although some succeeded, a number did not. Maame Mensah, for instance, had just lost her pregnancy after some complications when she got to know that she was HIV positive. During my first conversation with her some weeks after she had received the news, she blamed her predicament on a curse, since a friend during a feud had told her “You will see (wobehunu)!” About six months later, however, she reckoned that her husband might have infected her. “He is a public figure with much power and authority, and many women want to have him,” she said. Although she trusts him very much she claimed that sometimes she “just knows that he is sleeping around.”

Maame Mensah had not told her husband about her HIV positive status because she claimed that if he found out “he will kill me, and then kill himself too.” She had therefore rejected all attempts by the professionals at the ART centre to get him to come in and also take an HIV test. Initially, she told her husband that she could not have sex because of the effects of her health condition – she was visibly ill, looked extremely pale and wasted, and was bed ridden. Her husband had therefore allowed her time to recover without any sexual intercourse. After taking the antiretroviral medicines for a while, Maama Mensah had become healthy again but did not want to infect him or re-infect herself, and thus she did not agree to have sex. But her husband could not wait any longer: “He raped me over and over.” Maame Mensah had on two different occasions called me after midnight to sobbingly tell me what had happened.

Several accusations were heard from the HIV positive people and from some members of the community about people they suspected or knew to have the infection, who were having sex with unsuspecting others. As noted in earlier chapters of this dissertation, the majority of the HIV positive persons in the study who were accessing therapy had not informed their sexual partners about their
infection, yet continued to have sexual intercourse with them. In some cases, however, the partners were found to be unwillingly stuck in the relationship, even though they knew their spouses to be HIV positive. They were thus very conscious of the importance of practicing safe sex. An example of this is the husband of Memunatu, who had wanted to divorce her after she told him about her infection. But because they owned a large cocoa plantation together on her family’s land, the divorce never took place. Memunatu’s husband felt that he would lose the property and go broke if he separated from her, so he reluctantly stuck to the marriage. Although Memunatu knew that he had grown indifferent about their relationship and had other sex partners, she was content with the current situation as he was satisfying her sexually and keeping her status secret.

There were other incidences of members of society who may not necessarily have gone for the test, but about whom people had ample evidence to suspect that they were infected (see ‘Other ways of getting to know’ in Chapter 3). Some clients at the ART facilities were also found to be careless and to knowingly have unprotected sex, which gave support for the commonly held perception that HIV positive people “do not want to die alone” and thus indiscriminately infect others. The following discussion is about those who were perceived to be consciously spreading the infection.

Mama Sɔfɔ had lost her husband from a previous marriage and as a result was finding it difficult to cope with the demands of raising five children single-handedly. Though she received infrequent support from both her own and her late husband’s family, it was still not enough to make ends meet. She explained:

That was when Bonku came into the picture. Because he was an old man I didn’t think he was basabasa [one who messes about] so we didn’t do enough checks on him. He comes from my mother’s village so when my mother okayed it, it was just a matter of time and he would marry me. In fact, I thought he was too old to hurt a fly.

After undergoing a fibroid operation in the hospital in Offinso, however, Mama Sɔfɔ realized that her husband⁷, Bonku, had knowingly infected her with HIV. It was also after she was diagnosed as HIV positive that she realized that Bonku had already infected his first wife, who was sick and on the verge of dying.

It was then I realized that he needed a sexual companion at the time he met me because she [his wife] was dying. I later understood that he had refused all attempts by the hospital [that was treating his wife] to go for a test, and because he is a slim old man, nobody suspected that he would be positive.

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⁷ Although Mama Sɔfɔ referred to Bonku as her ‘husband’, they were not formally married. However, because he was financially meeting her needs and those of her children, she was obliged to satisfy him sexually. This system is known asmpenatwe, a publicly known relationship that is not formally ratified.
Mama Sɔfɔ explained that Bonku was not shocked when she told him that she had been diagnosed HIV positive.

It was like he expected it. He just sat there for some time; about thirty minutes. He didn’t say anything. Then, he got up and went away. He didn’t come back to me again. I sent for him after about a week. I asked them to tell him I was very sick and I needed money to go back to the hospital. He came the following day with some money. And then he left, and didn’t come back again.

Since not every sexual encounter leads to an HIV infection, many people may lead a risky sexual lifestyle and still not be infected with the virus. However, if someone has had sex with a person who is later found to be HIV positive, they may no longer care to protect themselves, such as in Bonku’s case with his first wife. They may become careless, not wanting to protect themselves, and will just continue to live a normal life. Even though at this point they may unknowingly not be HIV positive, there is the possibility that they may acquire the infection if they continue to engage in risky sexual behaviours in the belief that they could already be infected. The study found that some people engaged in risky sexual behaviours in the belief that they may already be infected. Many others also failed to inform their sexual partners about their HIV positive status. These behaviours pose serious questions about both individual and public health issues.

In addition, some of the HIV positive people were noted as being intent on locating others with whom they planned to have unprotected sex and thus transmit the infection to. From observations and listening to gossip, some of these HIV positive people seemed to have knowingly engaged in unprotected sex with others. During a PLHIV association meeting, for instance, an interaction between two members revealed this:

Member 1: So how did it go?
Member 2: Everything went well only that I feel a little bad about it now. Just after I got there, he got the news and he came. He was all over me; he just wouldn’t give me any breathing space. So I gave it to him. I thought he would be surprised how I gave in willingly to him this time round, but I told you he is a fool … he thought he was enjoying himself.

Member 1: It serves him right; he thought he has got it cheap … little did he know that he was scooping it [the infection] (Otwea, na ɔdwen se wanya no fo, na ɔnnim se ɔretete).

Later, Member 1 explained that Member 2 had been living in her hometown until about two years ago when she moved to Kumasi. This was because the man at the centre of the conversation above had been harassing her sexually. After persistent refusal from Member 2, he arranged for a meeting and forcibly raped her. After the incident, the two families had agreed for him to marry her, but she loved another man who had promised to marry her prior to the incident. Her true love (the second man) refused to marry her, however, as a result of her humiliation from the rape. She felt disgraced and therefore left for the big city. She went home to the village about six months before the incident described in the conver-
sation above to find the man still pestering her, which made her leave again unannounced. She knew her HIV positive status and had been trying to avoid sex, as she had been counselled. It was when she came back to the city, and upon reminiscing, that she decided that she would teach this man a lesson the next time he pestered her.

According to Member 1, when Member 2 went home for her late uncle’s (mother’s brother) funeral, she expected the man to hassle her again and so she set out to “give it to him so that he gets what he deserves [the virus] since she blamed him for making her move out of her village and exposing her to conditions that culminated in her infection.” The conversation I eavesdropped on during the meeting was therefore a report of the proceedings at the funeral. She went for the funeral and, as she expected, the man came to her and she gave in.

Informally, some of the clients also narrated how they suspected one person or another to have been the cause of their infection. Some vowed to make sure to pay them back by infecting other people close to them, mainly friends. Some of the HIV positive women in this study, however, noted that when men find them attractive and still unmarried, they “pester” them. When they cannot withstand the harassment anymore, they give in. Some of those who knew that they were HIV positive made all attempts to avoid sexual relationships with others in order not to infect them; giving in only occurred when they felt that they had no choice. Opokuwaa, for instance, said that she avoided all sexual relations with men until she could not handle her landlord any longer, as he threatened to evict her if she did not give in to his advances. She narrated:

When my rent advance ended, he [the landlord] said that he was going to double the monthly payments. He also said that he was no more taking a year’s advance but for three years. I knew he was up to something, because he had been worrying me a lot. I had resisted up till this point. But I didn’t have the money to move away from the house. I couldn’t also pay the increment. So I gave in. It was difficult in the beginning. Now, I don’t only live in the room for free, he even gives me money occasionally.

Further conversations also showed that Opokuwaa had given in to other people who had pressured to have sex with her. In one case, she said that she had lied to the man, telling him that she “was pregnant and collected GHS 70 to ‘wash it out [abort]’. I tricked him (Meyee no “azaa”).”

This behaviour of some of the HIV positive people is not as contradictory as it might at first appear. The cases of Bonku, Opokuwaa, Kaakyire, Daniel, and Sis Ellen (who eventually married Mr. Sam without telling him about her HIV status) show that there may be more to it than malicious slander that some HIV positive people continue to have unprotected sex without their partner’s knowledge. Indeed, these examples explicate the impossible situations and experiences of ambiguity that many people encounter after finding out about their HIV infection and taking ARVs, exemplified by the complaint of being
normal and yet not normal – looking normal enough to be pressured to have relationships and even marry, for instance, yet only doing so against their will. It needs to be stressed that in the majority of cases, while these HIV positive persons behaved in ways that may seem deleterious to societal cohesion, they only did so as a means of feeling safe in a highly unsafe environment, due to the repercussions of being found to be HIV positive.

These safety mechanisms notwithstanding, some PLHIV nevertheless experience antagonism from some people in their communities. HIV/AIDS causes tensions in society because of the perception of ‘intentional’ transmission on the part of infected people. This perception is aired via rumours in the media, which perpetuate the antagonism against PLHIV. During the course of fieldwork, for instance, a news report by the Ghana News Agency (GNA) from the Volta Regional capital Ho referred to some PLHIV deliberately spreading the disease. The report alleged that they were taking advantage of their good looks to “wilfully engage in unprotected sex in the Ho Municipality.” According to the report, the target for the HIV positive males were Senior High School girls in town, while their “fashionable looking” female counterparts went in for middle-aged men with whom they had babies. This allegation supported a dominant perception held among the people in the communities in which I conducted fieldwork that HIV positive people “do not want to die alone” and thus deliberately infect others. Several people in the communities were suspected of having HIV, and their sexual behaviours were questioned and criticized in the communities. Women who were seen to be promiscuous were accused of having contracted HIV and of deliberately wanting to spread it by snatching people’s husbands. Men too were subjected to these accusations (see for instance Odotei 2006). Like Nsiah in the introduction, the majority of people who had reasons to suspect that a person was willfully spreading the infection became infuriated.

