HIV/AIDS treatment in two Ghanaian hospitals : experiences of patients, nurses and doctors

Dapaah, Jonathan Mensah

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Jonathan Mensah Dapaah

This book is dedicated to:

My mother, Madam Afia Nsiah,
My wife Dorcas and
My two daughters, Adoma and Nyarkoa.

Contents

Preface

This thesis is the outcome of fieldwork carried out in the voluntary counseling and testing centres and antiretroviral therapy clinics in two Ghanaian hospitals, St. Patrick's Hospital at Maase-Offinso and Komfo Anokye Teaching Hospital in Kumasi, both in the Ashanti Region. Data on counselling and testing was also collected in the VCT centre of Suntreso Government Hospital in Kumasi. I owe a lot of gratitude to large number of people and institutions for their contribution to this work.

First and foremost, I want to thank Professor Dr. Sjaak van der Geest, my principal supervisor who read all the drafts of this thesis with insight and patience. His thoughts, ideas and suggestions have been valuable and important to me. I really benefited from his questions and critique which encouraged me to work hard to complete this monograph. Indeed, Sjaak was a 'father' who guided me at every step throughout my PhD. programme.

I also thank Dr. Rachel Spronk, my other supervisor who closely followed the progress of my dissertation from the onset to the end. Her insightful comments and suggestions have not only been encouraging but also made me feel that I was on course with the write-up. Rachel together with Sjaak were constantly in touch with me during fieldwork and visited me in the field to see my progress of work. In fact, the two supervisors supported me in my difficult moments during the writing of this monograph and this encouraged me to persevere and pull through. My thanks to both of you will never end (*Meda mo ase ɛnsa*).

I am grateful to Professor Dr. Kodjo A. Senah of the Department of Sociology, University of Ghana, my home supervisor for his useful comments on the earlier versions of this thesis. I appreciate his helpful advice which impacted greatly on me throughout the period for my PhD programme. I wish to thank Dr. Frances Owusu Daaku of Department of Clinical and Social Pharmacy, Kwame Nkrumah University of Science and Technology, Kumasi who generously allowed me to use her office to work on my dissertation whenever I was in Ghana.

My deepest gratitude goes to the staff of the hospitals for this study. I am particularly grateful to health workers in the voluntary counseling and testing centres and the antiretroviral therapy clinics in the hospitals for allowing me into their work setting to participate in and observe various activities and events during provision and use of services. Special thanks goes to Dr. Maxwell Kankam, the former medical doctor in-charge of the HIV/AIDS programme at St. Patrick's Hospital and Suzane (pseudonym), the nurse-in-charge of the HIV/AIDS clinic in Komfo Anokye

Science Research (AISSR), which made it possible to organize the Stakeholders workshop in December 2009 in Kumasi.

I acknowledge with sincere gratitude the role of my family in this academic endeavour. My mother, Madam Afia Nsiah, my siblings, Dr. Harrison Kwame Dapaah, Harrison Kwabena Dapaah, Maxwell Bruku Dapaah, Fredrick Dapaah, Felix Dapaah, Dapson Dapaah, Richard Denteh and Mary Dapaah were very helpful with practical support that spurred me on to work hard. I wish to thank all my friends and colleagues in Ghana and the Netherlands who contributed to the successful completion of my study.

This research involved almost one year of coursework in Amsterdam followed by one year of fieldwork. I was away from my wife and children for the first year and rejoined them during the fieldwork. I was away from them again most of the time during the third and fourth year of my study. During these long periods of my absence from home, my wife, Dorcas, bore the burden of taking care of our two lovely daughters, Adjoa Adoma Mensah Dapaah and Yaa Nyarkoa Mensah Dapaah. I wish to express my deepest gratitude to her for her trust and support. Her encouragement during the fieldwork greatly inspired me. My heartfelt thanks also go to Adoma and Nyarkoa who had to miss the company of their father for a long period of time, but quickly bonded with me when I came back.

Finally, I am particularly grateful to God for seeing me through my PhD. trajectory successfully. To God be the glory for bringing me this far in my academic career.

Jonathan Mensah Dapaah
March 2011

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Introduction

Setting the scene

It was early in the morning around 7:30 when a lean and frail patient walked into the antiretroviral therapy clinic with a referral note from the voluntary counselling and testing centre, which showed that she tested HIV-positive. Serwaa reported to the clinic unaccompanied, looking tired for walking from the centre to the clinic, a distance of about 300 metres. Benedicta, a nurse, received Serwaa and offered her a seat. She welcomed her and asked about her health. Serwaa replied:

> Madam Nurse, what I am feeling within my body [she demonstrated this with her hands] is a sign that it is not well with me at all – not healthy. In fact, I find it difficult to walk because my heartbeat is faster than normal. I easily get tired after walking over a short distance. So, I have to stop and rest for a while and continue again. It took me more than thirty minutes to walk here from the centre where I was given this paper/note. I can see that I am really sick…

Benedicta assured her that her health problem could be treated in the clinic. She told her that there were medicines to help her get better after going through certain procedures. The nurse registered Serwaa as a new client and filled some laboratory test request forms for her. Benedicta escorted the client[1] to a laboratory outside the clinic to do one of the tests, then hired a taxi and paid the fare for the client to be taken home. In fact, the nurse stopped the work she was doing in order to help Serwaa access services and get back home.

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[1] People who accessed services in voluntary counselling and testing centres and antiretroviral therapy treatment clinics are referred to as clients in this study. The reasons why they are called clients and not patients, especially those who accessed services in the clinic are explained in Chapter Three of this thesis. Besides, people living with HIV/AIDS or HIV-positive patients are also referred to as 'positive persons' in this study.

About one month later, this researcher met Serwaa in the clinic, this time looking slightly healthier compared to that first day. She said in the course of conversation that nurse Benedicta had turned out to be her 'saviour' (*agyenkwa*) on her first visit to the clinic. According to her, the nurse's support had helped her stay alive and she had felt encouraged to continue accessing services. She added:

> I have not forgotten what this nurse did for me at a difficult time my relatives were less concerned about my ill-health… When I recover fully and start working again, I will do something special to show my appreciation for the time and money she spent on me. Although I did not know her, she was so good to me and made me feel that there are still some nurses who are interested in the welfare of helpless patients like me…

On another visit to a voluntary counselling and testing centre to discuss the possibility of sitting in counselling sessions with staff, I met a counsellor in conversation with a client who had been referred for HIV testing by a medical doctor. The time was about half past noon the lunch break for most Ghanaian workers. Below are excerpts of the conversation between the counsellor and Bonsu, the client, who looked desperate from his facial expression:

> *Counsellor*: Why are you coming for counselling and testing at this time of the day again? Frankly speaking, I am tired and I cannot talk any more for the rest of the day. Even teachers who are noted for talking too much often stop talking to take a rest when they are tired. I have been talking, counselling clients the whole morning and I am too tired to talk again now. Maybe you can go and come back later because I am taking my lunch break at the moment. Or you can come back tomorrow early morning.

> *Client*: Please, I beg you; help me! You remember I was here yesterday around 4 PM and you said it was late. I went back home in another community outside town. Today, I have managed to come earlier than yesterday, yet you are complaining of tiredness. Please, attend to me today because I need the test result as soon as possible...

After the lunch break around 2 PM, the counsellor assisted the client and the test result was negative. In conversation, Bonsu explained that he needed the HIV test result urgently to process his documents for travelling abroad. According to him, the embassy of the country he wanted to visit has made HIV-negative status a requirement for granting travelling visas. It took Bonsu more than one day to access a service that should have taken just an hour. He pointed out that the behaviour of the counsellor nearly discouraged him from doing the test at all. To the client, the counsellor behaved as if he were doing him a favour although he is paid for the services he provides. Bonsu added:

> [...W]hat the man [counsellor] must know is that it is because of patients that health care providers are working in the hospital. But I did not have a choice and I had to persuade him to attend to me without further delay… otherwise I would have stopped the test altogether… If you [researcher] are also a worker here, you have to advise your colleagues to behave well towards people who come to them for services…

Perhaps the counsellor's behaviour towards Bonsu was genuinely due to tiredness from heavy workload, but he could have interacted and talked to the client in a more

polite manner than what has been described above. He could have asked the client to allow him some time to take his lunch break and arranged to see him afterwards, which I believe Bonsu would have understood.

The cases of Serwaa and Bonsu are two somewhat extreme examples of the kind of social interaction between health workers and clients, and the outcomes of such interaction. These are multi-faceted attitudes and behaviours and reveal layers of meaning within the ways health workers relate to and treat clients during clinical encounters in centres and clinics. The two cases contrast with each other in many respects and need to be looked at critically. While the nurse warmly received Serwaa, assisted her in accessing services and paid her transport costs, the counsellor was rather impatient and talked impolitely to a client who voluntarily wanted to access services. More importantly, the case of Serwaa shows that some health workers who provide these services do treat clients well, contrary to the often-held view found in most literature that they mostly show negative attitudes towards them. Besides, as Serwaa pointed out, the good attitude and behaviour of the nurse encouraged her to continue accessing care and treatment. On the other hand, Bonsu said that the counsellor's impolite behaviour nearly discouraged him from using the service altogether. This could negatively influence the client's use of the service in the future.

Further, both encounters show that the provision and use of services is not only influenced by the availability of health care facilities and personnel, as is generally believed to be the case in Ghana and certain other sub-Sahara African countries. They indicate that other factors such as health workers' professional practices and conditions in the health care facilities also influence how services are provided and used. These critical but under-recognized factors form the principal themes of the present study. Understanding them is crucial if the country is to take realistic steps to encourage Ghanaians to access voluntary counselling and testing and antiretroviral therapy services as part of the national effort to reduce the spread of HIV/AIDS.

HIV counselling, testing and treatment in Ghana
In Ghana, the scale of HIV/AIDS infection and suffering is not comparable to that in the countries of East and Southern Africa. As of the end of 2008, the infection rate had fallen to a comparably low 1.7 per cent from 1.9 in 2007, though the prevalence rate in 2009 did increase slightly to 1.9 per cent from 1.7 per cent in 2008. Despite these relatively low figures, the Ghanaian government has acknowledged HIV/AIDS as a potential threat to the country's developmental efforts since those infected with the disease are mainly in the productive ages of 25-49 years (Ghana AIDS Commission 2000). Through the Ministry of Health and local and international non-governmental organizations, the government has implemented various intervention programmes to reduce or prevent the spread of the virus since the first case was

reported in the country in 1986. These have led to a general awareness of HIV/AIDS in Ghana. Antwi & Oppong (2003) and GDHS (2003) report that awareness of HIV/AIDS is nearly universal among men and women of reproductive age a fact they attribute in large part to the massive public information campaign aimed at the prevention of HIV infection.

This notwithstanding, Ghana is struggling to contain the disease through the provision and use of HIV/AIDS-related health care services. Initially it was believed that a lack of health care facilities and personnel providing these services accounted for the limited success in increasing voluntary counselling and testing (VCT) (Antwi & Oppong 2003). A UNAIDS country report indicated that in 2002, although Ghana had set out plans to provide antiretroviral therapy (ART) to some 6,000 HIV-positive people, concerns among donors and the Ghanaian authorities themselves regarding the Ghanaian health service's absorptive capacity meant that in the end only an approximate 2,000 people were put on the treatment. As of December 2004, just 1,200 people were receiving treatment through two urban hospitals, with a further 800 cases receiving treatment through two rural providers in the heavily affected Eastern Region of the country. In other words, issues of supply significantly limited access. In contrast, a study on behalf of the WHO in relation to the '3by5' initiative had proposed a target of providing ART to 29,000 people out of 62,000 HIV-positive people who were considered as urgently needing treatment by the end of 2005.