Informal conversations with people in the communities – families and friends of HIV positive people, focus group discussion members, and other informants – showed that many of them (several of whom had not personally undergone counselling and testing) felt that HIV positive people subscribed to this fatalistic attitude and deliberately went about infecting others. Awo, for instance, mentioned that when these people find out that they are infected, no matter whether they are religious or not, “evil enters into their head (adwenbɔne ba won tiri mu). They then think that because someone had infected them they also have to do the same.” It is important to note here that this and all other negative perceptions of PLHIV are based on gossip and assumptions.

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These community members thought that current legislation was not enough to protect the general public. With this frustration looming, they often decide to fight back, as Awo shows:

You just have to protect yourself by keeping them away from you. When you do that, they say you are withdrawing from [stigmatizing] them. But how can you keep them close to you when it is obvious that they will give it [the infection] to you, and there is nothing you can do to cause them to be held responsible.

For those respondents who were HIV positive, they felt that legislation may not be enough to deter people from having unprotected sex indiscriminately, since any reporting of such activities by the victim would lead to loss of their privacy, disclosure of their own HIV positive status, and consequent stigmatization. Mama Sɔfɔ, for instance, lamented:

Later, after about a month, after things had gotten better, Bonku [whom she suspects to have infected her] came back again wanting to sleep with me. I refused. He doesn’t come back very often these days. Now, when I ask him for money, he tells me how can he give me money and not sleep with me?

I have asked him to go for a test. He said even if the doctors come to his house he wouldn’t do any test. I told him I would report him to the police, but he doesn’t care. I hear he is now going after another small girl in the next village. This man is wicked. He knows I cannot talk about this, since if I come out and say it, everyone will know I also have AIDS. He is really wicked.

Speaking about those PLHIV perceived to be deliberately infecting others, the members of the focus group discussion in Offinso were also agitated at the fact that “the government is wasting so much money and resources to keep these evil people alive.” Although Awo had earlier lost a son to HIV and had firsthand experience of caring for an HIV positive person, she shared this opinion since she felt that “if all those who are found to be positive are quarantined … it will go a long way to protect the rest of society from being intentionally infected.”

In a study by Adjei, Owusu & Ablordey (1993), which was based in the Ashanti and Northern Regions of Ghana, a large number of the focus groups participants held a similar view, that persons diagnosed as HIV positive should be surreptitiously injected with poison by the doctors so that they would not be able to spread the disease. For my carpenter informant, he found nothing good about the ARV medicines, since previously people who had AIDS were easily found out, making people more careful when relating to them. “Now they look normal like all other human beings and because of that they lure unsuspecting members in the communities and infect them.” Awo added:

Why are you [pointing at me while referring to the hospital staff] keeping these [HIV positive] people alive for them to come and worry us? Look at all these young girls around. They are walking here as if all is well. They are all carriers. Yet they won’t stop chasing people’s husbands. The medicines you give them are contributing to the spread of this virus. If people don’t die anymore and yet they keep spreading it because they are chasing people’s hus-
bands, won’t the disease spread? Who will go in for someone who has a pitiable sight and is in excruciating pains? But you give them medicines, and no one gets to know that they are sick, and then they infect others. So whom are you helping? Which is better – to keep more people alive living with the infection, or let the few who have it die?

To Awo, and the other worried members of the community, quarantine would be one way of preventing HIV positive people from sleeping with unsuspecting members of the community and infecting them. Quarantine as a way of reducing the incidence of HIV has, however, been contested. The reactions and seemingly antagonistic stance of the people in the communities, which may be classified as stigmatization, must be seen in the context of a society struggling to cope with the perception of the deliberate infection of others by HIV positive persons.

Others were accused of actually using the tag of being HIV positive to dupe unsuspecting members of society. One day as I travelled from Kumasi to Accra, for instance, I encountered a self-proclaimed HIV positive person who was soliciting money to buy his medication. The man mentioned that he had been diagnosed HIV positive six months prior to our encounter and had lost all his life chances – his job and his family, while his landlord had evicted him. He mentioned that he needed GHS 7 to buy some food and medicines. He sounded convincing when using the medical terms – CD4 count, antiretroviral medicines, and drug resistance – though no one on the bus offered to help. He left a few seconds after his unsuccessful appeal, at which point a few people commented:

Passenger 1: Why would someone want to dupe others by pretending to be HIV positive?

Passenger 2: Say it again my brother! Couldn’t he have found another disease, other than this scourge? Who in the right sense would, if indeed he is HIV positive, go about broadcasting it?

Passenger 3: And he is not ashamed …

Passenger 1: That is what he is been doing. Today is the third time I am meeting him with this tale. The storyline is the same. He should pray that he gets unsuspecting people to part with their monies, not people like us.

The Public Agenda newspaper also reported the case of Charles Gardiner, a trickster who “duped many people using false pretences as an HIV/AIDS victim,” including the editor of the paper. Charles Gardiner was reported as

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9 For instance, Mensa-Bonsu (1995) questions the use of quarantine for people living with HIV when there are other infected but healthy looking persons who are equally or perhaps even more dangerous to the uninfected population. How can all HIV positive persons be found out without compulsory testing of all citizens? With what frequency would such mass testing be done in order to isolate those who become infected after mass testing? Can any country afford the expense of such testing with the frequency that would make the policy effective? These and other such questions, none of which have obvious or easy answers, render the prospect of quarantine an exercise in futility.

10 In Ghana, it is not unusual for people to stand in buses as they load passengers or to ply the bus routes to sell goods (including books and medicines—traditional, herbal, Chinese, and biomedicine), solicit funds to treat a disability or ill health, or simply to preach from the Bible and pray with the passengers for a safe journey.
narrating stories about being “abandoned by his family” and being “sacked” as an engineer with Top Industries “after he contracted HIV/AIDS,” and therefore relied on the benevolence of strangers to assist him to buy his medicines from the Pantang Psychiatry Hospital. Such people exploit society’s negative attitude towards HIV positive people to try to make money.

Conclusion

The expectation for a normal life course is that a child is born, reaches adolescence, marries and brings forth children, grows old living with the grandchildren, and dies peacefully. Even for the very old, death in Ghanaian society is considered abnormal and unnatural when it occurs due to sickness or other external causes (Owusu 2009: 43). People therefore refuse to prepare for abnormal death (Oppong et al. 2009). A very sick (and terminally ill) person would prefer to think positively about life, and pursue all forms of healing and cure, rather than plan for an organized afterlife after their demise. The logic that a dying person would “put her/his house in order” before the fatal day does not apply to such people.

For an HIV positive person, whose death warrant is perceived as signed when s/he becomes infected, death – as inevitable as it is to all mankind – seems to loom especially close. However, the extent of the housekeeping that occurs before the final event varies when it comes to PLHIV. This is especially true since the arrival of antiretroviral medicines, which to a large extent are effective at postponing the HIV positive person’s funeral. For the PLHIV, therefore, they have another chance at life. However, several people expressed fear that the use of ARV medicines will decrease transmission concerns among HIV positive people (Greeff et al. 2008) and will increase risky behaviours (see for instance Holstad et al. 2006). It is assumed by these people that death will come when it will, but until then there is a life to live – “Should we not sleep because we will die?” Some of the HIV positive people were therefore “sleeping in spite of death.”

The primary reason given for wanting to “sleep in spite of death” was because the PLHIV found themselves in an awkward position between normalcy and abnormality. The continuous physiological, psychological, and clinical discomfort brought about as a result of the medicines, and especially the many dos and don’ts regarding food, alcohol, and particularly sex and having children, made them feel abnormal. Yet for many the medicines had delayed their death and restored their health, and in the eyes of the public they were cured and therefore normal (again). Plummer et al. (2006) and Holstad et al. (2006) have noted that HIV positive persons and their partners may themselves believe that because their viral loads are undetectable and they feel so much better, the virus is absent
or dead and they are incapable of transmitting HIV to others. This was also found
to be true for some of the PLHIV in this study, the ramifications of which were
that some experienced their ‘normalcy’ as a sense of security and therefore did
not bother to adhere to the rules and regulations. They did most of what they
were not supposed to do, and did not do most of what they should do. Others
used their seeming ‘normalcy’ to get money (for food, clothing, shelter, educa-
tion, medicines, etc.) and gave in to pressure from society (to get married, have
sexual partners, have children). Since most had not disclosed their sickness to
others, they were compelled to live these normal lives, sometimes against their
own volition. To them, the dishonour resulting from people finding out about
their infection would be more bitter than keeping their status secret and “sleeping
in spite of the death before them.” To some others, this “extra time” bestowed
upon them by ARVs was a way of avenging wrong deeds, for example through
knowingly having unprotected sexual relations. Other HIV positive persons were
suspected of intentionally spreading the infection to unknowing individuals,
especially in the case of sexual and marriage partners who had not disclosed their
positive status to their partners.

In all these cases, most people in the communities felt that people who are
HIV positive do not want to die alone and would thus want to intentionally
spread the disease. Some of the HIV positive people linked their infection to
others who did not want to have the test. These attitudes of the PLHIV – to sleep
in spite of death – because of pressure from society and also in some cases as
retaliation to being infected, also contributed to the communities’ ambivalence
and hatred in most situations towards HIV positive people. This ambivalence was
also observed among leaders of PLHIV associations and among some of the
health workers, who observed that good living, a by-product of antiretroviral
therapy, seemed to have brought about forgetfulness (*asetena pa ma awerefre*).
The HIV positive people who were redeemed by the medicines were seen to have
forgotten about their former state when they were dying from the infection, and
were thus being less careful.

Some members of the community, out of fear of becoming victims of those
HIV positive people who do not want to die alone, withdraw from all contact
with them. This raises the obvious question of whether this act of ‘withdrawing’
from all interaction with HIV positive people is an act of self-protection or
stigmatization. The answer obviously depends on the side one finds oneself on;
the HIV positive persons feel it as stigmatization, while for the general public it
is considered self-protection. This demonstrates the many complexities –
especially the contradictions regarding the lives of the infected *vis-à-vis* the
uninfected or untested – in the management of HIV where treatment is available.
This chapter has shown how HIV positive people in particular navigate these
difficulties by making decisions in ostensibly impossible situations. Although in a few cases the PLHIV in this study were found to knowingly engage in unprotected sexual relations with the intention of infecting others, many were rather constrained and pressured by the expectations of living normal lives in society, and for this reason ended up engaging in unsafe activities.
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 (Sandellowski 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.¹ 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

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-
quentely 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 associated 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 kredi 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 Abrante’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.\(^2\) It is not enough to talk about stigma; leader-

\(^2\) 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. An appeal for a similar action 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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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,⁵ 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.

⁵ 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.
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**Appendix 1: List of acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno-deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral medicines</td>
</tr>
<tr>
<td>CD4</td>
<td>Cluster of Differentiation 4</td>
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<tr>
<td>CT</td>
<td>Counselling and Testing</td>
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<tr>
<td>DA</td>
<td>District Assemblies</td>
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<tr>
<td>DHS</td>
<td>Ghana Demographic and Health Survey</td>
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<tr>
<td>EC</td>
<td>Ethical Clearance</td>
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<tr>
<td>FBO</td>
<td>Faith-Based Organisation</td>
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<tr>
<td>FCUBE</td>
<td>Free Compulsory Universal Basic Education</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GAC</td>
<td>Ghana AIDS Commission</td>
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<tr>
<td>GDHS</td>
<td>Ghana Demographic and Health Survey</td>
</tr>
<tr>
<td>GFATM</td>
<td>Global Fund to Fight AIDS, Tuberculosis, and Malaria</td>
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<tr>
<td>GHC</td>
<td>Ghana Cedi(s)</td>
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<tr>
<td>GPHC</td>
<td>Ghana Population and Housing Census</td>
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<tr>
<td>GSS</td>
<td>Ghana Statistical Service</td>
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<tr>
<td>HIV</td>
<td>Human Immune deficiency Virus</td>
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<tr>
<td>HRU</td>
<td>Health Research Unit</td>
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<tr>
<td>KATH</td>
<td>Komfo Anokye Teaching Hospital</td>
</tr>
<tr>
<td>KBTH</td>
<td>Korle Bu Teaching Hospital</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education, and Communication</td>
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<tr>
<td>IGA</td>
<td>Income Generating Activities</td>
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<tr>
<td>ISD</td>
<td>Information Services Department</td>
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<tr>
<td>JHS</td>
<td>Junior High School</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<tr>
<td>NACP</td>
<td>National AIDS Control Programme</td>
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<tr>
<td>NAP+</td>
<td>National Association of People Living with AIDS</td>
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<tr>
<td>NIC</td>
<td>Nurse-in-charge</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<tr>
<td>PCC</td>
<td>Pentecostal Charismatic Church</td>
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<tr>
<td>PLHIV</td>
<td>Person(s) Living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
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<tr>
<td>PPAG</td>
<td>Planned Parenthood Association of Ghana</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
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<td>---------</td>
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<tr>
<td>SHS</td>
<td>Senior High School</td>
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<tr>
<td>SPH</td>
<td>St. Patrick’s Hospital</td>
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<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>UNAIDS</td>
<td>The Joint United Nations Programme on HIV and AIDS</td>
</tr>
<tr>
<td>UNFPA</td>
<td>United Nations Fund for Population Activities</td>
</tr>
<tr>
<td>USD</td>
<td>United States Dollar</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
Appendix 2: The ART sites in the Ashanti Region (2008)

Komfo Anokye Teaching Hospital
Bomso Clinic
Kumasi South Hospital
North Suntreso STI Clinic
Kwadaso SDA Hospital
Aniwaa Hospital, Emena
Obuasi Government Hospital
AngloGold Ashanti Hospital, Obuasi
St. Michael’s Hospital, Pramso
St. Patrick’s Hospital, Offinso
Agogo Hospital – Asante Akyem
Asafo Agyei Clinic – Daban
Mampong District Hospital
Ejura District Hospital
Kasei Hospital
St. Martin’s Hospital, Agoroyesum
Bekwai District Hospital
Tepa District Hospital
Nynahene Government Hospital
Adansi West MOH Clinic
Agona Asamang Hospital
Appendix 3: Questionnaire

Dear Sir/Madam,

You are invited to participate in a research on opinions and experiences on the HIV/AIDS disease among people in the Ashanti Region. Your contribution is crucially important in achieving the objectives of the study and your response will be kept highly confidential. Thank you in advance.

--------------------------------------------------------------------------------------------------------------------

1. Gender of respondents  Male[   ]  Female[   ]

2. Age range

   < 15  16 - 21  22 - 30  31 - 39  40 - 49  50 <

3. Occupation  .................................................................

4. Ethnic group

   Ashanti  Other Akan  Ewe  Ga  Other Ghanaian  Non - Ghanaian

5. Marital status

   Single  Married  Divorced  Separated  Widowed  Cohabiting

6. Level of education

   None  Primary  JSS  MSLC  Sec/Tech  Tertiary  Other (specify)

7. Religious affiliation:

   Christian  Muslim  Traditional Religion  No religion  Other (specify)

8. Do you know about HIV/AIDS?  Yes [   ]  No [   ]

9. If yes, how did you know about HIV/AIDS?

10. Do you think you are at risk of having HIV?  Yes [   ]  No [   ]

11. Do you know about Voluntary Counselling and Testing?  Yes [   ]  No [   ]

12. Do you know anyone who has undergone VCT?  Yes [   ]  No [   ]

13 a. Have you undergone VCT?  Yes [   ]  No [   ]

   b. If No, do you plan to go for VCT?  Yes [   ]  No [   ]

14. Do you know where to go for VCT?  Yes [   ]  No [   ]

15 a. Have you tested for HIV?  Yes [   ]  No [   ]

   b. If No, do you plan to have an HIV test?  Yes [   ]  No [   ]

16. Do you know where to go for an HIV test?  Yes [   ]  No [   ]
17  a. Do you know there are medicines to manage HIV? Yes [ ]  No [ ]
b. If yes, do you know where such medicines are available? Yes [ ]  No [ ]
c. If Yes, please show where?

Listed below are a number of statements. Each represents an opinion and there are no right and wrong answers. Please indicate the extent to which you agree or disagree by ticking the letters in the appropriate columns

<table>
<thead>
<tr>
<th>Statement</th>
<th>ABSOLUTELY AGREE</th>
<th>PARTLY AGREE</th>
<th>PARTLY DISAGREE</th>
<th>ABSOLUTELY DISAGREE</th>
<th>NO OPINION</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you contract HIV, you will die in a few years no matter what</td>
<td></td>
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<tr>
<td>It is very easy to identify someone who has HIV/AIDS by the way s/he looks</td>
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<tr>
<td>Only people who have multiple sexual partners are at risk of having HIV/AIDS</td>
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<tr>
<td>It is possible that you may look strong and fit on the outside and have HIV inside</td>
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<tr>
<td>Some herbalists and medicine men in Ghana have a cure for HIV/AIDS</td>
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<tr>
<td>You can be infected with HIV/AIDS through curses, witchcraft, or any other evil/spiritual means</td>
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<tr>
<td>When people know you have HIV/AIDS, they stop respecting you</td>
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<tr>
<td>Someone who has HIV/AIDS brings disgrace to her/himself, the family, and all s/he relates to</td>
<td></td>
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<tr>
<td>We must be very suspicious of those infected with HIV/AIDS since they would want to infect others</td>
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<tr>
<td>Condom use is not good to prevent HIV/AIDS because it can fail even where it is used to prevent pregnancy</td>
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</tr>
<tr>
<td>Statement</td>
<td>Reason</td>
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<td>---------------------------------------------------------------------------</td>
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<tr>
<td>It is not possible to get HIV/AIDS if you talk to, eat and sleep with, or even embrace one who already have it</td>
<td></td>
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<tr>
<td>Those who have HIV/AIDS should do things differently in the home to protect others</td>
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<tr>
<td>The doctors and nurses can neglect people who have HIV/AIDS because they deserve to die</td>
<td></td>
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<tr>
<td>All those who are found to be infected with HIV/AIDS should be camped in one place to avoid further spread</td>
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<tr>
<td>Everyone who goes to hospital must have an HIV/AIDS test to detect those who have the virus but don’t know</td>
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<tr>
<td>I will willingly have the HIV/AIDS test to know my status if I know where to go for it</td>
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<tr>
<td>I will rather die than for people to know that I am infected with HIV/AIDS</td>
<td></td>
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<tr>
<td>My family would be very supportive if they find out that I am infected with HIV/AIDS</td>
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<tr>
<td>I have to disrespect someone who has HIV/AIDS so that others will try not to be infected</td>
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<tr>
<td>My Church/Mosque would be very supportive if they find out that I am infected with HIV/AIDS</td>
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<tr>
<td>It is better for me and for the general public if everyone knows her/his HIV/AIDS status</td>
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</tr>
<tr>
<td>I will travel long distances to places where I would be least known for treatment if I find out I am infected</td>
<td></td>
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</tr>
</tbody>
</table>
Appendix 4: Report of HIV/AIDS Workshop – From Research to Policy to Action

**Date:** Wednesday, 2\textsuperscript{nd} December 2009  
**Venue:** Engineering Guest House, Kwame Nkrumah University of Science and Technology (KNUST), Kumasi.  
**Participants:** Participants included policy makers, health workers, people living with HIV/AIDS, and people from academia and the media.