In 2005, the government secured funding from the Global Fund to fight AIDS, Tuberculosis and Malaria to scale up VCT and ART services all over the country as part of the national prevention campaign to combat the HIV/AIDS epidemic. The scale-up exercise was mainly aimed at extending HIV counselling, testing and treatment services to 50 per cent of the 138 districts in Ghana by year end 2007 and all district health facilities by 2009 (NACP 2007). (The present study was not in a position to verify whether this target was achieved or not when it was concluded at the end of 2010.) To increase the accessibility of services across the country, the scale-up trained more health care providers and established new VCT centres and ART clinics throughout the regions with the expectation that availability of services would likely translate into uptake.[2]

Indeed, following the exercise treatment for adults and children increased 63.6 per cent (from 7,338 in 2006 to 11,534 in 2007), while the number of people tested

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[2] It is worth noting that the scaling up has led to a significant increase in the number of voluntary counselling and testing centres and antiretroviral treatment clinics in the country. In 2007, there were 91 clinics comprising public, private and faith-based health facilities, which have been accredited (75 operational) to deliver treatment compared with 46 sites in 2006, and only four sites in 2004 (NACP 2007). In the case of counselling and testing and prevention of mother-to-child transmission, 422 sites had been established at the end of 2007 (NACP/GHS 2008), compared with only 25 operational sites in 2005 (GHS 2005).

for HIV increased dramatically from 71,307 in 2006 to 183,866 in 2007 (cf. NACP, 2007). However, the Ghana National AIDS Control Programme (NACP 2007:5) reports that despite the reasonable success of the scale-up plan, use of these services remains low due to certain factors. They suggest that the persistent stigma and discrimination associated with the disease has discouraged many people from accessing counselling and getting tested. The need for HIV patients to pay fees for some services such as ARV drugs is a further deterrent, as is the general reluctance of many Ghanaians to access health care services at all. It appears that the expected rise in service uptake following the increased availability of VCT and ART services in the country has not been achieved due to a variety of social, cultural and economic factors. This study focuses on a phenomenon that Van der Geest & Finkler (1994) observed in their introduction to hospital ethnography, namely that the hospital setting both reflects and reinforces dominant social and cultural processes of society. As demonstrated earlier in the attitudes and behaviours of the health workers towards Serwaa and Bonsu, the decisive role these socio-cultural factors play in hospital settings, particularly their influence on the provision, uptake and use of services warrants in-depth analysis.

This study set out to accomplish just such an analysis in two hospitals during the VCT and ART scale-up exercise in Ghana. In particular, the study was to conduct an in-depth investigation of the social and cultural factors that discourage or inhibit HIV-positive persons and other people from using VCT and ART services, largely from the supply (provider) side but also to some extent from the demand (patient/client) side. Understanding these factors can inform the government's future plans for the scaling-up exercise to improve the quality of service provision and encourage more people to use services as part of the national effort to reduce the spread of HIV/AIDS.

This study is part of a larger project made up of three interrelated studies on the provision and use of VCT and ART in Ghana. This study, Project A, was carried out in two health facilities providing voluntary counselling and testing and ARV therapy. It examined how conditions in those institutions influenced use of these services. The health facilities were St. Patrick's Hospital at Maase-Offinso, owned by the Catholic Mission, and the Komfo Anokye Teaching Hospital in Kumasi, a public health facility, both in the Ashanti Region of Ghana. Data on counselling and testing was also collected at the VCT centre of Suntreso Government Hospital in Kumasi. With around 4 million people, Ashanti is the region with the largest population in Ghana (GSS 2000) and an HIV prevalence rate of 3.9 per cent as of 2009. This rate is higher than the national rate of 1.9 per cent and is the second highest out of the ten regions in Ghana, after the Eastern Region (GHS/NACP 2009). Project B was also conducted in the communities served by the above-mentioned hospitals. It examined the clients' points of view regarding VCT and

ART and the way the services are provided through medical channels. Social and cultural perceptions of blame, shame and stigma took a central place in this research. Lastly, Project C considers policy-making processes and will synthesise the findings of the above two projects, relate them to district, national and international policies and then translate them into practical recommendations to policy-makers.

This multi-level perspective is a departure from the most common approaches in anthropological research. The approach permits the examination of a problem from the perspectives of different stakeholders at different levels of social organization because different types of actors have different (sometimes conflicting) interests, expectations and agendas (Van der Geest *et al*. 1990). Consequently, the findings are placed in a wide social and political context including national policy, local medical service and people with HIV/AIDS.

Brief historical overview of HIV voluntary counselling and testing and antiretroviral therapy in Ghana
The provision of HIV/AIDS-related care and treatment is a comparatively new service area in Ghana's health delivery system. It took various efforts at the global level over a couple of years before antiretroviral (ARV) drugs were made easily available in developing countries, including Ghana. The introduction of ARV drugs in 1996 and their spectacular results in developed countries was followed by an intensive campaign by different parties at many levels to make the drugs available in developing countries. According to the WHO (2004), the use of the drugs in developed countries has led to a 70 per cent decline in deaths due to HIV/AIDS. Individuals infected by the disease were not only living much longer but also more productively. The drugs brought new hope to millions. Furthermore, they also greatly helped to transform the perceptions of HIV/AIDS from that of a hopeless fatal disease to one of a more manageable chronic illness – a dramatic shift that has effectively motivated people to know their status.

However, the benefits of drugs were reserved almost exclusively for industrial-ised countries, which bear only five per cent of the global burden of the disease. In 2003, of 38 million people living with HIV/AIDS in developing countries, between five and six million in the advanced stages of the disease urgently needed treatment, and only about 300,000 had access to it. In sub-Saharan Africa, more than four million people needed treatment, but only 50,000 had access: slightly less than two per cent (WHO 2003). In other words, in poor countries where HIV/AIDS was spreading rapidly, and individuals, families and communities continued to reel under its devastating health, social and economic impacts, there was limited access to drugs. A vigorous and sustained campaign was needed to address this disparity and make the drugs available in resource-poor countries.

The main reasons for the lack of access to the drugs in developing countries were prohibitive prices and a lack of funding for health care. Prohibitive drug prices are often the result of strong intellectual property protection.[3] Governments in developing countries that attempted to bring down the prices of medicines came under pressure from industrialised countries and the global pharmaceutical industry not to do so because that would adversely affect their profits. For instance, in 2001, 39 drug companies took the South African government to court over its Medicines Act designed to provide affordable drugs to people living with HIV/AIDS (MSF 2005).

However, the persistent efforts of the United Nations, UNAIDS/WHO, the governments of developing countries, the donor community, non-governmental organizations (NGOs), AIDS pressure and advocacy groups, and individual actors on the global scene generally led to the reduction of ARV drugs prices.[4] This paved the way for the drugs to be made available in resource-poor settings including Ghana. They were first introduced in the Ghanaian public health sector in September 2002; although ARVs were already available in some private health facilities and through individual sources, they were offered at exorbitant prices, and only a few Ghanaians living with HIV/AIDS had access to the drugs at that time.

With regard to voluntary counselling and testing, which is a relatively new area in Ghana Health Service, its provision started in a different form in the early 1990s before the advent of ARVs. Awusabo-Asare (1995) observed that counselling in the health care system was beginning to be offered around this time in Ghana and other sub-Saharan countries, mostly in the form of advice from 'experts' to patients and their relatives (1995:232). The services as they are provided presently became more widely available during the early 2000s with the steady increase in the HIV infection rate. They were provided by a few government health facilities, mission hospitals and some NGOs working in the area of sexual and reproductive health.

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[3] The 1995 World Trade Organization (WTO) Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement sets out minimum standards for the protection of intellectual property, including patents on pharmaceuticals. These standards derive from wealthy Western nations and they are not necessarily appropriate for developing countries. TRIPS Agreement has come under fierce criticism for this "one-size-fits-all" principle because of its effects of increased levels of patent protection on drug prices (Médecins Sans Frontières [MSF] 2005).

[4] It is worth mentioning one important event that facilitated access to ARV drugs in developing countries including Ghana: The United Nations General Assembly Special Submit on AIDS (UNGASS), held on June 25, 2001. The summit was dominated by debate over generics and merits of investing in prevention versus treatment. The consensus was that these were inseparable, and that treatment could be used to bolster prevention efforts since people needed to be tested in order to receive care. At the UNGASS amid more protests led by Health GAP (the Health Global Access Project), world leaders signed a Declaration of Commitment that served as a roadmap for the current rollout. It reflected nations' new-found political commitment to AIDS treatment as an issue of human rights. Under the leadership of Kofi Annan, the then-UN Secretary General, the Global Fund for Tuberculosis (TB), AIDS and Malaria was launched to fund nascent national programmes as a follow up to the UNGASS (UN 2001). It is through the Global Fund that Ghana for instance received funds beyond World Bank financial support for the on-going scale-up of VCT and ART all over the country.

Following the increased access to ARVs in 2002, HIV clinical activities in Ghana began to undergo a dramatic change. Family Health International, an international NGO, in collaboration with the Government of Ghana started the Support and Treatment for Antiretroviral Therapy (START) project. The project was aimed at integrating antiretroviral therapy into comprehensive care for people living with HIV/AIDS, and it was funded by the United States Agency for International Development (FHI 2006). Voluntary counselling and testing and antiretroviral therapy services in Ghana were given a further boost following the preparation of various policy documents including the 2002 Guidelines for Antiretroviral Therapy and the 2003 National Guidelines for Development and Implementation of HIV Voluntary Counselling and Testing.

START began project implementation in 2002 by establishing voluntary counselling and testing centres in the project area. This was followed by prevention of mother-to-child transmission (PMTCT) activities, and clinical care services at Atua Government Hospital and St. Martins de Porres Catholic Hospital, Agomanya in Manya Krobo and Yilo Krobo Districts respectively. The health facilities for these two rural districts located in the Eastern Region were selected for the VCT and ART pilot study because they had the highest HIV infection rates in the country. According to the 2003 HIV Sentinel Survey Report, each of the two districts had an average prevalence rate of more than five per cent, higher than the national average HIV infection rate of 3.6 per cent. With such a high prevalence rate, positive people were easily identified in the communities and were often stigmatised (FHI 2006). Skinny and very sick people were suspected of having the infection which in many cases led to stigmatisation by relatives and community members.

In 2002, only women were targeted for antiretroviral therapy treatment services for the prevention of mother-to-child transmission (cf. Antwi & Oppong 2003). Voluntary counselling and testing were effectively made the entry point for access to treatment. Working with local NGOs, the START project developed a comprehensive communications strategy to promote the services, increase prevention efforts and reduce the stigma associated with the disease. The project report indicated that most of the positive people who began antiretroviral therapy became healthy and lived longer.

In August 2003, the British Department for International Development (DfID) awarded Family Health International an additional grant to expand its activities in the two rural districts. The project introduced treatment for other positive people in addition to its services to prevent mother-to-child HIV transmission. Other stakeholders also collaborated on the project, including USAID, the Ministry of Health (MOH) Ghana, the National AIDS and STI Control Programme, the Ghana AIDS Commission, the Ghana Health Service, UNICEF, UNAIDS, local NGOs and faith-based organizations.