The workshop was held over two sessions, one in the morning and one in the afternoon. During the morning session, the three researchers presented some of the main findings of their studies. For the purpose of the workshop, the findings presented were mainly on the influence of stigma on the provision and uptake of VCT and ART.

The afternoon session was used to discuss questions and issues arising out of the presentations from the morning. The discussions were conducted in three parallel groups made up of community members, health workers, and policy makers, in line with the three perspectives of the research design.

**Morning session**  
The programme for the day started with a welcome address by Dr. Frances Owusu-Daaku, Head of the Department of Clinical and Social Pharmacy of KNUST. As the organizer of the workshop, she formally welcomed participants and briefly talked about administrative issues. This was followed by an opening address by Prof. K.A. Senah, Department of Sociology at the University of Ghana. In his capacity as the home (Ghana) supervisor of the researchers, he gave a brief overview of the multi-level perspective research project. He said that the research aimed to look at how the uptake of VCT and ART can be increased in the context of their ongoing scale-up. In order for the objectives of the research topic to be achieved holistically, the three researchers had considered the subject from three different perspectives – the community level, the hospital level, and the policy level. He further explained that the presentations of each of the researchers would centre on their particular perspectives.

Prof. Senah indicated that the rationale for the workshop was to give stakeholders an opportunity to express their views and opinions on the findings of the research before the final reports were made. He therefore entreated participants to freely express their views and opinions on the research findings, alluding to the
fact that their comments would be subsequently incorporated into the final research report. He also asked participants to feel free to speak in any language that they could best express themselves in, including local dialects.

_The first presentation_

After the welcome address, Mr. Benjamin K. Kwansa was the first researcher to present the findings of his study on the community perspectives on the research topic. Mr. Kwansa’s presentation mainly considered the issue of stigma and how it plays out between PLHIV and their spouses, relatives, and community members. He ended his presentation with a number of questions for discussion during the afternoon session.

_Reaction to the first presentation_

As per the workshop programme, Mr. Assan, a person living with HIV, was invited to respond to issues raised in the first presentation. Mr. Assan thanked Mr. Kwansa for his presentation and also agreed with him on the findings of his study. Mr. Assan pointed out that stigma as a barrier to uptake of VCT and ART is a reality, but he attributed this to the lack of information about HIV/AIDS among most members of the general public. As a result, people spread incorrect information about the disease thereby contributing to the persistent stigma surrounding it. He specifically mentioned people in the media who, according to him, have limited knowledge about HIV/AIDS and often describe the disease as ‘disgraceful’ and ‘deadly’. He also questioned the rationale behind setting aside a particular day(s) for care and treatment for PLHIV in the clinics and hospitals. Mr. Assan explained that this practice exposes the identities of PLHIV because some people find out the days on which PLHIV go to the clinics for care and treatment and are thus able to closely monitor and scrutinize them. When they see clients they know accessing care and treatment on those days, they go to the community and broadcast the news about their HIV positive status, leading to stigmatization.

Mr. Assan further stressed the need for peer educators to be formally integrated into the provision of care and treatment in the clinics. According to him, HIV positive peer educators are in a better position to counsel their peers than health workers who have no firsthand experience of living with HIV. He was also of the view that PLHIV are more likely to believe peer educators with whom they share a common problem than health workers. He did say, however, that the formal integration of peer educators into service delivery in the ART clinics should also be matched by some form of support – either in kind or (especially) in cash – to boost their morale to continue to complement the work of health workers and help their peers.
Participants were allowed to ask a few questions or make comments on Mr. Kwansa’s presentation and the response of Mr. Assan. The first comment, from a PLHIV, was that efforts at reducing the spread of the disease often lack political leadership, from the national down to the community level. This, he said, has negatively affected efforts to reduce the spread of the disease in Ghana. A policy maker, however, disagreed (to some extent) with the opinion and rather mentioned that politicians have over the years helped in diverse ways to push forward the fight against HIV/AIDS. He nonetheless agreed to the fact that more needs to be seen from the politicians, especially those at the very top – the President, Vice President, etc. – to make this stance more authentic. “We also must see them openly declaring their status, for instance,” he indicated.

The second presentation
Mr. Jonathan M. Dapaah presented the findings of his study on the hospital perspective of the research, which looked at how the attitudes of health workers and some structural/institutional challenges in the hospitals expose the identity of clients as PLHIV during the uptake of VCT and ART services. He also showed how this has in many cases led to the stigmatization of clients, as a result of which some people refuse to take up VCT and ART.

Reaction to the second presentation
Dr. Maxwell Kankam of St. Patrick’s Hospital, Offinso, responded to the presentation on behalf of health workers. Dr. Kankam thanked the presenter and said that the findings of the study were largely a true reflection of the situation in the VCT centres and ART clinics. He said that facts and figures in the facilities show that uptake has increased over the last couple of years. He pointed out, however, that uptake could be much higher if health workers more frequently went on outreach programmes to provide VCT services in the communities. According to Dr. Kankam, experience has shown that most people prefer to undergo HIV testing in their communities rather than walking or travelling all the way to VCT centres in the hospitals. Another reason is the fear that some people have that when they go for the services in VCT centres, they may be observed and/or identified by other people, and thus be stigmatized.

Dr. Kankam also indicated that the attitudes of some health workers in many respects put clients off from accessing VCT and ART. Dr. Kankam explained that the indiscrete utterances of some health workers, for example, have in many cases exposed the identities of clients to people from whom they (the PLHIV) had wanted to conceal their status. He also said that some health workers were not able to keep the status of clients confidential and as a result informed other people about it. He therefore asked health workers to respect the rights of clients
and keep their status confidential, to ensure that they are not stigmatized in their families and communities.

Dr. Kankam further expressed concern about the seeming lack of interest in HIV/AIDS activities by the hospital management. He said that there have been many instances in which the hospital management had refused to release funds for outreach programmes aimed at providing VCT services in the communities. He said that this had constrained the efforts of VCT and ART health workers to reach out to more people for HIV testing, and if tested positive to put them on ART.

When the floor was opened for questions or comments on Mr. Dapaah’s presentation and Dr. Kankam’s response, a participant (a policy maker) said that the study should acknowledge the progress that had been made in reducing the stigma associated with HIV/AIDS over the years. This was because “the study creates the impression that nothing has been done to reduce stigma over the years.” He was of the view that even though stigma is still a problem when it comes to the uptake of services, compared to a few years back the situation has seen some massive improvements.

Another participant (an academic and policy maker) also said that sometimes the reluctance of management to release funds for HIV/AIDS activities in the hospitals and districts is largely due to lack of accountability. She pointed out that in some cases health workers are not able to account for funds released for programmes because they have used such funds for other activities unrelated to HIV/AIDS. According to her, whenever this happens management insists on proper accountability before releasing the next batch of funds for planned activities.

The third presentation
Dr. Owusu-Daaku presented the third perspective of the research: the policy making level. She gave the presentation on behalf of Dr. Rachel Spronk, who had carried out the study but could not attend the workshop due to taking maternity leave. The presentation mainly looked at how HIV/AIDS related policies are formulated, as well as the linkages between policy formulation and implementation. The researcher was of the view that HIV/AIDS policies in Ghana are largely on track but that what is lacking is effective implementation of the policies in the hospitals and districts. The study reported that lack of logistics is also a major factor constraining effective implementation of HIV/AIDS policies in Ghana.

Reaction to the third presentation
Prof. Irene Agyepong responded to Dr. Owusu-Daaku’s presentation on behalf of policy makers. She said that the current success in the reduction of HIV infection is largely due to the prevention policy that has been put in place. She said,
however, that future research should focus on how policies are put into action at all levels of the health care delivery system. She also questioned the meaning of the term ‘logistics’, as it was used in the research findings (as indicated above). According to her, logistics means more than lack of funds, which is often cited as the main constraint to project implementation (often by using the phrase ‘logistical constraints’). “It is important that what we mean by logistics should be clarified in research findings,” she added. She gave examples where ‘logistics’ could include funds, means of transport, and personnel, among other things.

Prof. Agyepong also noted that in the Strategic Framework II on HIV/STI Policy, there are no clear guidelines addressing stigma. The reasons for this include the general international lack of guidelines to address stigma, low prevalence fuelling complacency, lack of political will (unlike, for instance, that visible in Uganda), among other reasons. The situation brings to the fore a number of dilemmas; for example, there is more focus on HIV programmes than on HIV within the health system as a whole. Prof. Agyepong therefore noted that the challenge went beyond those in the workshop: “Dialogue should be more up there,” she stressed.

In conclusion, Prof. Agyepong raised a number of questions regarding Mobile Counselling and Testing (MCT): what do you do if a particular programme proves successful? Why is it that MCTs are more successful? What is attracting people to MCTs? Maybe the District Assemblies should assist through their share of the Common Fund.

*The afternoon session*

Participants broke up into three parallel groups based on the three presentations to discuss questions posed in the presentations and other related issues. The presenters moderated each group and a secretary was chosen to record and present proceedings to the larger group. The parallel discussion segment lasted for a little over one hour, after which participants gathered again for the group secretaries to present what they had written down.

*Plenary discussion*

*Community*

Mr. Assan was the first to present on behalf of the community group. The group was of the view that the general public still lack adequate information about HIV/AIDS. As a result, many people believe that PLHIV contracted the disease by choice (through ‘immoral’ behaviour, for instance), and thus they do not deserve sympathy, support, and care. In addition, many people believe the disease to be deadly and that it has no treatment at all. According to the group, lack of information about the disease is the underlying cause for the stigmatiza-
tion of PLHIV in their families and communities. The group was of the view that even though awareness about the disease is near universal in Ghana (about ninety-five percent or more), there is still the need for intensive education about the disease and how it can be managed with ARVs.