The lessons learnt from the START pilot project helped to scale up services to Ghana's two teaching hospitals; Komfo Anokye Teaching Hospital in Kumasi and Korle-Bu Teaching Hospital in Accra. In 2004, the two teaching hospitals – which are also tertiary health facilities – started providing voluntary counselling and testing services, and antiretroviral therapy treatment to people who tested positive for HIV. Three privately owned health facilities were allowed in 2005 to provide VCT and ART services after satisfying the necessary human resources, logistics and equipment requirements of the National AIDS and STI Control Programme and Ghana Health Service. The private health institutions were Holy Trinity Hospital, Nyaho Medical Centre and Akai House Clinic, all based in Accra. The scaling up of services to health facilities located in Accra and Kumasi meant that positive persons in the northern and central regions of Ghana, and those at the coastal areas did not have to travel long distances to access ARV drugs at Atua and Agomanya in the Eastern Region.

The key components of the initial voluntary counselling and antiretroviral therapy programme in the two rural health facilities in Manya Krobo and Yilo Krobo districts included counselling, testing, home-based care, referral networks and linkages to such existing services as spiritual and social support, and support for orphans and other vulnerable children. However, when the services were expanded to include the two teaching hospitals, other clinical care services such as tuberculosis treatment in addition to those mentioned above were provided.

Presently, with more funding from the Global Fund for Tuberculosis, AIDS and Malaria and World Bank, the government is continuing the scaling-up of voluntary counselling and testing and antiretroviral therapy services in all parts of the country. The scaling up includes government, faith-based and private health facilities across the country and it was expected that this would make services more accessible to the approximate 71,000 Ghanaians who needed to be placed on ARV drugs as at the end of 2006, according to the National AIDS/STI Control Programme.

This brief overview shows the conscious effort made at the international and national levels to make HIV/AIDS-related health care services, particularly antiretroviral therapy, accessible in Ghana. Despite these provisions to improve access to care and treatment, the National AIDS/STI Control Programme reports that uptake of these services is still low. To understand why, more analysis is needed, particularly with respect to the social and cultural dynamics of the provision and use of these services. This empirical study aims to fill some of those gaps, joining in the debate on the potential reasons for the low uptake of HIV counselling, testing and treatment, as well as ways to encourage more people to access services.

Study questions and objectives

Voluntary counselling and testing and antiretroviral therapy are relatively new concepts in Ghana's health policy and have not been studied much from the social sciences perspective. Some early exceptions are Awusabo-Asare & Marfo (1997), Awusabo-Asare (1995), Brugha (1994) and Ego & Moran (1993). The study by Awusabo-Asare & Marfo reported that the refusal to treat positive persons, refusal to work in HIV/AIDS facilities, maltreatment of positive persons and inequality in treatment between infected and uninfected patients were forms of HIV/AIDS-related discrimination shown by health care professional in the health care facilities. The other study by Awusabo-Asare was mainly a description of the approaches adopted in three district hospitals to provide community education and counselling for communities, patients and their relatives on HIV infection. Brugha's study, which was also carried out in a district hospital, dealt with approaches to the provision of HIV counselling services. The author recommended that a primary health care approach, mobilizing community participation and intersectoral support should be used to provide services. Lastly, Ego & Moran's study looked closely at a counselling training project in a district hospital. They recommended professional counselling training for all counsellors because it offers appropriate skills to enhance medical and nursing care for positive persons.

These studies were mostly centred on the logistics of providing counselling or treatment to positive persons with little emphasis on the socio-cultural factors that influence the provision and use of VCT and ART. There is evidence however of under-utilisation of VCT centres and ART clinics even while efforts were underway to scale up provision (GAC/GHS 2007) For this reason, research needs to be conducted in order to inform the government and other stakeholders on how the scale-up of services throughout the country can be carried out effectively. In addition, more systematic studies of the services as social and cultural phenomena in health care institutions are needed to foster a broader understanding of the factors which influence their provision and use. This study focuses on health workers and their activities in VCT centres and ART clinics. Clients are the secondary target group.

The main objective of the entire project is to determine how the uptake of VCT and ART can be increased in the Ashanti Region and, more generally, in Ghana. In this specific study, the central question is: How do the attitudes and behaviours of health workers influence the provision and use of voluntary counselling and testing and antiretroviral therapy treatment? To answer these questions, the channels and mechanisms by which health workers provide VCT and ART will be described. The hospital is often presented as an arena of social relations which affects the well-being of clients (Van der Geest & Finkler 2004). This study, therefore, attempts to

describe the perception and approach of health workers towards clients. It further looks at the workload of staff and how this affects services. The study also examines the issues of confidentiality and privacy in the provision of counselling, testing and treatment services. Finally, the study analyses the influence of the issues mentioned above for the use of voluntary, counselling and testing and antiretroviral therapy treatment.

In Ghana, most HIV-positive persons prefer to keep their status secret from relatives and friends due to the fear of stigma. The findings of this study will help the Ghana Health Service and other Ministries, Departments and agencies in the country develop appropriate new information, communication and education (IEC) messages for the general public on the available care, treatment and support clients and caregivers can expect. The study will further contribute to the body of knowledge that will help shape policies on treatment and care by the Ghana AIDS Commission (GAC) and the National AIDS Control Programme (NACP), which is part of the Ghana Health Service (GHS). Most of the activities and interventions so far developed and implemented to prevent and control HIV/AIDS in this country have been developed elsewhere. Most of the programmes aimed at reducing the spread of HIV in Ghana were adapted from East Africa where efforts at combating the disease have achieved reasonable success. The local social-cultural milieu of such interventions and their impact on beneficiaries have not been adequately explored. Findings from this study will enable the implementation of culturally sensitive interventions that address the needs of positive persons and their caregivers. Ghana has received financial assistance from multilateral and bilateral agencies for HIV/ AIDS prevention and control of which the on-going scale up of VCT and ART forms part. The findings of this study will provide a firm empirical basis to support future applications to the Global Fund and other funding agencies from which additional assistance will be sought.

Leading concepts

Three concepts run throughout this thesis to help explore the key influences and processes of the provision and uptake of voluntary counselling and testing and antiretroviral therapy treatment. One, stigma, is a common theme in HIV/AIDS literature. I will study the mechanisms of stigma to understand the fear associated with the use of HIV/AIDS-related health care services. Second, in order to analyse interaction between health workers and clients, the concept of agency is helpful. Third, I look at how clients use people in the clinic as members of their therapy management group (Janzen 1987) to take decisions on treatment and other related issues instead of their relatives.

Stigma

This study takes the concept of stigma as the overriding factor which influences the provision and use of HIV counselling, testing and treatment services. The word 'stigma' comes from the Greek term meaning a bodily sign cut or burned into individuals such as slaves, traitors, and criminals whose moral character was considered tarnished (Goffman 1963). Goffman defined stigma as "an attribute that is deeply discrediting within a particular social interaction," a "spoiled identity" and a "deviation from the attributes considered normal and acceptable by society" (Goffman 1963). Mbonu *et al*. (2009) contend that today the term 'stigma' is applied more to social disgrace than to any bodily signs (2009:2) as it is used in relation to certain diseases like leprosy. They also observed that stigma is used to set affected persons or groups apart from the normalized social order ('us' against 'them') and this separation implies devaluation. For the analysis of this present ethnographic data, I will adopt Van Brakel's definition of stigma: a social process or related personal experience characterised by exclusion, rejection, blame or devaluation, that results from experiences or reasonable anticipation of an adverse social judgement about a person or group (2005:3).

As an illness, HIV/AIDS has several attributes that render it likely to evoke stigma. HIV infection is frequently considered to be the result of immoral or deviant behaviour that is viewed as the responsibility of the individual. It is perceived as a threat to the community because it is contagious. AIDS is also considered a degenerative disease resulting in death (Alonzo & Reynolds 1995, Herek 1999, Niehaus 2007). Mwinituo & Mill (2006) report that in Ghana, particular behaviours such as prostitution are considered disgraceful, and persons practising prostitution are often stigmatised. The authors point out that the early association of AIDS with prostitution, combined with the reality that most cases of AIDS in Ghana are acquired through sexual transmission have provided fuel for the stigmatisation of the disease and those who are infected (see also Radstake 2000 & Crentsil 2007).

According to Brown *et al* (2003), there are two forms of stigma: felt/perceived and enacted (see also Van Brakel 2005). Felt stigma refers to real or imagined fear of social attitudes and potential discrimination arising from particular undesirable attributes of a disease (such as HIV) or association with a particular behaviour or group (e.g. homosexuality, promiscuity). Enacted stigma on the other hand refers to actual experience of discrimination such as health workers disclosing clients' status to others, denying clients treatment or distancing themselves from clients.

Consequently, the HIV/AIDS epidemic has led to a wide range of reactions from individuals, communities, and even nations, ranging from sympathy and caring to silence, denial, fear, anger, and violence. In Ghana, HIV-positive persons often experience shame (*animguaseɛ*), loss of respect (*onni buo*) and honour (*ɔnni animuonyam*) in the eyes of relatives and members of society. These manifestations

of stigma might also lead to negative repercussions such as divorce, rejection, ostracization, discrimination and loss of job.

Studies have shown that stigma can have many negative effects on HIV testing and treatment-seeking behaviour, willingness to disclose HIV status, health-seeking behaviour, and quality of health care received, and social support solicited and received (Brown *et al*. 2003, Niehaus 2007, Nbonu *et al*. 2009, Chijioke *et al*. 2009). Since the focus of this study is on the provision and use of services, I will apply the fear of stigma to help explain why people with HIV fear going for counselling and treatment and to help understand the choice of locations in the hospitals where people can access VCT and ART and keep their status private. It will also be useful to analyse clients' views on issues of confidentiality in relation to the provision of services and on preventing others from knowing their seropositive status. Besides, the concept of stigma will help to explain the attitudes and behaviours of health workers towards clients during interactions in clinical encounters. Lastly, it will be used for further understanding of the reasons for the utilization or non-utilization of VCT and ART by some clients and other people.

Agency

The persistent stigma associated with HIV infection makes it imperative for clients to devise strategies and secretly use counselling, testing and treatment services. This will enable them to conceal their status from relatives and friends and also prevent stigmatisation. To understand how clients manage the fear of stigma related to the up-take of VCT and ART, I will contextualize them as actors who have the capacity to act and take decisions to use services in the facilities in safety. I am interested in how clients appraise the risk of being exposed as positive persons against the benefits they will derive from accessing services, leading to a particular choice of action or inaction. The term agency, then, suggests intention or consciousness of action, sometimes with the implication of possible choices between different actions (cf. Giddens 1984). Hays (1994) also contends that agency can be understood as human social action involving choices among the alternatives made available by the enabling features of social structures, and made possible by their structural constraints. Hays use the term 'choice' to denote agency because it directs our attention to the central point that is implied in the definitions of agency: alternative courses of action are available, and the agent therefore could have acted otherwise.

These tenets of agency also apply to the provision and use of health care services in the hospital. Patients do possess the ability to act and make choices on the use of services. Gerrits (2010) reports in her study of a Dutch fertility clinic that women with fertility problems make decisions about entering, not entering or withdrawing from the medical field, and – once having entered the clinic – they decide what treatments they want to undergo. Clients making the decision to use HIV/AIDS-

related health care services face a similar choice of action on a scale of possibilities that entail both medical benefits and social risks.