The group also pointed out that people in the media – both electronic and print – lack information about HIV/AIDS, and they often show this in the way they report on the disease. Mr. Assan said that they often use ‘bad language’ or dreadful phrases, such as that HIV is a ‘terrible illness that will result in death’ (yadee kodi awuo) to describe the disease and its sufferers, which also feeds into the stigma associated with HIV/AIDS. In addition, some do not even know the difference between HIV and AIDS, so they are not able to explain to the listening public the difference between the HIV infection and the AIDS disease. The group therefore suggested that media men and women also need to be educated properly about the disease in order for them to accurately report on it. This, the group believed, would help reduce the stigma associated with the disease rather than contribute to its persistence.

Mr. Assan further reported that the group called for formal integration of peer educators into the provision of care and treatment in the VCT centres and ART clinics. The peer educators are PLHIV who have been trained in counselling to complement the work of health workers in the VCT centres and ART clinics. The group explained that as people who are also living with the disease, peer educators are in a better position to counsel their peers to accept their HIV positive status and adhere to the ARV medication. This is because they often counsel their peers by sharing their personal experiences of the disease with them, which always impacts positively on them.

The group further suggested that peer educators should be supported financially when they are integrated into the provision of services in the VCT centres and ART clinics. They think that this would motivate peer educators to be committed to the work they do in the health facilities. It is important to mention that this call for formal integration of peer educators into service delivery and the need for them to be supported financially was made following the lack of recognition for their work in one of the ART clinics in which this study was carried out.

In addition, the group called on health workers to try as much as possible to keep information about clients’ status confidential. Any time that they want to disclose information about a client’s status to others, such as spouses or relatives, they should seek the client’s consent before doing so.

Finally, the group suggested that ARVs should be supplied free of charge to clients, because most of them are not able to pay the cost of the drugs every month due to the fact that prolonged illness means that most of them are unemployed. The group contended that even though clients can buy drugs on credit, it
would be better if the drugs were given to clients free of charge to encourage them to come for their refill at the end of every month.

Health workers

The second presentation was by Mr. Samuel Amanor on behalf of the health workers’ group. The group generally agreed that the negative attitudes of some of their colleagues towards clients deter many people from taking up VCT and ART. But the group observed that it is mostly health workers who are not directly providing these services who show negative attitudes towards VCT and ART clients. For instance, health workers in the admission wards were said to be putting PLHIV in side wards in order to distance themselves from these clients due to their HIV positive status.

Health workers also admitted that there is a lack of respect for confidentiality among some of their colleagues, as mentioned earlier by the community group. They pointed out that health workers who are not trained professionals are noted for talking about clients’ HIV status outside the hospitals, and that this has on many occasions exposed clients as PLHIV in their communities, leading to stigmatization by relatives and community members.

The group also responded to the concerns of some clients that the secrecy they needed to take up VCT and ART is not guaranteed due to open locations of VCT centres and ART clinics in the hospitals. The group suggested that integration of VCT and ART into general health care services would be the best solution to these concerns. But health workers pointed out that isolating VCT centres and ART clinics in the hospitals (as is now sometimes the case) likely results in stigmatization of the sites, because most people do not want to be seen entering or coming out of the centre or clinic, which is often taken as grounds for suspecting someone to be HIV positive. VCT and ART should be included in general care services and be accessed through the OPD like any other disease, rather than being secretly located within the hospitals.

Furthermore, there was the suggestion that health workers should embark on outreach programmes in the communities to provide VCT services. This is because experience has shown that most people prefer to take up VCT outside of the hospital premises, due to the lack of secrecy in terms of the locations of VCT centres. In outreach programmes, clients can avoid being seen at VCT centres, accessing a service which is a justification for being suspected as a PLHIV with its attendant stigmatization. They also proposed using outreach programmes to educate members of the general public about the disease and the availability of ARV drugs to help PLHIV to live longer with the disease.

Health workers contended that inasmuch as stigma has negatively influenced many people not to take up VCT and ART, they believe that something can be
done to reduce its persistence. They admitted that the fight against stigma is a difficult one, yet they do not have to be pessimistic. According to them, they need to assure clients during pre- and post-test counselling that their status will not be made known to other people without their consent. In addition, clients should be assured that information about their status will be kept confidential. Above all, health workers should assure clients that they will endeavour to do their work as professionals so as to provide quality care and treatment. This, they said, would make clients feel that health workers are interested in their welfare beyond the routine provision of services.

Finally, health workers said that they have to find positive ways to encourage PLHIV to accept their status and live with the disease for the rest of their lives. They explained that through ongoing counselling, they could help clients to willingly disclose their status to at least one trusted person, as a coping mechanism to reduce the stress associated with the disease.

Policy makers
The last presentation was by Dr. Raphael Obeng on behalf of the policy making group. This group agreed that even though there is a policy to reduce HIV-related stigma and to encourage more people to take up VCT and ART, there is no clear-cut effort to implement the policy. They therefore suggested that conscious effort should be made at all levels among stakeholders to ensure that the policy for stigma reduction is properly implemented.

Further, the group indicated that one major policy which has boosted the provision of care and treatment for PLHIV is the National Health Insurance Scheme (NHIS). Even though ARVs are not on the list of ‘essential drugs’ covered by the NHIS, most of the PLHIV can access other health care services almost free of charge. For instance, through the NHIS, the opportunistic infections of PLHIV are treated at little or no cost, which has largely contributed to improvements in their health and welfare.

The group also stressed the need for policy makers to regularly make funds and logistics available to implementers in the districts and hospitals, in order for effective implementation of HIV/AIDS programmes. The group pointed out that without funds and logistics, all the good policies on HIV/AIDS will remain on paper without implementation to benefit the intended target groups.

Conclusion
In conclusion, there was a consensus among the three groups that stigma is the main barrier to increased uptake of VCT and ART. They therefore suggested that efforts should be intensified at all levels to reduce stigma and encourage more people to take up these services. All the groups were of the view that stigma could be reduced through intensive educational programmes and campaigns on
HIV and AIDS for members of the general public, people in the media, and health workers (in the latter case, especially those who do not provide VCT and ART). It was expected that such efforts will help people to understand the disease better and also behave positively towards PLHIV to reduce stigmatization.

Prof. Sjaak van der Geest, the main supervisor of the researchers in Amsterdam, gave the closing remarks for the workshop. On behalf of the research team and organizers of the workshop, he expressed his gratitude to all the participants for making time to attend the workshop. He thanked participants for their good comments and suggestions on the research findings and assured them that they would be incorporated into the final research report. He added that the workshop had shown that it is possible for policy makers, health workers, and PLHIV to sit in one meeting as ‘equals’ to dialogue and find solutions to the challenges posed by HIV/AIDS. Participants were then paid their per diem and transport costs, after which, at around 4 p.m., they took their lunch packs and left for their respective destinations.
Appendix 5: List of PLHIV associations/NGOs in Ashanti Region (2008)

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<thead>
<tr>
<th>#</th>
<th>NAME OF ASSOCIATION</th>
<th>CONTACTPERSON</th>
<th>PLACE/LOCATION</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>God Cares Association</td>
<td>Edward Boame Daniel Kwabla</td>
<td>Asokwa St. Marcus Hospital</td>
</tr>
<tr>
<td>2</td>
<td>Hope for the Best</td>
<td>Martha Osei Lawrence Osei</td>
<td>Offinso Kokote</td>
</tr>
<tr>
<td>3</td>
<td>Professional Alert of Action</td>
<td>Hagar Ackah</td>
<td>Regional Health Administration</td>
</tr>
<tr>
<td>4</td>
<td>Ahodwo Bia</td>
<td>MichaelEunice</td>
<td>St. Markus Hospital, Asokwa</td>
</tr>
<tr>
<td>5</td>
<td>Happy Family Association</td>
<td>Stephen Osei George Arthur</td>
<td>Radisco Asokwa</td>
</tr>
<tr>
<td>6</td>
<td>Social Action for Development</td>
<td>Mr. Awuku Don Cynthia</td>
<td>Santasi New Site</td>
</tr>
<tr>
<td>7</td>
<td>Hope Association</td>
<td>M. Pokua Mr. Osei</td>
<td>Nkawie</td>
</tr>
<tr>
<td>8</td>
<td>Living Aid Association</td>
<td>Pastor Frank</td>
<td>Revival Church</td>
</tr>
<tr>
<td>9</td>
<td>Ewurade Beye Kuo</td>
<td>Collins Yeboah Mr. Safo</td>
<td>Ejisu Juaben</td>
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<tr>
<td>10</td>
<td>Nkunim Kuo</td>
<td>Tony Amoateng Mr. Okyere</td>
<td>Atonsu Agogo</td>
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<tr>
<td>11</td>
<td>Nananom Kuo</td>
<td>Gabriel Oppong Agnes</td>
<td>Breman West</td>
</tr>
<tr>
<td>12</td>
<td>Yapred Annidaso</td>
<td>Ofori Boateng A. Frimpomaa</td>
<td>Effiduase</td>
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<tr>
<td>13</td>
<td>Preach the Word Association</td>
<td>Ibrahim Dwumfour</td>
<td>KATH</td>
</tr>
<tr>
<td>14</td>
<td>Compassionate Care Foundation</td>
<td>Mrs. Alice Alex Boateng</td>
<td>Mamponteng</td>
</tr>
<tr>
<td>15</td>
<td>Christ our Hope Foundation</td>
<td>Kofi Amofa</td>
<td>Offinso Kokote</td>
</tr>
<tr>
<td>16</td>
<td>Kyere wo do Kuo</td>
<td>Elizabeth Adu Charles Gyimah</td>
<td>North Suntreso Hospital</td>
</tr>
<tr>
<td>17</td>
<td>Gyidie Believers Association</td>
<td>Robert Abana Mariama Abdalla</td>
<td>Obuasi Nankaba Junction</td>
</tr>
<tr>
<td>No.</td>
<td>Name</td>
<td>Leader</td>
<td>Location</td>
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<tr>
<td>18</td>
<td>Embracing Life</td>
<td>Cynthia Yankey</td>
<td>Obuasi</td>
</tr>
<tr>
<td>19</td>
<td>Rising Hope</td>
<td>Joana Panka</td>
<td>Education Office</td>
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<td></td>
<td></td>
<td>Obuasi</td>
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<tr>
<td>20</td>
<td>B.A.K Plus</td>
<td>Mr. Barnabas</td>
<td>Pramso Hospital</td>
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<tr>
<td>21</td>
<td>Providence Club</td>
<td>Harrison K. Asare</td>
<td>Adum Pampaso</td>
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Summary

This study is part of a larger research project consisting of three parallel projects that investigated some of the key issues hindering people from taking up voluntary counselling and testing (VCT) and antiretroviral therapy (ART) services in Ghana. While two of the projects focussed on the institutions and the policy terrain (A and C respectively), this project (B) concentrated on those who utilize the services – the general public and people living with HIV (PLHIV). It assessed perceptions of VCT and ART, focused on problems associated with (and motivations for) taking up counselling and care, and looked at issues relating to stigmatization, in the communities accessing the services at Komfo Anokye Teaching Hospital, Kumasi, and St. Patrick’s Hospital, Offinso, both in the Ashanti Region of Ghana. Between September 2007 and August 2008, and November 2009 and January 2010, the researcher lived in the same communities as the HIV positive respondents and their families and friends. Through conversations, observations, in-depth interviews, focus group discussions, and a household survey, the experiences of living with HIV and AIDS, and the firsthand knowledge of being affected by the infection, were explored.

Having a good name and thus a positive identity in one’s community is of paramount importance to the majority of members of these communities. PLHIV are stigmatized because the disease gives them a bad name. Ordinary members of the general public thus tend to be reluctant to go for VCT because of the fear of being stigmatized if the result is positive. Those who do find out about their HIV positive status try every means possible to conceal it to avoid stigmatization.

Only a few of the participants in this study were tested for HIV after sensitization campaigns or through walking into a VCT centre. The majority found out about their HIV positive status after reporting sick at the hospital, where they were tested, mostly without their knowledge let alone their consent. Furthermore, after the test has taken place, issues and challenges may arise in terms of receiving the test results. Firstly, some counsellors find it difficult to tell clients that they are HIV positive. Thus these health workers often use euphemistic phrases, such as “there are worms/small animals in the blood,” which are ambiguous and leave room for the clients to interpret the results in different ways. Secondly, due to fear of the possible consequences of testing HIV positive, many refuse to pick up the test results.

After finding out about their HIV positive status, in most cases these persons consider their next line of action to be to conceal their sero status from those who
they do not want to know it. Death (by suicide) was found to be one of the main considerations at this stage, though only a few went through with it. Considering the public condemnation of suicide in Ghana, the fact that some choose to do so tells of their desperation. Some HIV positive people opt for a concealed form of suicide by refusing to enrol onto an ART programme and thus deciding to die slowly. Most feel lonely and become isolated. A significant number resort to alternative treatments, including local and herbal medicine and ‘spiritual therapy’, for fear of being discovered using ART.

The PLHIV in this study were preoccupied with feeling safe, in particular safe from the (possible) effects of stigma. Stigma is experienced in two main ways: they anticipate negative reactions from others (perceived stigma) and experience real discrimination and mistreatment (direct stigma). As a result, they generally hide their sero status from their spouses or partners, the family members they live with, and their friends and neighbours. Though HIV positive persons are encouraged by health workers to disclose, especially to their partners, the fear of possible consequences prevents many of them from doing so. Out of fear, people devise strategies to avoid being found out, such as (among other things) finding excuses to explain their frequent visits to the hospital; taking their medicines in secret; circumventing the rule of disclosing to a treatment monitor by using a passer-by from the street; and enrolling in clinics far away from their community.

Of those PLHIV in this study who did start ART, the vast majority claimed that they were relieved when they started treatment and were able to regain their former lives. However, treatment poses its own challenges, such as the initial side effects when starting the medicines, the longer term side effects, and the hassle of the daily intake of drugs. Furthermore, for many of the PLHIV in this study who tested at the hospital when their health condition had become very serious, they were at the end-stage of their HIV trajectory, and this severely impeded the possibility of effective treatment with ART and reduced their chances of living a longer, healthy life in spite of the infection.

In general, the PLHIV on ART took their drugs religiously, but side effects such as nausea, throwing up, and initial lack of appetite prevented proper drug intake, while the huge appetite ultimately brought about by the medicines, as well as mood swings or depression, also restrained proper treatment. Economic constraints further prevented proper treatment when PLHIV had no means to travel to the clinic or maintain a proper diet. Some even discontinued their treatment after having regained their former health, thus ignoring or denying the fact that the treatment is lifelong.

Many PLHIV experience financial problems, which severely impede their adherence to ART. As many do not seek treatment at the ART facility early in their disease trajectory, or only get there after seeking treatment elsewhere (such
as at prayer camps, traditional healers, etc.), they often come to the clinic impoverished. Many have sold their property, such as tools and farming lands, in their pursuit for a cure to their ailment. Their expenditures, however, keep increasing after starting ART, as they need money for food, transportation to the clinic, medical expenses additional to ART that are not covered by the National Health Insurance Scheme (NHIS), as well as for their own private needs. As they are often unable to contribute to the financial upkeep of their household, they can also expect less assistance from their relatives. In cases where they are cared for by family members, once the resources are depleted because of the increasing costs, the whole family suffers economically. This study shows how, for example, transportation costs may prove a heavy burden, forcing infected persons to skip appointments, or how a number of PLHIV are compelled to take their medications without food.

To maintain or regain their dignity and good reputation and to be safe in the midst of stigma, the majority of the HIV positive persons in this study lived as if they were not infected. They continued their lives ‘as normal’ without informing others. However, this seeming normalcy poses further acute dilemmas, as they are expected to have partners, get married, and have children. The study shows the painful problems that PLHIV face when, for example, they resist marriage proposals for a long time but eventually give in as others start to question their motivations. Knowledge or rumours of such behaviour cause acrimony among community members who feel that HIV positive persons on antiretroviral medicines are intent on deliberately spreading the infection to others. On the other hand, some PLHIV do disclose their status to their family members, though the study found that the majority of those who did so did not receive appropriate assistance. Only a small number of families cared well for them.

As ART is a lifelong treatment, PLHIV must therefore develop new relationships with three new groups of people: the medical staff offering treatment, care, and support; other HIV positive people; and home-based care professionals, including those from PLHIV associations. These groups are therefore crucial for successful adherence to treatment, maintaining successful clinical programmes, and scaling up VCT and ART. ART clinics and PLHIV associations may be important safe havens where PLHIV can share worries, seek advice, and find consolation. Income-generating activities by these associations – such as farming, soap making, and animal husbandry – can help to provide a new course of life. Investing in these supportive circles may seem less direct in terms of offering help and support to PLHIV, but they in fact may prove to be the cement crucial to ensuring the future success of efforts to help people to access HIV testing and counselling services; to access ART if discovered HIV positive; to
regain their health and live positively; and thus to reduce the further spread of HIV.
Samenvatting (Dutch summary)

Deze studie maakt deel uit van een groter onderzoek dat bestaat uit drie parallelle projecten die zochten naar de hoofdoorzaken van het lage gebruik van HIV vrijwillige counseling en testen (Voluntary Counselling and Testing, afgekort VCT) en antiretrovirale HIV behandeling (antiretroviral therapy, afgekort ART) in Ghana. De twee andere projecten richtten zich op ziekenhuizen (A) en het beleidsveld (C). Dit project (B) concentreerde zich op gebruikers van de VCT en ART diensten – de algemene bevolking en mensen die leven met HIV (People Living with HIV, afgekort PLHIV). Het peilde de heersende percepties over VCT en ART, met name de problemen (en motivaties) gerelateerd aan het gebruik van counseling en zorg; en kwesties gerelateerd aan stigmatisering in de gemeenschappen met toegang tot de diensten van het Komfo Anokye Teaching Hospital in Kumasi en St. Patrick Hospital in Offinso, beide in de Ashanti regio van Ghana. Van september 2007 tot augustus 2008 en van november 2009 tot januari 2010 heeft de onderzoeker in dezelfde gemeenschappen gewoond als de geïnfecteerde personen en hun familie en vrienden. Om de ervaringen van leven met HIV en AIDS en de persoonlijke ondervindingen van direct en indirect getrof- nen te verkennen is gebruik gemaakt van conversaties, observaties, diepte-interviews, focus groep discussies en een huishoudenquête.

Het hebben van een goede naam bleek van uiterst belang voor de meerderheid van de leden van een gemeenschap. Mensen die leven met HIV worden gestigmatiseerd omdat de ziekte hen een slechte naam geeft. Degenen die seropositief bleken te zijn probeerden dit op elke manier te verbergen om stigmatisering te voorkomen. Doorsneeleden van de algemene bevolking waren terughoudend om zich te laten testen uit angst gestigmatiseerd te worden als het resultaat positief zou zijn.