Hays' definition of agency also implies that agents' freedom of choice is not stable since choices are always socially shaped and this could have an impact on their decisions to act. Hays cites Emile Durkheim's contention that agency in this sense is not a matter of 'pure will' or absolute freedom, but is instead an individual and collective autonomy made possible by the constraining and enabling features of social structure. From this perspective, the uptake of VCT or ART can seen to be not simply an issue of free will but of certain social and structural or institutional factors within and outside of the health care setting that could obstruct or facilitate the use of services. The constraining factors in this case are those which could reveal clients' status to others in the hospital, whereas the enabling factors are those that could enhance clients' use of services and conceal their status from others.

The Durkheimian concept of agency will thus be useful for explaining how clients manoeuvre in the hospital setting to use counselling, testing and treatment services in the face of the persistent stigma associated with HIV/AIDS. It will help to analyse how clients act and strategize to access services in various locations in the hospitals and avoid identification. In addition, I will use this concept to explore different ways that clients use the clinic that go beyond its role as a public health facility and a place for accessing services. I will also use the concept to examine the relationship between clients and health workers and to consider what other things health workers do for clients besides providing care and treatment. Lastly, using this concept I will look at the ability of peer educators (who are also positive persons) to manage their relationships with the health workers in the clinic and their continued presence in the facility in a volunteer capacity. I address clients and peer educators as active social agents with their own experiences and actions in the hospital setting. Instead of viewing clients as passive subjects in the centres and clinics, I consider them as having an active role in deciding how and where to use services because this will help them to live longer lives with the disease.

Therapy management group
In Ghana, patients are mostly cared for by their kin and in some cases, the patient's friends and neighbours also help care for him. Crentsil (2006) in her study on death, ancestors and HIV/AIDS among the Akan pointed out that caregiving during sickness signifies one of the most important periods in which the encompassing nature of their matrilineage becomes visible. Caring for the sick person means trying to restore them to health, and it also contributes to the way people make sense of ill-health and illnesses in general. The role of close relatives as carers extends to the hospital setting, where they accompany the patient to access services and help him with informal care in the admission ward. This assures the patient of the constant

social support of his relatives, and he will never completely lack someone to care for him in times of difficulty.

The kinship group members who come together to play this social role for the patient are referred to as the therapy management group (Janzen 1987). Janzen espoused the therapy management group concept in his study on the search for therapy among the BaKongo of Lower Zaire.[5] He defines the therapy management group as a 'special-purpose group' – a set of individuals involved with the sufferer to lend assistance or assume authority in a diagnosis and therapy. Janzen characterises the group mainly as a set of close kinship group members who care for the sick person.

The group works on the principle that whenever an individual or a set of individuals becomes ill or is confronted with overwhelming problems, various maternal and/or paternal kinsmen, and occasionally their friends and associates rally for the purpose of sifting information, lending moral support, making decisions and arranging details of therapeutic consultation. The therapy management group thus exercises a brokerage function between the sufferer and the specialist (1987:68). Similarly, Bossart (2003) who studied the role of social networks in times of illness in Cote d'Ivoire observed that the main source of assistance in response to affliction is household members. Apart from emotional and moral support, relatives outside the household and non-kin such as friends also play a role in the care and treatment of the sick person. They sometimes provide financial support to the patient.

However, in the case of HIV infection, the stigma associated with the disease makes it difficult for positive persons to use their relatives as members of their therapy management group. Clients would have to reveal their status to relatives, which they generally prefer not to do, given the risks of social rejection, divorce and discrimination. Since they need people to help them make crucial decisions about treatment and other issues related to their status, clients have to find other ways of forming this group. Employing the concept of the therapy management group, we can identify how clients used other people outside their families as 'therapy managers', forming another type of therapy management group in the facilities, away from their family homes. We will examine how clients work with these alternative, non-kin therapy management groups within the hospital to make important decisions and to avoid identification as positive persons, in particular concealing their status from relatives and managing the persistent stigma associated with the disease.

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[5] Zaire is now called Democratic Republic of Congo.

Outline of the book

This book is divided into eight chapters, with the present chapter providing an introduction to the research topic. It also presents the research questions and objectives, and the overarching concepts and themes that will appear throughout the course of the book.

Chapter 2 is about hospital ethnography. It describes the ethnographic methodology used in this study including issues related to gaining access to the hospital, taking on the role of researcher and approaches to data collection. The chapter ends with methodological reflections, which highlight some of the challenges of conducting an ethnographic hospital study.

Chapter 3 mainly describes the study sites: the hospitals, their locations and the locations of the VCT centres and ART clinics in the hospitals. The second part of the chapter is a description of the procedures for the provision and use of services. It concludes with some general comments on service provision.

Chapter 4 is about the possible repercussions of accessing treatment – social risks of using HIV counselling, testing and clinical services. As one of the four empirical chapters of the study, it presents individual and structural/institutional factors which influence the provision and use of counselling, testing and treatment. These factors are mainly centred around confidentiality and privacy in the provision and use of services. It further discusses the implications of these factors for clients who access the various services.

Chapter 5 describes how health workers deal with clients during the provision and use of services, looking at their attitudes and behaviours during interactions in the centres and clinics. Describing health workers' perceptions of and approaches towards clients during clinical encounters, it also addresses how these factors influence the use of services. This chapter rebuts the common view that health workers mostly display negative attitudes towards clients and highlights the good practices of health workers that can encourage use of services.

Chapter 6 has peer educators as its main focus. It analyses their work and role in the clinic. The chapter examines the challenges peer educators face in the clinic and how they have themselves benefited from their work despite their own status as HIV-positive persons, which is very often stigmatising in Ghana.

Chapter 7 explores the use of the clinic as a home by clients to safely go about some activities and conceal their status from spouses, relatives and others. The chapter further discusses how clients have used the clinic to avoid identification as positive persons and stigmatisation.

Chapter 8 is the conclusion of the book. It looks at the implications of the methodological approach used in this study. The chapter further examines the significance of hospital ethnography with emphasis on the clinic versus society. It

analyses the relationships between doctors, nurses and clients and their implications for the provision and use of services. Finally, it explores how policy makers and health workers can deal with the perceived stigma associated with the use of services and encourage more people to take up counselling, testing and treatment services. This is formulated as a series of questions and answers, which health workers could consider as a guide in their campaign to reduce or solve the problem of HIV-stigma.

Hospital ethnography

> I like the way you are doing the research …because, apart from interviews, which we are used to in the hospital here, you always find time to join health workers to see how we do our work. Whenever you come to the counselling room here, the conversations we engage in have personally helped me to understand what your research is about... I believe this has also helped you to get the appropriate information you are looking for… (Prince, a counsellor).

This chapter describes procedures used to collect data in the health facilities for the present study. It enables readers to assess the validity and credibility of the study findings. The quotation above illustrates the positive reaction to the research methodology in the health care setting. The comment shows that some health workers appreciate the need for the researcher to participate in and observe provision of services in the centres and clinics. It also suggests however that the anthropological approach is not common in the hospital.

Through methodological reflection, I present some experiences in the facilities, in particular the support received from health workers during data collection. This chapter begins with the examination of various data collection approaches used and why they were chosen. The second part contains reflections on a number of methodological issues and their implications for the study.

Gaining access

The 'field' for this study was the hospital. Studies have shown that it is often difficult for social scientists to gain entrée into medical settings for various reasons. For instance, the resistance of physicians to external review or regulation of professional prerogatives (Freidson 1970), and non-public spaces or 'backrooms' in medicine such as operating theatres which are supposed to be entered by only physicians and nurses (Pope 2005) can limit social science research. Van der Geest

(1989) discussed the case of social science research that took place in a Dutch cancer hospital and resulted in conflict when the data were published, to the extent that the report was banned and destroyed by court order. In their introduction to a special issue on hospital ethnography, Van der Geest & Finkler (2004) suggest that the defensiveness of hospital authorities and their hesitation to allow observers in their workplace might be one possible explanation for the limited number of ethnographic studies being carried out in hospital settings, particularly in Western countries.

However, in the case of the present study, the researcher did not encounter serious difficulties in gaining access possibly due to the access route chosen. I used gatekeepers in the hospitals and to some extent my identity as a native of Ghana to gain access to the field (see also Zaman 2003, Gerrits 2010). Gatekeepers are key people or officials in the hospitals who often influence decision-making. I used such people as intermediaries in two different ways: (i) To get permission or approval for the research. (ii) To gain entry into hospital setting for data collection.

Permission

The research team had to obtain two separate ethical clearances for data to be collected in the study hospitals. To get permission from the Ghana Health Service for the study was tortuous to say the least. The process of obtaining permission for the study began with the submission of an application to the ethics committee of Ghana Health Service[1] of the Ministry of Health, Ghana, in August 2007. The expectation was that the application would receive an early consideration since the ethics committee was due to meet in September 2007. However, it took the ethics committee seven months to give clearance to the study, even though the first phase of data collection had been scheduled for twelve months starting from August 2007 to July 2008. The ethical clearance process was characterised by many queries back and forth, some of which were petty and unnecessary to some extent. For instance, the committee insisted that the three projects in the research programme had to state the exact number of study participants. The researchers responded that in most qualitative research, the number of participants is often not clearly stated in the planning stages since it is the fieldwork situation that determines this. The committee initially objected to the researchers' explanation, which delayed approval for the study for another two months. It can be assumed that there were no social scientists on the committee vetting the research proposal for approval; only medical scientists who were not familiar with ethnography.

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[1] The Ghana Health Services (GHS) is the implementing agency of all health-related policies of the Ministry of Health, Ghana. As a results, it is the GHS which is based in Accra, the nation's capital vets all health-related research proposals and gives approval for the studies to go ahead or otherwise.

Throughout the clearance process, the committee raised queries regarding the research proposal that delayed the study by the social science researchers, who are often considered 'outsiders' in the domain of biomedical research. From this researcher's experience, it is clear that the addition of social scientists to the committees that vet health research proposals for approval in Ghana and elsewhere is long overdue. Mulemi (2010) also made a similar observation in his study in the cancer ward of a Kenyan Hospital. He indicated that hospital ethnography did not have a place in the hospital's protocol for research clearance. At the very least, social scientists could sit on these committees to help assess qualitative research protocols, which would promote the role of ethnography in hospital research. Its findings could then be used to improve the quality of care.

This particular study had to start on a low-key level in St. Patrick's Hospital at the insistence of the hospital administrator who was acting as a gatekeeper. Before I arrived in Ghana from Amsterdam to start fieldwork, my supervisor at the Amsterdam School for Social Science Research had contacted the administrator through an email and given him an overview of the research I intended to carry out in the hospital. This initial contact elicited a positive response from the administrator who was of the view that the objectives of the study were laudable and that it therefore could be carried out in the hospital. The very first day I visited the hospital, I met the administrator and identified myself as the Ghanaian student from the University of Amsterdam whom my supervisor had earlier on mentioned to him with regards to a proposed research project at the hospital. He assured me of his support for doing the research in the hospital.

Under normal circumstances, the permission by the Ethics Committee of Ghana Health Service is the first step in the process of gaining access to carry out a study in the hospital, but this was not the case in St. Patrick's Hospital. When it became obvious that the ethical clearance by the Ghana Health Service would take longer than expected, I got the administrator's support to start some data collection activities while I waited for approval. The administrator took my request to the hospital management and I was given internal permission to carry out some limited activities in the VCT centre and ART clinic. Through him, getting permission in this hospital was relatively easy compared to Komfo Anokye Teaching Hospital. With internal clearance by the hospital's management committee I was able to observe and participate in certain activities in the centre and clinic without interviewing health workers and clients. If not for this internal clearance, entry into the hospital to collect data would have been delayed by seven months leaving only five months for the researcher to do the first phase of data collection.

This particular study also required permission from the ethics committee of Komfo Anokye Teaching Hospital. As a teaching hospital, it is autonomous from Ghana Health Service and has its own committee that often gives approval for

research to be carried out in the hospital. The gatekeeper I used to gain access in this facility was the director of the medicine department of the hospital. Before I submitted the application for ethical clearance for the study to this hospital, I learnt that my research topic would be directly under the medicine department's remit. In addition, the director of the department was also a member of the hospital's ethics committee that vets applications for research in the hospital. I therefore contacted him first to get his personal approval for the study, after which I submitted the application to the committee for clearance. Although there was initially a bit of a delay before he gave his personal consent to the study, the director made a case for the application to be approved at the ethics committee. After the application was submitted in August 2007, it took the hospital's ethics committee a little over two months to give the study the go ahead, which they finally did in October 2007. Clearance was delayed due to the fact that the hospital's committee could not meet to vet proposals because some of its members had travelled abroad on official assignments.

Entry into hospital setting
In Komfo Anokye Teaching Hospital, I again used the director of the medicine department as the gatekeeper to gain entry to the hospital for data collection. After the study was given approval by the hospital's ethics committee, the director introduced me to the nursing officer-in-charge of the ART clinic and asked her to give me the support necessary to carry out the study. This set the stage for me to start fieldwork activities in the clinic without problems.

On the first day in the clinic, the nursing officer introduced me to staff as a researcher/student. These included doctors, nurses, pharmacists, dispensary technicians, community health nurses, laboratory technicians, disease control officers, health assistants, health aides, peer educators and a cleaner. It is also worth mentioning that the senior nursing officer and staff in the clinic often introduced me to clients and asked them to cooperate with me whenever I wanted to talk to them.

Similarly, in St. Patrick's Hospital, the hospital administrator who had acted as gatekeeper also helped me gain entry to the hospital setting, in this case by introducing me to the medical doctor in charge of the HIV/AIDS programme in the hospital before I started data collection. After the administrator asked for his support so that I could carry out the study in the VCT centre and ART clinic, I easily gained access to the hospital for data collection. The medical doctor in turn introduced me to the staff in the centre and the clinic as a student/researcher. I was also introduced to clients from time to time by the staff.

The medical doctor in charge of the HIV/AIDS programme at the Suntreso Government Hospital, Kumasi also acted as a gatekeeper for me at that institution. With his support I was able to gain access to the VCT centre of the hospital to

collect data. This was after the refusal of some staff of the Komfo Anokye Teaching Hospital VCT centre to allow the researcher to do participant observation during counselling and testing.

Taking on a role

Once I had gained access to the hospital setting, I still needed to take on a role in the centres and clinics in order to collect data. According to Van der Geest & Finkler (2004), the canons of anthropological research pose special problems for carrying out fieldwork in a hospital, especially how to realize the participatory aspect of the research. To overcome this challenge so that the researcher could be a 'natural' person with a continuous presence in the hospital to collect data, they have suggested three possibilities to choose from: joining the staff, the patients or the visitors. However, in the specific case of this study, I took on the role of an academic researcher as opposed to any one of the three possibilities suggested by Van der Geest & Finkler for the following reasons.

The role of staff in which I could have posed (as a medical doctor, nurse or a counsellor) in the centres and clinics was not attractive because data collected this way would tend to represent the professional's point of view more than that of patients (Van der Geest & Finkler 2004) and others like peer educators. Although this study had health workers as the main target group, clients were to be the secondary target group, and their views were also important. This consideration made the role of staff, which most researchers in hospital ethnography such as Jones (1994), Kuckert (2001) Pool (2000) and Gibson (2004) have taken on, seem inappropriate for the collection of objective data in this case.

In the absence of playing the role of staff, I could also have taken the role of a patient which researchers like Rosenhan (1973), Goldman *et al.* (1970), Nijhof (2001) and Van der Geest & Sarkodie (1998) used to collect data in the hospital. However, as Van der Geest & Finkler (2004) rightly observed, collecting data in the hospital from the patient's perspective is more challenging practically and ethically. With this role, it is possible that the researcher would have to conceal his identity in order to collect data without the consent of the people being studied. Carrying out research in the hospital without the consent of study participants (as is often done when adopting the role of a patient) might be at odds with ethical principles guiding social science research. Besides, many of the researchers who pretended to be patients to collect data in hospital later acknowledged the many problems involved, which made it unattractive for use in the present study. For instance, Rosenhan (1973) described how eight researchers who posed as psychiatric patients and collected data in a psychiatric hospital had problems convincing hospital staff later on that they were not insane. In this study, it was suggested that I might run into a

similar situation to that described by Rosenhan (1973) if I took on the role of an HIV-positive person to collect data in the facilities. In the communities where this study was carried out, one's status as a positive person has serious negative social repercussions for the individual among community members as can be seen in the study of my colleague researcher, Kwansa (2011), and sometimes among health workers – as would be seen later in this thesis – in all facets of life. The role of patient was therefore unsuitable for the researcher to gather data in the centres and clinics.

Apart from the roles of staff and patient, I could have taken the role of visitor as Mpabulungi (1995) did in the ward of a Ugandan hospital, which gave her a natural presence for studying the role of relatives in patient care. The role of visitor, especially in the ART clinics could have given the researcher a natural presence to collect data. On the other hand, I could not have been present in the centres as counselling and testing is confidential and often done on one-on-one basis. It would have been a bit difficult to play this role in the clinics; unlike in the admission wards, visitors to the clinics who are not adherence monitors are not often allowed into the ART clinics to visit patients and help carry out some minor tasks of patient care.

The last possible role I could have taken out of the roles suggested by Van der Geest & Finkler (2004) was to combine for instance the roles of staff – (doctor) and academic researcher during data collection as Gerrits (2010) did in her study in a Dutch fertility clinic. Though this liminal role gives the researcher the freedom to manoeuvre between acting as staff member and visitor at different times and collect data, it would not have been appropriate in the present study. For instance, I would have found it difficult to act as staff in the centres where clients came for counselling and testing, and later act as a patient in the clinics where clients who tested positive at the centres were referred to for treatment. The liminal role, if taken, could have eroded the trust clients had in me as a researcher because I was changing my identity as I went between the centres and the clinics, where almost all the same clients accessed services.

In light of these challenges, I chose the outsider role of academic researcher to collect data in the centres and clinics. Through this role, I collected data with some reasonable level of neutrality among staff, clients and visitors. I clearly introduced myself to health workers, clients and visitors as a researcher who was interested in knowing more about the provision and use of VCT and ART from the perspectives of health workers and clients. As a researcher, I was in the centres and clinics for a period of fifteen months[2] to collect data for academic purposes. In addition, I explained that the data I was collecting would be used to improve the quality of

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[2]   Fieldwork was in two phases. The first was twelve months – from August 2007 to July 2008 and the second was three months – from November 2009 to January 2010.

services provided as part of the national campaign to reduce the spread of HIV/ AIDS in Ghana.

It must be explained that the decision not to take any of the roles suggested by Van der Geest & Finkler (2004) was largely due to the belief that there was no cause to suspect that the study would not be given approval by the ethics committees of the Ghana Health Service or the hospitals involved in the research. Green & Thorogood (2005) point out that the need for researchers to be pseudo-patients for instance to collect data in the hospital arises when there is the likelihood that ethics committees would not approve the study. Nevertheless, I sometimes played the role of a health worker in certain situational demands in the facilities as will be seen later in this chapter.

Data collection

I used various qualitative research methods including participant observation, informal conversations and in-depth interviews to collect data. These were complemented with quantitative methods such as the analysis of hospital records and socio-demographic characteristics of clients. In this section, I provide information on how the qualitative methods were used to collect data.

Participant observation
Participant observation was the main technique for data collection. Ever since Malinowski (1922) set the golden standard for 'doing ethnography', the common understanding of participant observation in ethnographic research has been to live in a community for a substantial period of time and to participate in the daily lives of the people. Although the field chosen for this study was the hospital, Malinowski's views on ethnography motivated the choice of participant observation as the main data collection approach. In line with Malinowski's ideas, Spradley (1980) contends that through participant observation, the researcher goes into a social situation with two purposes: to engage in activities appropriate to the situation and to observe the activities, people, and physical aspects of the situation. Spradley further points out that participant observation allows the researcher to record relevant features of everyday life in the social setting that might not appear worth commenting on in an interview and the context within which they occur. It was largely for these reasons that I took on the role of an academic researcher in the hospitals and had a continuous presence for a period of fifteen months to collect data. During this period, I participated in daily activities in the centres and clinics and observed interactions between health workers and clients, asking questions of both for clarification.

However, some authors have expressed reservations about the term 'participant observation.' In the specific case of participant observation in the hospital, Van der Geest & Finkler noted:

> Many anthropologists have come to realize that in a hospital, participant observation in the true sense of the term is an oxymoron (Van der Geest & Finkler 2004:1999).

To some extent, it could be argued that as an outsider, the researcher is not able to participate 'fully' in all daily activities or events in the hospital while at the same time observing to collect data. Nevertheless, the method remains relatively reliable in terms of getting closer to study participants and understanding them better to obtain relevant data in ethnographic research. For instance, in the present study, through participant observation, the researcher had the rare opportunity to participate in counselling sessions and observe the interactions between counsellors and clients. Participant observation thus gave the researcher a deeper understanding of how these services are provided, compared to what he would have gathered through data collection by means of interviews.

Informal conversations

Next to participant observation, informal conversation was one of the study's main data collection tools. During participation in activities or observation in the centres and clinics, I engaged in conversations with health workers, clients and their relatives to get their views on provision and use of services. Unlike interviews, which often feel formal, conversations with health workers and clients were more informal and were therefore less likely to impel the participant to say what would please the researcher. This way of collecting data provided valuable information on the research topic which I could not have gleaned from respondents in interviews.

I also used conversations with clients and health workers in a car[3] to collect data for the study. At the end of the day's work, I often gave a lift to clients who came for care and treatment on my way home. Some health workers also joined me in the car when they had finished work. Riding in the car, I engaged in conversations with clients on a wide range of issues bordering on their personal experiences as positive persons and their views on how services are provided in the centres and clinics. Conversations with health workers in the car mostly centred on the challenges they face providing services. These conversations also elicited useful information on the research topic because they were so informal, which encouraged both health workers and clients to express freely their views and opinions.

During on-site participant observation and conversations or conversations in the car, I could not immediately write down information gathered in the presence of health workers and clients. I thought that writing notes openly in the process of observing, participating and conversing might distract me from paying attention to

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[3] During fieldwork, I travelled to the hospitals by car.

important issues and actions, thereby missing some important information. It could also draw health workers' and clients' attention to the fact that they were being closely studied in every step of providing and using services, respectively. This might have made some of the health workers and clients adjust their attitudes and behaviours on purpose, defeating the objective of collecting data through normal social interaction between health workers and clients during care and treatment.