De meerderheid van de mensen die hun positieve HIV-status ontdekten, waren getest nadat ze zich ziek bij het ziekenhuis hadden gemeld. In de meeste gevallen werden ze getest zonder hun medeweten, laat staan toestemming. Op dit punt hadden ze wellicht al andere behandelingen geprobeerd, inclusief lokal juridische en ‘spirituele therapie’. Slechts enkelen hebben zich laten testen naar aanleiding van bewustmakingscampagnes. De meerderheid van de mensen uit deze studie die leven met HIV ondergingen pas een test tegen het einde van het HIV-traject, toen hun toestand kritiek werd. Dit belemmerde ernstig de effectiviteit van behandeling en een verlenging van hun leven met HIV/AIDS.
Geïnfecteerde personen waren in de eerste plaats uit op veiligheid, met name tegen degevolgen van stigma. Ze ondervonden twee varianten van stigma: de verwachting van negatieve reacties (‘perceived stigma’) en de feitelijke (directe) discriminatie en slechte behandeling (‘experienced stigma’). Als gevolg hiervan hielden ze hun serostatus geheim tegenover hun echtegeno(o)tt(e)/partner, familieleden met wie ze samenwoonden, en vrienden en buren. Hoewel HIV-positieve personen door gezondheidszorgpersoneel aangemoedigd werden om hun status te onthullen, vooral tegenover hun partner, was het de angst voor mogelijke consequenties die velen daarvan weerhield. Uit angst ontwikkelden mensen strategieën om hun regelmatige bezoek aan het ziekenhuis te verklaren; om hun medicijnen onopgemerkt in te nemen; om de verantwoordelijke te omzeilen door een toevallige voorbijganger te vragen; om niet gesignaleerd te worden in het ziekenhuis door behandeling te zoeken in een kliniek ver weg van hun woonplaats; etc.

Andere problemen die deze studie heeft geïdentificeerd betreffen het onderdeel van de testprocedure waarbij de testuitslag bekend wordt gemaakt. Ten eerste vonden sommige counselors het moeilijk om hun cliënten in te lichten over hun positieve status. Vaak gebruikten ze de uitdrukking dat er “wormpjes/kleine beestjes in het bloed zitten,” wat tot onduidelijkheid leidde en cliënten de ruimte gaf om hun uitslag anders te interpreteren. Ten tweede weigerden mensen uit angst voor de mogelijke gevolgen van een positief resultaat om zich te laten testen of, wanneer ze dat wel deden, om terug te komen voor de uitslag.

Na een positief testresultaat betrof de eerste doelstelling van de getroffene vaak het verbergen van hun status voor degenen van wie ze niet wilden dat dezen het te weten zouden komen. Sterven (zelfmoord) bleek een veelvuldige overweging, hoewel slechts enkelen dit daadwerkelijk uitvoerden. Gezien de publieke afkeuring van zelfmoord in Ghana geeft het feit dat sommigen hier toe over gingen hun wanhoop aan. Sommige geïnfecteerde personen kozen voor een verkapte vorm van zelfmoord door behandeling te weigeren en zo een langzame dood te sterven. De meesten voelden zich eenzaam en raakten geïsoleerd. De klinieken en verenigingen waren belangrijke veilige havens waar men zorgen kon delen, advies kon zoeken, en troost kon vinden. Een aanzienlijk aantal zocht zijn toevlucht tot alternatieve behandelingen uit angst betrapt te worden op het gebruik van ART.

Alle geïnfecteerde personen beweerden dat ze opgelucht waren om met behandeling te beginnen en hun leven weer op te pakken. De behandeling bracht echter weer nieuwe problemen met zich mee, zoals directe bijwerkingen, lange termijn bijwerkingen, en het gedoe om elke dag medicijnen in te nemen. Over het algemeen namen deze mensen trouw hun medicijnen, maar bijwerkingen zoals
misselijkheid, braken en gebrek aan eetlust stonden een juiste inname in de weg. Onderwijl zorgden toegenomen eetlust, stemmingswisselingen of depressies voor sociale en economische lasten die een effectieve behandeling verhinderden. Economische beperkingen beletten een effectieve behandeling ook wanneer patiënten geen mogelijkheid hadden om naar de kliniek te reizen of een aangepast dieet te volgen. Sommigen stopten met hun behandeling zodra ze hun gezondheid terug hadden; ze hielden zich blind voor het feit dat ze permanent onder behandeling moesten blijven.

Velen ondervonden financiële problemen, wat een trouwe opvolging van de behandelinstructies ernstig verhinderde. Omdat ze niet op tijd voor behandeling naar een ART centrum waren gegaan, of hier pas heen gingen na elders genezing te hebben gezocht (zoals in bidkampen, bij traditionele genezers, etc.), waren ze berooid toen ze uiteindelijk bij de kliniek aanklopten. Ze hadden hun bezittingen, zoals gereedschap en akkers, verkocht ter bekostiging van de zoektocht naar een remedie voor hun kwalen. Ondertussen bleven hun onkosten stijgen omdat ze (meer) voedsel nodig hadden, net als geld voor vervoer naar de kliniek, medische uitgaven die niet gedekt werden door hun verzekering (NHIS) of ART, en voor andere persoonlijke behoeften. Omdat ze vaak niet bij konden dragen aan het huishouden konden ze ook weinig verwachten van hun familieleden. In de gevallen waarin familieleden wel goed voor hen zorgden, leed het hele gezin wanneer de financiële middelen uitgeput raakten door de toegenomen kosten. Deze studie toont in detail aan dat bijvoorbeeld vervoerkosten een zware last kunnen zijn die geïnfecteerde personen er toe dwingt om afspraken te laten lopen; en hoe een aantal van de geïnfecteerde mensen de medicatie innam zonder voedsel.

Om hun waardigheid en goede reputatie te behouden of te herwinnen en zich veilig te stellen te midden van stigma leefden de meeste HIV-positieve personen alsof ze niet geïnfecteerd waren. Ze vervolgd hun leven zonder anderen in te lichten. Deze schijnbare normaliteit bracht echter ook acute dilemma’s met zich mee omdat ze geacht werden te trouwen en kinderen te krijgen. Deze studie toont de pijnlijke problemen waar geïnfecteerde mensen mee geconfronteerd worden wanneer ze, bijvoorbeeld, huwelijksaanzoeken blijven afslaan en uiteindelijk maar accepteren wanneer anderen aan hun motieven beginnen te twijfelen. Dergelijke besluiten veroorzaakten boosheid onder gemeenschapsleden die meenden dat HIV-positieve personen onder antiretrovirale behandeling doelbewust het virus verspreidden. Anderzijds wijst deze studie uit dat de meerderheid van degenen die hun status wel onthulden aan familieleden, van hen niet de nodige steun kregen. Slechts een klein aantal families zorgden goed voor een geïnfecteerd gezinslid.
Omdat ART levenslang is, ontwikkelden de mensen die leven met het virus nieuwe relaties met de medische staf die hun behandeling, zorg en steun bood; met andere geïnfecteerde mensen; en met thuiszorg-professionals inclusief PLHIV Verenigingen. Deze groepen mensen waren daarom van cruciaal belang in het slagen van behandelingen, het handhaven van succesvolle klinische programma’s, en het opschalen van VCT en ART. Inkomst-genererende activiteiten van deze verenigingen, zoals landbouw, zeepfabricatie en veeteelt, hielpen bij het verschaffen van een nieuwe levensrichting. Investeren in deze ondersteunende activiteiten mag dan Weinig acuut lijken, in feite zou deze het cement kunnen blijken voor toekomstig succes.
Tɔfa (Twi summary)

Saa adesua yi ye nhwehwemu a wɔye faa deec ntia Ghanafoɔ beebree mpe se wɔye VCT anaa ART no fa bi. Adesua yi fa A ne C ye nhwehwemu a efa ayeresa adwuma no ne ne nhyehye ahodoɔ ho. Ɛfa B ye nhwehwemu a efa ɛmanfoɔ ne nnipa a wɔɛɛ yaree-kodi-awuo HIV/AIDS mmoawa no bi ho. Ɛye mpensempensemu fa adwenhodɔ a ɛmanfoɔ anya wɔ VCT ne ART ho, na esane twε adwene gyina ɛhaw ahodoɔ bi a nnipa a wɔkɔgye ayeresa ne ɛho afotusɛm, ena nsem a efa animguasee a etare saa animɔntuo yi ho. Nhwehwemu dwumadie yi kɛɛ so wo Komfo Anokye Teaching Hospital wo Kumase ne ne mptɔtam ena St. Patrick’s Hospital ne ne mptɔtam wo affinsɔ. Saa beee mmienu yi nyinaa wɔ Asanteman mu wɔ Ghana. Efiri Ɛbɔ 2007 - ɛsanaa 2008 kɔsi Obubuo 2009 - ɛpɛpɔ 2010, onipa a ɛye saa nhwehwemu yi ye ɛmanfoɔ a na wanya yaree mmoawa, mekyere HIV no bi ne wɔn abusuafɔɔ ne wɔn mmufonɔm nyinaa na eboom tenaa saa mptɔtam mmienu a adesuadee yi kɛɛ so no. Ɛnam nkɔmɔɔ so, nhwehaa, nsemniisa a emu dɔ, nnipakuo adwene ntotoho, afie mu nsrahw, nkɔfrɔɔ suahunu wo HIV ne AIDS ho ena wɔn a afei koraa na wɔahunu fofɔɔ so wɔanya yaree-kodi-awuo HIV mmoawa no bi suahunu so na edii dwuma yi.

Nnipa a wɔtete saa mptɔtamu yi nyinaa mpe se wɔn anim begu ase nti daa wɔbɔ mmo/end se wɔnyny a din mmo/end biara. Ɛno nti seekɔba se obi nyaa yaree mmoawa (HIV) no bi, na ebeɛ dwa a, na aye animguakwεedee kesee, eno nti wɔbɔ mmodo/end biara de sie seekɔye a ɛmanfoɔ mfa wɔn nsa nkyerekyere wɔn so. Seekɔba saa, wɔnyny ahomeka biara nkyɛ VCT.