I always had a memo book in the centres and clinics, and also in the car. During observation, participation and conversation, I made a mental note of issues and actions that might be of interest to the study. I then intermittently withdrew to one of the staff rooms to write down what I had noted in my mind in the memo book in the form of observations and quotations. I followed up on the observations that needed to be further elaborated upon in order not to forget them. On occasions that I found the staff rooms not convenient for this purpose, I went back to my car (which was always parked outside the centres or the clinics) to do so. With regard to conversations in the car, I wrote down issues of interest to the study in the memo book after I had dropped off the clients or health workers . Later in the evening when I was home, I would add my notes to my computer-based field diary, writing down my observations and conversations in greater detail. I always tried to finish writing out the detailed observations and conversations made each day before the following day's fieldwork. In the memo book too, I kept notes about new ideas and things I need to do next time in order to keep track of how the data collection was going.

In all, I observed, interacted and conversed with about 40 health workers who permanently provided VCT and ART and more than ten health workers who provided these services on a shift basis in the two health facilities. These health workers included medical doctors, nurses, pharmacists, pharmacy technologist/assistants, counsellors, laboratory technicians, disease control officers, health assistants, health aides and cleaners. I also observed, interacted and conversed with countless clients and their relatives in the centres and clinics.

In-depth interviews

In-depth interviews were used to gather information to complement data collected through participant observation and informal conversations. Through interviews I was able to get accounts from health workers and clients on the provision and use of services. The selection of respondents for interviews was as follows.

As the main target group, 24 health workers who provided counselling, testing and treatment in the two health facilities were selected and interviewed. The group was made up of six nurses, five medical doctors, one pharmacist, one pharmacist technologist, two laboratory technicians, one disease control officer, five counsellors, one health assistant and two cleaners. In addition, I interviewed a medical doctor and a counsellor in a private clinic in the Offinso Municipality. Twenty-two

clients were also selected and interviewed in the facilities as the secondary target group for this study. They included 12 women and ten men. More female than male clients were interviewed because according to records in the VCT centres and ART clinics, the majority of clients were female. (This issue will be elaborated upon in Chapter Three.)

The selection criteria for interviews were mainly purposive for both health workers and clients. I selected health workers according to those who had the most contact with clients on daily basis through service provision and their individual work experience in providing VCT or ART. In addition, the position of the health worker at the centre or clinic, contribution to the provision of services and the person's willingness to be interviewed constituted the main selection criteria. A health worker was selected for an interview if he/she satisfied at least two of these requirements including willingness to be interviewed. This is because some health workers satisfied most of these criteria but they tacitly refused to be interviewed by giving excuses on the several occasions I approached them. It was also not possible to interview all the health workers in the centres and clinics due to the limited duration of the study. The selection of clients on the other hand was based on a client's health condition, for example, not too ill and not psychologically trauma-tised by HIV infection, willingness to be interviewed and being above eighteen years of age.[4] Unlike health workers, most of the clients were willing to be interviewed but it was also not possible to interview all of them due to time constraints.

With the consent of health workers and clients, most of the interviews were recorded with a tape recorder. The few interviews I could not record were hand written in a notebook during the interview and later typed out.

The final source of information came from consulting various registers and files in the centres and clinics. These provided data on clients' socio-demographic background and figures on the number of people who accessed services. Although I had planned to hold at least two focus group discussions with health workers towards the end of fieldwork, this was not possible due to scheduling difficulties,[5]

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[4]   In Ghana, one is considered to be an adult at the age of eighteen years and above. At this age the person is said to be mature enough to make his or her own decisions and to be responsible for them. In the case of those under eighteen, parents are obliged to be present during an interview. The presence of a parent in the case of this study could influence the responses of the interviewee. Therefore people below eighteen years were excluded from interviews in this study.

[5]   This was mainly due to health workers' tight schedules as some of them were assigned to other units of the hospitals besides the centres and clinics.

Ethical considerations

During the clearance process, the ethics committees vetted the research proposal for this study, especially the data collection instruments and consent form. The objective was to ensure that the study would not negatively affect the emotional and psychological well-being of the study participants. This is in agreement with the observation by the British Department of Health (2001) that it is often the role of the ethics committees to consider the interest of research participants as primary, but also to ensure that any proposed studies use appropriate designs for reaching sound conclusions. Below is a description of how the interest of study participants was ensured during data collection following the approval of the ethics committees.

Informed consent
The use of informed consent was meant to give study participants the choice of whether to take part or not. I used a consent form which basically summarised the goal and objectives of the study and the possible implications in terms of benefits and disadvantages of one's participation. The consent message was given to those clients and health workers I wanted to recruit to read so they could make an informed decision on their participation. In the case of clients who could not read and understand the consent form, I read the consent statement to them and explained it in the local language (Asante Twi).

The form had a column which a participant signed or thumb printed after he/she agreed to be an interviewee based on his/her understanding of the consent statement. The researcher also countersigned the consent form to show that the two parties had entered into an agreement to corporate with each other during the study period. The consent statement also had a provision that allowed a study participant to withdraw at a later date without any negative consequences. Most health workers and almost all clients who were approached to be recruited as study participants voluntarily agreed to be interviewed. In the end, all study participants who were recruited continued their participation in the study through to its conclusion.

Seeking consent for interviews was only one way of addressing the ethical concerns of study participants; as noted above, much of the research was conducted through participant observation and informal conversation, and obtaining an adequately-informed consent from participants in these activities proved more challenging. Many qualitative researchers have pointed to the problematic side of this ethical principle, particularly when doing observational studies in the hospital setting (cf. Green & Thorogood 2005:57-66). In the hospital, the VCT centres and ART clinics, data is often collected from an ever-changing pool of study participants and on different occasions. For instance, some health workers worked in the centres and clinics on a shift basis with a constant inflow of new clients on an almost daily

basis. A situation like this makes it difficult to inform all participants to the fullest degree about the study objectives and ask their consent.

In the present study however, with the ethical clearance letters, the heads of departments were fully informed and their permission or consent was asked before participation and observation. With regard to staff, they were informed of the researcher's presence in the centres and clinics and of the study objectives, but their consent to the researcher's presence was never asked. When participating in various activities such as counselling and consultations, I always asked for individual doctors' and other health workers' verbal consent before doing so. Although in principle the health workers could decline my request – as happened in the VCT centre of Komfo Anokye Teaching Hospital – nearly all of them agreed because their superior officers had consented to the study. Similarly, along with the health workers' permission, I had to seek clients' verbal consent before participating in their counselling sessions. To some extent, this helped satisfy the ethical principle of informed consent before doing participant observation.

Anonymity and confidentiality
It is expected that the identity of people and places involved in the research will be protected where possible (cf. Green & Thorogood 2005:60). This is done to ensure that members of the general public are not able to identify study sites and partici-pants, a situation which could have negative implications for the places and people involved in the study. In this study, however, the facilities where the research was carried out are easily identifiable since it is public knowledge which hospitals provide VCT and ART in the Ashanti Region of Ghana. It is rather the study participants, both health workers and clients, who had to be made anonymous. Before interviews for instance, I fully discussed the issues of anonymity and confidentiality with participants and assured them that their identities would not be disclosed in the study findings or any study-related publications. In relation to participant observation, I always assured study participants of their anonymity and confidentiality in the introduction when I sought their consent to participate in the research and to allow me to observe activities that concerned them. Consequently, I have given clients fictitious names, and their participation was not identified in any way in the records of the health centres and clinics. Although health workers were aware that I spoke to some of the clients as study participants, I tried as much as possible to avoid sharing information I received from the clients with them to protect their confidentiality. The health workers have also been given fictitious names, but they are referred to by their positions such as medical doctor, nurse, pharmacist and counsellor. The heads of the departments have also been identified as such although they played a minimal role in the study.

In spite of these measures taken to ensure the anonymity and confidentiality of study participants, I cannot fully guarantee that they will not be recognised. By identifying the health facilities it is theoretically possible for someone to guess the identity of some of the health workers who are seen to carry out certain specific roles in the centres and clinics. At the same time, however, one can never be fully sure that it is indeed that particular person.

Methodological reflections

This section describes the researcher's reflections on a number of issues that are particularly relevant to the current study and in some respects may have impacted the objectives of the research, the type of data collected, their interpretation and presentation. Although the effects of the issues cannot be exactly known, these reflections could contribute to a better understanding of how they have affected the findings of the study.

How the researcher was received in the hospital setting
Although I identified myself as an academic researcher, health workers, clients and relatives who accompanied them to access services received me in different ways. In relation to health workers, I was often confronted with the following questions: "Who are you? Are you a medical doctor, a trained nurse, a student nurse or a counsellor? In which hospital were you working before you came here?" These questions imply that some health workers were more interested in knowing my professional background as a health worker and not as an academic researcher. The questions were probably based on the belief that the health care setting is the preserve of health professionals, so anyone seen working in the hospital must be a doctor, a nurse or a pharmacist.

I was also suspected of being a monitoring and evaluation officer who was in the facilities to assess their work and write a performance report for the hospital authorities. It follows that some health workers in the centre of Komfo Anokye Teaching Hospital objected to the study being carried out in the facility. During interactions with the staff to explain more about why I needed to do the study in the centre, a counsellor commented as follows:

> We, staff are not certain that you [researcher] are not here to judge our work because you are not a trained counsellor…

Another counsellor remarked that:

> ... If you [researcher] want to know how VCT services are provided, you can do that without sitting in counselling sessions to see how we do our work…You are even not a trained counsellor, so how can you know that we are doing our work well or not…?

Some health workers also took me for a national service person or an Intern on attachment for on-the-job-training in the centres and clinics. In Ghana, it is obligatory for students who have completed tertiary education to do one year of national service in any sector and part of the country. National service persons are often posted to the health sector to complement the work of health care professionals. It is for this reason some health workers assumed that if I was not a health professional then I must be a national service person. My reception as a service person or an intern could also be due to the way I was introduced to health workers as a student/researcher who wanted to know more about the services they provide. There were many instances when some health workers, particularly those who worked shifts in the clinics, asked me:

> My brother [researcher], you are still doing your national service here in the hospital? So, when is your service ending... or you have now been employed here permanently...?

These questions were possibly due to my long presence in the facilities, which lasted almost the same as the length of time it takes for someone to do his/her national service.

However, I was appropriately received as an academic researcher by almost all the health workers directly involved in this study. I also received the necessary support from them to collect data. Some doctors, pharmacists, nurses, counsellors and laboratory technicians intermittently asked me: "How is your research going? Are you getting the relevant data you are looking for? Is there anything some of us can do to help you if you are not getting the relevant data you are looking for?" In fact, I was encouraged by such questions and felt that I was recognised by most health workers as a researcher who may need their help or support in one way or the other. Further, I received the maximum cooperation from the health workers I had interviews with. In spite of their tight schedules, they often found time to grant me interviews. On those occasions when I could not complete interviews I started with health workers, they came back for the interviews to be continued after they completed what they were doing. For instance, I interviewed a medical doctor around 6.30 p.m. after he finished work in the theatre. I also interviewed a nurse in her home after she finished work. A health assistant often helped me to get access to relevant records and documents on clients in a clinic as part of data collection. These are a few examples to show how most health workers cooperated with the researcher to successfully collect data in the study facilities.

Many clients received the researcher as a new health worker in the centres or clinics. Some clients addressed me as 'Doctor' but this is not new in Ghanaian hospitals. It is common for clients and visitors to the hospitals to address particularly male health workers as Doctor (*Dɔkita)*. They also addressed a female health worker

as 'Aunt' or 'Madam Nurse' (*Auntie or Maame Nurse).*[6] This way of receiving the researcher may be due to the health worker role I sometimes played in the centres and clinics as will be elaborated upon later in this chapter.

Other clients also approached me with some technical health problems and questions about their treatment because they thought that as a health worker, I could solve such problems or answer their questions. For example, I was asked by some clients to explain why they were given a particular combination of ARV drugs different from what their colleagues were given. I often politely explained to them that I was not a professional health worker but a researcher and was not in a position to give the appropriate answer. In such cases, I always urged clients to either talk to the medical doctor who wrote the prescription or to talk to a nurse or a pharmacist who would be in better position to answer. It was however observed that most of the time clients were reluctant to talk to medical doctors, some of whom they described as "not being friendly" or "too formal" (*wɔnnte wɔn anim).* According to clients, this makes it difficult for them to approach most doctors in an informal way with such questions about treatment and other related issues. However, one doctor in St. Patrick's Hospital was often praised by clients as being kind and willing to help solve their problems whenever they approached him.

Some clients received the researcher as a colleague client or an adherence monitor. Likewise, some adherence monitors received me as one of them or as a client. In the centres and clinics, apart from visitors who come there to contact health workers on some other matter, people are not allowed to visit clients accessing care and treatment the way they can in the admission wards. Relatives are often the ones who accompany clients when they come to use services or clients' adherence monitors and have easy access to the facilities. This suggests that if a non-health worker is seen regularly, especially in the clinic, he/she is assumed to be a client or an adherence monitor. My continuous presence in the clinic possibly made some clients think that I was a client who has been getting care and treatment. Clients who wanted to know whether I was also a client often asked; "So, when did you start accessing treatment here? How long have you being accessing treatment here? Where do you always come from to get treatment here?" In the same way, some monitors also asked questions like: "Whom did you accompany here? Did you come here with your wife? How is the person you accompanied here doing on the treatment?"

I was also received in the hospital setting as an 'unwelcome' friend by some clients who came from my hometown or the area near my hometown. These clients

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[6] There is no specific explanation for why clients and visitors, most of whom are illiterate, address male health workers as doctors and female health workers as nurses. But it is possible that most of these clients and visitors assume that it is only male health workers who are called doctors while their female counterparts are called nurses. In that case some clients and visitors do not even know that there are male nurses.

had not expected to see someone from their region in one of the clinics where this study was carried out. During data collection, it was observed that clients preferred to access treatment in health facilities which were located far away from their hometowns or the places where they currently live. This is a strategy clients often employ to avoid having people they know identify them as positive persons while accessing treatment. Hiding their status helps them avoid the stigma associated with HIV/AIDS in Ghana. It is for this reason that some clients from my hometown had decided to access services in one of the study hospitals which is far away in a different region. Unfortunately for them, I was in the clinic on several occasions they came for scheduled monthly visits. It is likely that my extended presence in the clinic defeated their objective of accessing services in a distant facility to avoid identification as positive persons and prevent stigmatisation.

The body language of some of these clients whenever I saw them in the clinic gave the impression that they were not happy to see me. One managed to avoid any contact with me on several occasions in the clinic. Another client had no choice but to come to me for her CD4 count test result that was on the table where I was seated. When the client came to the table, I casually engaged her in conversation and assured her that she should not be worried that I had seen her in the clinic because I would not mention her status to other friends. Another client initially tried to avoid contact with me by looking the other way; he did not seem to realize that I had seen him as soon as he had entered the clinic. He also came to the place I was seated to see a nurse to help him get re-supply of ARV drugs without wasting too much time in the clinic. After exchanging greetings, he asked whether I was working in the clinic. I briefly explained the research to him and added that I would be in the clinic for a period of eight months.[7] When the client heard this, he paused momentarily and shifted his attention to the nurse. The way he suddenly ended our conversation created the impression that he was uncomfortable with something. I asked to see him after he finished accessing treatment. In a conversation, I allayed whatever fears he may have had by assuring him I would not disclose his status to friends back in our hometown. I urged him not to let my temporary presence in the clinic be a barrier to his accessing treatment. The smile on his face suggested that he was relieved with the assurance I gave him.

Some clients I had attended secondary school[8] with received me as a schoolmate and not as a researcher. I had not seen some of these clients since our schooldays. Like the clients from my hometown, some of my former schoolmates appeared to feel uncomfortable that I saw them in the clinic. I recall that on one clinic day, one of these clients who was my senior in school saw me seated with some health workers in the clinic. Under normal circumstances he would have come up to say

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[7] I saw this client during the fourth month of my twelve months fieldwork.
[8] Secondary school is the equivalent of senior high school in Europe and United States of America.

hello as we had not seen each other since we left school. However, the former senior turned his back towards me while he went through his treatment procedures. He did not seem to know that I had recognised him from a distance when he entered the clinic. Moments later, I approached him and engaged him in a conversation. It was then that he said that he saw that I was seated with the health workers but he was not sure whether I was the one. He looked very sick and I had to help him round the clinic to access treatment without much delay. In the case of one other schoolmate, she came to where I was seated and wanted to know what I was doing in the clinic. She was happy to see me after so many years. I told her about the study I was carrying out in the hospital and also assured her that I would not disclose her status to other schoolmates.

Lastly, there was another client who saw me foremost as her former school-teacher rather than a researcher. I had taught in the Junior Secondary School[9] when I did national service a couple of years ago. She was also happy that we met again and willingly told me how she got the disease. During the fieldwork period, I maintained close contact with her because I was the only person apart from her mother who was aware of her status. I advised her on a prolonged presence in the clinic. According to her, I was the only person she was able to discuss issues about the disease with because as her former teacher she trusted that I was someone she could confide in. She pointed out that even her husband was not aware of her status.

The anthropologist as a 'health worker'

The work situation at the centres and clinics did not allow me to play the academic researcher role I had chosen as strictly as I would have liked, or to remain neutral with the health workers and clients and collect objective data. In the health clinics, for instance, attendance is always high on clinic days and the relatively few health workers present are sometimes overwhelmed with a heavy workload. Clients have to wait in long queues for many hours before they get treatment. On such occasions, I felt it would be improper if I only participated in or observed activities in accordance with my chosen role while the health workers struggled to attend to clients. I felt somehow compelled to help the health workers assist clients by carrying out some minimal tasks contrary to the objectives of the academic researcher role.

I was nevertheless concerned, however, that my need to help the health workers would make me lose track of my 'neutral' position on site. Carrying out some of the duties typically belonging to health workers could make clients and visitors see me as a health worker myself, which could have negative implications for the data I would collect. To preserve my role as an academic researcher but still be able to help health workers whenever necessary, I decided to carry out clerical tasks that any non-professional health worker could do. For instance, I helped medical doctors

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[9] Junior secondary school is the equivalent of junior high school in Europe and United of States of America.

and counsellors in the consulting and counselling rooms respectively by writing the names of clients they had attended to in attendance books for records purposes. I also helped health workers by filling out registration forms for new clients who had been referred to the centres for treatment as well as various laboratory tests request forms (for tests such as CD4 count and haemoglobin). I provided clients with their CD4 count test results from the laboratory before they were attended to in the clinics, and would sometimes get the clients' files from the shelves for the attending nurses.

Because I was not involved in the core work of client-facing care provision, it can be argued that my work did not make clients, their relatives and visitors think I was a health worker. Since I earlier introduced myself to clients and others in the centres and clinics as a researcher, I reintroduced myself whenever necessary to let them know that this position had not changed despite the assistance I had been giving to health workers. Nevertheless, I was seen as a 'health worker' by a few clients, as the questions I was approached with implied. I also got complaints from some clients about certain things they were not happy with at the facilities; they urged me that 'as a staff member,' I should help them find solutions. For example, I was asked by a client to advise a colleague 'health worker' to stop wasting time through unnecessarily long conversations with visitors and to attend to them without further delay. These examples suggest that some clients might have withheld information that was relevant to the study from me because they thought that I was a health worker and therefore not neutral with respect to whatever was going on in the facilities.

On the other hand, thanks to the small part I played in fulfilling some of the duties of a health worker, I also got access to some relevant information for the study that I otherwise would have missed. While filling out registration forms for new clients, for instance, I had the opportunity to engage in conversations with many clients on how they were counselled both pre- and post-test. Clients who perceived me more as a researcher also appreciated the limited role I played as a health worker and I was commended for contributing to the provision of services. Health workers were also highly appreciative that I played this role willingly to help them at certain times. It is possible that the limited health worker role I played might have contributed to the generally positive support and cooperation I received from most health workers in the centres and clinics. In essence, my dual role in the facilities as researcher and to some extent a 'health worker' led to a good rapport with both health workers and clients for the collection of relevant data.

I also played the role of a buddy to most of the clients I interacted with in the centres and clinics. Since many clients and their monitors considered me a friend, it was not surprising that I did not have any difficulty in getting clients to participate in this study. To them, I was someone with whom they could share their personal problems related to treatment, marriage and family. More importantly, they saw the

researcher as someone who always had time for them and lent an ear to the problems they faced at home and at the facilities. It was easy to find clients to converse with and to elicit their views on the provision and use of services as part of data collection. Clients approached me on many occasions to intercede on their behalf when they had problems with health workers. To date, I have kept in touch with some of them (including my former pupil) to keep track of how they are doing on treatment or whether they have managed to carry out some of the decisions we discussed before I left the field.

Relevance of qualitative research in the hospital setting
As noted earlier, some of the health workers' comments on this study's data collection tools suggested that they did not see the importance of qualitative research in the medical setting. The perception has often been that the hospital is the domain of health professionals, and anthropologists like me have no business in that setting. I often spent time with such health workers and explained to them that qualitative studies such as the present one could significantly contribute to improvements in service provision.

There was an instance in which a medical doctor I became familiar with in one of the hospitals asked what I was studying because I had earlier introduced myself to him as a student/researcher during a conversation. When I told him that I am a medical anthropologist studying the provision and use of VCT and ART, his next question was: "But as an anthropologist, I think you could research into this topic better in the community and not in the hospital? So, what specifically are you studying about VCT and ART?" I explained that the provision and use of these services in the hospital involves social interaction between health workers and clients. Such interactions often have implications for how clients perceive the quality of care provided by health workers, which also influences their use of the services at other times. As an anthropologist, I was interested in studying how the social interactions between health workers and clients play out in the hospital setting and how they can influence the utilization of services in the future. The impression I got from the doctor was that he thought anthropologists were well known for working in the community rather than in the hospital. I hope my explanation about this research made him see why anthropologists might also need to study interactions in hospitals.

During interviews with health workers, it became clear that most of them did not understand why I was using interview guides typed out in one page of A4 paper. I was often confronted with the following question: "Are you not giving me the questions to answer myself?" This question implies that health workers expected me to give them questionnaires to answer instead of engaging them in lengthy interviews which sometimes had to be continued the following day if not completed

on the same day. Some of them said that they were more familiar with the use of questionnaires, which generally take less time to answer. I remember a case in which a senior health worker asked in an interview why I was using interview guides instead of questionnaires. The guides contained open-ended questions that helped the researcher ask about issues of interest to the study during interviews. The official insisted that he wanted to see the interview guides, possibly to be convinced that I was doing a serious interview with him. After I gave the guides to him and briefly read through them he commented:

> Just look at this question, how can I answer a question like: To what extent are VCT and ART services utilized? As for you social scientists, you are noted for asking difficult questions. If it were to be questionnaires, I would just tick them and write short responses in the spaces provided between the questions without wasting too much…

I explained to him that because this research was qualitative in nature, the use of questionnaires would not be helpful. With this answer, I was able to continue the interview with him.