Wɔn a wɔhanunu se wɔnyny saa yaree yi bi no amfiri wɔn ara pe mu ankɔye wɔn mmogyaa mu nhwehwemu, na mmon nyareewa ahodoɔ bi na efe wɔn kprɛe ayeresaɓa ho maa wɔhwehwee wɔn mmogyaa mu a na wɔnɔmim mpo. Deeddaa anie wɔ dwumadie yi mu bako nso nε se, ebedurε tebea sei mu no, na yareɛfoɔ yi afa kokoɔm akwεn bi so ape ayeresa a ɛnam – abibiduro, nhahamna, nnun-sifoone ahonhomsem so. Nnipa kakraabi na wɔn ara tumi kɛɛ ayeresaɓa kyyεe nhwehwemu bere a wɔtεe apomuden ho kɛkɔbɔ nsem no. Se wohwe mu a, nnipa dodoɔ a wɔyεe wɔn mmogyaa mu nhwehwemu no ye wɔn a na yaree mmoawa no adokoro wɔn akye, a wɔye wɔn ho hwee a, na eνεε yie no. Ye nti wɔnyny mponwua wɔn ayeresa mu sedee na ese se wɔnyaa. Ebinom koraa deewɔntumi antena nkwa mu ankɔye.

Ɛnam se nea wɔn a wɔnyny HIV/AIDS no bi de ahye wɔn adwene mu se, se ebeda badwam a wɔn anim begu ase nti na wɔwɔchwaw akeseem mmienu mu. Dee edi kan, na wɔn ara dwendwene deewɔsusɔ se nkɔfrɔɔ beka afa wɔn ho no ho.
Afei dee na won ara nso nim a eya nokore a efa won ho no maa won adwendwene. Yei boa won ma wtumi de won tebea no siee won ahokafu, abusuafo, namfoo ne afipamfo a won ne won tee no. Aporomuden adwumayefo bu bu won koko see wonka won yaree ho nsem nkyere won adfonom, nanso wuantumi enam de na woredwene nti. Ehuu nti wotwaa atoro kyeree won adfo fo wo deee nti a wtaa ko ayesabae no, wowiaviaa won ho na na wonom won nnuo a na ayesabae de ma won; na wnantuminko ayesabae a whwe won no wo bere ano bere ano, efiri se na wape se wwee saa wo bera a obiara nhu won; ebinom koraad deeo asopiti a na emmen won na na wko se obiara nhu won nti. Nhwehwemu yi da no adi se, se wwee obi HIV gyinapen mu nhwehwemu wie na ayesa adwumayefo no hunu se oniko no anya yaree no bi a, na aye den se wbeeka no potee akyere no. Wotumi kakyere oniko no se “wany a nsonono mma anaa mmoawammoawa wo ne mogya mu.” Yei bu bu kan maa wo yi kyeree won yaree mu wo akwan fofo bi so a emma wonnye ahodasoo. Afei Emm se wswa suro se won yadee no beba abeet dwa nti na enko nkye nhwehwemu no kraa. Se wokyee ye nso a, na aye den se wbeeka akogyee hoe mwuma no.

Se wtumi kgyee won yaree mu nhwehwemu no ho mwuma na se wshunu se wany a yaree no bi a, wobo mmoden biara si afofo no kwan se wbehunu se wgyare. Afei wtaa nya adwene bi se wnni won ho awukoraar na dee ebeba mmra. Ebinom tumi di won ho awu ampa. Yei kyere se tebea a wko mu no, ano ye den pa ara. Ebinom koraa deee, ekwan a na wafa so di won ho awu kokoam ne se, won abe mu bu nti wmmfa won ho nkto ART so. Wotena ase wu nkakrankra saa ara. Nnipa dodo no ara wonnkum won ho no nso beye ankonam aayaresa adwumayefo ne nnipaku ahodoor bi na wghye won nkuran ne won di nkitaaro. Afofo wo ho a won ldeee enam se wome se won nkrofo behu no se wrofa ART anaa se wmmi siika a wde betuua eho ka nti won ankasa faa won akwan so pee won yaree ho aduyo.

Obiara a na wany a yaree-kodi-awwo yi bi a chye eho nnuo nom ase no de betoo dwa se wany a ahooden a eyen ne kane tebea no. Nnuro yi nso a wonnom yi de shaw bone fofo bi bese won. Adunom ho nsusuanso bone a nnpa ta nna nga wo bere wofri aduro bi nom asem, anaa nsusuansoo a wtaa nga enam se obi nom aduro bi kyere pii nti. Afei dada adunom nso ye anito yie. Nsusuanso bi te se afefeafefee, anumu etoo ne anisobirie nso anyee won amma wquantumi amfa nnuro no sede en ese fata. Bio, eduru bere bia siika kakra a wde befa kaa akogyee won nnuro no na eho aye den. Afei deee wde beto nnuanede adi amtu anom nnuo no nso etoo da a na eho aye den ama won. Ebinom nso deee, se wtumi nonom nnuo no na wany a ahoeden pe a, na wogyaee nom efirise wssusu se wate apo nti eho nhia se w foo so nom nnuro biara bio.

Nnipa dodo no ara a na wany a yaree-ko-ankor a yi na wo wohia buruburoo mu. Efirise, ansa na wereba ayesabae ahoode no mu ama wahwe won no na
wodzi kan ako kyinkinyi mnunsifo ce asafoc so w mpaedzie ahodoo mu
ahwehe ayaresa, atonten won agyapedee ne won ahodee dodoo no ara a
wamunya ayaresa. Won ka yi ko so ye akesee ara efirise toa ara na na etwa se
watao so didi nom won nnuro na wko so tua kaasika kagye nnuro wo ayersabea.
Afei eduru bere bi mpo a, apomudene nsi-akyi-baa NHS anaa ART ntumi ntua
won yaree no ka. Eto da nso a, wofia sika kakra ato won ho.

Ebinom ateetee bi nso ne se, enam se wontumi nye adwuma biara mfa sika
mma fie nti wannyammoa titire biara mfiri abusua fo ho. Abusua a won dee
wonya anigye boa won mma a wowo tebea saa mu no, enkye na wobfo fam w
sikasem mu. Yei tumi de ohia beto abusua no so. Sika kakra a obi de betua
kaasika akagye ne nnuro de bi ato nnuane adi atumi anonon ne nnuro no tumi si
kwan ma obi gyae ne nnuro nom kora.

Se ebeeye a wobekura won mudie mu na wonnya animguasee biara nti, nnipa
dodoo no ara a wowo yaree-ko-ankr no ho won bra se won a wonni yadee biara.
Wode yadee yi sie a wonka obiara nhunu. Eno nti se ekoo ba se worebeware a, na
aye kdaanna. Nokore ni, saafafo yi ya shaw kesee mu wo awaresem mu. Se obi
kose won pe na wampene so a wese wonnte won ase. Se wopene so nso a wese
wopo se won yadee no sae nkrofo ntira. Nhwehemu yida no adi nso se, nnipa
dodoo no ara a wobfo won adzfonon ne abusuafo amanee wo won yaree ho no,
annya mmoa biara amfiri won ho. Enu kakraa bi na wonnya mmoa kakra.

Enam se ART ye asfeoo nti, PLHIV ne ayaresa adwumayefoc ahodoo a won na
wotaa ne won a wonya HIV hyia no nyaa aynkofa soronko kora. Adwumayefoc
asfoor ci nso a wodi won dwumadie wo afie mu ena PLHIV akuo ahodoo ne
PLHIV fooc yi dii nsawrcoc a emaa won ahomeka. Woboo a won maawo ntumi t6 ko
so gyina VCT ne ART mu ara. Saa akuhodoo yi a won a wowo yadee-ko-ankr yi
bi na akeka won ho abobom no ateetee yi tumi boa ma ekuo mma no nya kuay wu
adesuahodoo ma eboa won asetena ne sikasem mu. Wkyerekyere won kuomma
samina yi ne ade a na etumi de sika bre won. Se yede sika hye saa akuo yi
dwumadie ahodoo yi mu a, eboaba abo ban ne fapem de mpontuo abre won a
wosyare yaree-ko-ankr yi, na ama won daakye asetena sem mu aye yie.
About the author

Benjamin Kobina Kwansa obtained his Master of Philosophy in African Studies from the Institute of African Studies, University of Ghana, Legon, in 2005. Between 2002 and 2006 he worked in various capacities at the Institute of African Studies, both at the Family, Population, and Development Unit, and at the Care and Globalisation Project (sponsored by the Norwegian Programme for Development, Research, and Education [NUFU]). In September 2006, he took the position of PhD researcher at the Amsterdam Institute for Social Science Research (AISSR), University of Amsterdam, the Netherlands. His research interests are in the areas of constructions of masculinities, gender, and health; HIV/AIDS; sexual and reproductive health; religion and health; and family, population, and development. He currently teaches part-time at the Institute of African Studies, University of Ghana, Legon.
Stigmatization of people associated with HIV can be devastating, even more so than the virus itself. It destroys the lives of HIV positive people and their loved ones. All too often in Ghana, those with no direct HIV experience do not see the depth of the impact of stigma on individuals, households and communities. This monograph, the result of fifteen months of ethnographic fieldwork in two communities in Ghana, brings to the fore the lived experiences of people infected with and affected by HIV from their own perspectives. In particular, their negotiations between resignation to fate and the struggle for survival as they cope with stigma are presented. Significantly, this book shows that being infected with or affected by HIV is as much a social issue as a medical one, and those associated with HIV/AIDS require more than medical care and support. Concentrated efforts by all stakeholders – social and political leadership, the untested, the uninfected, the infected, the affected, service providers and policy makers – would go a long way to reduce the main problem that persists with regard to HIV prevention and treatment in Ghana: stigma.

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