The insistence of the staff in the VCT centre of Komfo Anokye Teaching Hospital that they would not allow the researcher to do participant observation in counselling sessions also suggests that they did not understand the relevance of qualitative research as a tool to contribute to the quality of service provision. Their refusal to allow me to sit in on counselling sessions might have been due to the need to ensure clients' privacy as required by the protocol for service provision. However, in the case of this study, their refusal was also based on the fact that they had never seen research conducted in the centre that necessitated the researcher's presence in counselling and testing sessions also in order to observe how services are provided. This makes the data collection approach, which is core to qualitative research, unacceptable according to the health workers. It could be that the counsellors did not want the researcher to see how they provide these services because I was not a health professional and was therefore an outsider. It follows that Van der Geest & Sarkodie (1998) observed that sometimes health workers are reluctant to allow non-medical observers to their work because they dislike being watched by outsiders who will later put their observations on paper (see also Van Staa 1993).

Perception of health workers on research
The remarks and comments of some health workers when I approached them for interviews suggested that they were tired of being approached so often to participate in research projects, some of which they knew little about. According to those health workers, they had participated in research in the past and never had any feedback on the outcomes of those studies. They were of the view that it would be a waste of time for them to take part in this study because they assumed that, like earlier ones,

they would not hear anything about it after it has ended. One health worker remarked as follows when I approached her for an interview:

> We – health workers – are tired of research. Every day you do research but when you finish […], that is all; we do not hear anything from you as to what came out of the research... *(Yɛabrɛ ne research yi. Da biara moyɛ research nanso mowie a ɛno ara no no, yɛnte hwee bio. Sɛ ɛdeɛn na ɛfiri mu baeɛ momma mɛka hwee nkyerɛ yɛn...).*

Apparently, health workers are suffering from 'research fatigue' as they are often used as study participants without the researchers getting back to them with information on the study's findings and recommendations. I often assured the health workers and others who participated in this study as interviewees that every effort would be made to let them know the outcome.

Indeed, participants of the current study had the opportunity to be briefed about the interim findings. A one-day workshop was organized for this purpose and participants including policy makers, health workers, clients, peer educators, scholars, governmental and non-government organizations were invited to deliberate on the interim findings of the study. They subsequently gave their input with respect to the findings, some of which is presented in this thesis. At end of the workshop, most of the participants said that they were satisfied having had the rare opportunity to learn about the research findings and also to provide feedback on them. Health workers in the centres and clinics, for instance, commended the researcher for fulfilling the promise of giving them feedback from the study. They further pointed out that for the first time in many years, their participation in the workshop made them feel that their contributions to the study had been recognised. Peer educators also said that the workshop served as an appropriate forum for them to make their views and opinions known to policy makers and health workers on how services are provided and used.

With regard to health workers' perceptions of the research, some health workers made it clear they were reluctant to be interviewed by giving excuses such as: "I am too busy today to be interviewed, I am too tired today, so I cannot talk, not today, so postpone the interview to another time." Some health workers actually had tight schedules as they were not assigned only to the centres or clinics, but it could be that some of them were using this as an excuse on several occasions to avoid being interviewed. There were others I had to follow for days, weeks and even months before getting them for interviews. Those health workers probably had thought I would stop following them if they rescheduled the interview several times. As it happened, I did have to stop following some of them for interviews after chasing them fruitlessly for months.

Finally, some health workers were under the impression that the research was an evaluation of their work, and therefore avoided interviews by explaining that they did not know much about the services they were providing. They suggested to the

researcher to interview other health workers instead, claiming they knew better. I believe the health workers who responded thus were afraid their responses in interviews would not satisfy the researcher's expectations, which they felt might be seen as an indication that they were not doing their jobs well. I often explained to those health workers that I was not interested in right or wrong answers in interviews; the main objective was to learn their views on service provision and use. Although some of them were convinced with this explanation, others were not and continued to refuse to participate in the study. These instances gave the impression that health workers are saturated with too many research projects, hence their reluctance to participate in new ones.

Field work at home
A major challenge I anticipated in this research was my background as a Ghanaian studying at home and its implications for the collection of objective data during fieldwork. There is the general perception that when doing fieldwork in one's own culture or country, a researcher runs the risk of developing 'over rapport' with the research subjects which might hamper the attainment of objective information (Zaman 2005:31). Unlike the anthropologist in a small-scale society who lives and works twenty-four hours a day with an unchanging population, the encounter I had with the health workers in this study was confined to working hours and the client population was always changing. Moreover, Van Dongen (1998) argues that being an anthropologist at home does not mean that the identities of the anthropologist and people in the field are similar. People and cultures are diverse, different and divided from within. The familiar, as a result, becomes unfamiliar to the researcher as a matter of course. This diversity of identity that Van Dongen points out helped me avoid developing 'over rapport' with the study participants or losing objectivity.

It is however important to point out that my background as a Ghanaian studying in my home country was an advantage in many respects. For instance, as a native of Ghana, my presence in the centres and clinics did not indicate anything unusual, unlike in the case of a 'white' or 'coloured' anthropologist in a 'black' population. Moreover, during most part of the day, the centres and clinics were public places where relatives came with the sick, and food and newspaper vendors and others came to do business. In effect, I could have been taken as a relative who was accompanying a client or someone who was in the clinic to do business with health workers. With regard to language, I speak the same Akan language (Asante Twi) as most of the health workers and clients, so when they told their stories, I easily understood the meaning of the important events and even the layered meanings of their body language. This is not the same for anthropologists who study other cultures and have to go through a fairly long and painful period of adjustment to accumulate knowledge, competence and sensitivity. Being an Akan and therefore an

insider greatly reduced the cognitive and emotional efforts necessary to adjust and understand an otherwise foreign culture.

Lastly, being a Ghanaian did not make me take many things in the field for granted. Through the role of academic research, I tried to be as objective as possible during interactions with both health workers and clients to collect data, but in situations when I could use my identity as a Ghanaian to obtain relevant data or get access to something important for the study, I did so. This is in line with the observation by Van der Geest (1998) that instead of suppressing personal views and feelings, the researcher should examine them carefully and try to use them in conversation, observation and participation in order to understand the study subjects better. For example, I used my Ghanaian nationality to gain entry to the facilities where this study was carried out. In terms of reporting on the research findings, I have tried to be as self-critical, candid and reflexive as possible.

In conclusion, this chapter has provided detailed information about the various ethnographic approaches used to carry out the study. It attempts to provide a context for the study's findings and their interpretation to yield a better understanding of the research. In addition, I have presented some methodological reflections in relation to my own position and related experiences, following Brewer's (2000:130-132) assertion that a certain level of reflexivity on the impact that various contingencies had on the outcome of the research, can be helpful.

Research setting

This chapter discusses the setting of the health facilities where data was collected between August 2007 and July 2008.[1] These sites were St. Patrick's Hospital at Maase-Offinso and Komfo Anokye Teaching Hospital in Kumasi, both in the Ashanti Region of Ghana. The two hospitals were selected because they were among the few health facilities that had benefited from the initial national scale up of voluntary counselling and testing and antiretroviral therapy in the region.

This chapter gives an overview of the hospitals and how counselling, testing and treatment services are generally provided. It provides the context for subsequent chapters, which deal with analyses of the study. I begin with a description of the hospitals, followed by a description of voluntary counselling and testing centres and antiretroviral therapy treatment clinics. Next is a sketch of the procedures of counselling, testing and treatment services. I end with a discussion of general observations made on the provision and use of services.

The hospitals

St. Patrick's Hospital
The St. Patrick's Hospital is a non-profit Catholic mission institution, first established in 1951 as a clinic by St. Louis Sisters from Ireland. It was later upgraded to its present status as a hospital in 1957. It operates under the umbrella of the Catholic Archdiocese of Kumasi but is duly registered under the Christian

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[1]   There was a second session of fieldwork between November 2009 and January 2010. This makes the fieldwork period fifteen months in all.

Health Association of Ghana (CHAG)[2] and also the Private Homes and Maternity Board. The hospital is located at Maase, a suburb of Offinso, 45 km to the north of the Ashanti Regional capital, Kumasi. In view of its strategic location on the main Kumasi-Techiman-Tamale road to the north, the hospital serves as a referral point for all other health facilities in the Offinso-South Municipal Assembly[3], Offinso-North District Assembly and beyond.

The hospital has a total staff of 280 comprising professional nurses, medical officers, auxiliary nurses, administrative and support staff; and paramedical staff. It has 160 beds and the various services provided include a general out patients department (OPD), in-patient services, a laboratory, ultra stenography, antenatal and postnatal care, laundry, dental services, ophthalmology, surgical treatment for both major and minor cases including urology, antiretroviral therapy treatment, a pharmacy, maternal and child health, public health, a diabetes clinic, HIV counselling and testing, an x-ray unit and many other services. St Patrick's Hospital recently added a physiotherapy unit to its existing units with help from the O'RIEN Foundation from the Netherlands. Besides its busy hospital-based work, the hospital holds regular clinics in outlying villages reaching people who live in areas too remote from the facility to have access to care and treatment. The hospital has an adjacent midwifery training school, which is independently run but receives support from the hospital clinical staff.

The VCT centre at St. Patrick's Hospital is located close to the injection room and the x-ray unit. To access counselling and testing, clients must walk past other patients who are waiting for services in front of the injection room and the x-ray unit, and pass through the same corridors after the service. The ART clinic[4], on the other hand, is located near the main entrance of the hospital through which patients, visitors and vehicles get access to the hospital premises. Some food vendors used to sell at the main entrance of the hospital and they could see clients who entered or came out of the clinic. During the second part of fieldwork, the hospital authorities moved the food vendors away from the main entrance to another location where

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[2] Christian Health Association of Ghana is made up of missionary-based health facilities in Ghana. The association coordinates the activities of member institutions and also acts as the link between Ghana Health Service and its members.

[3] The Municipal Assembly is an administrative area under the local government system in Ghana. It is made up of a number of towns and villages within a specific region. The Assembly's membership comprises people elected through district level elections and government appointees. A Chief Executive nominated by the president and confirmed by the Assembly members heads it. Under the local government system of Ghana, an assembly area could be classified as Metropolitan, Municipal or District depending on the size of the capital town and the availability of certain social amenities in the administrative area of the assembly.

[4] This clinic is called the "Special Clinic." According to the medical doctor in-charge of HIV/AIDS programme, the clinic provides treatment services for special health problems like diabetes, hypertension, tuberculosis and HIV/AIDS. The name thus makes it difficult for other people to know that the clinic is for HIV treatment.

they could not see patients and visitors entering and leaving the hospital. There was also a parking lot for taxis at the main gate where patients and their relatives could take transport to town after treatment. Like the food vendors, the parking lot has been relocated to another place far away from the main entrance. The distance between the centre and the clinic is about 70 metres.

Komfo Anokye Teaching Hospital[5]

This is a public health facility established in 1954 and located in Bantama, a suburb of Kumasi. It was upgraded to a teaching hospital in 1975 and affiliated to the Kwame Nkrumah University of Science and Technology in Kumasi. It is the second highest tertiary hospital in Ghana after the Korle Bu Teaching Hospital[6] in Accra.

The hospital has a workforce of over 1,000 comprising professional nurses, medical officers, auxiliary nurses, administrative staff, support staff and paramedical staff. The hospital has specialised units in Medicine; Surgery; Obstetrics; Gynaecology; Paediatrics; Dentistry; Ophthalmology; Orthopaedics; Ear, Nose and Throat; Pathology and Communicable Diseases. The other major departments are Pharmacy, Radiography, Radiotherapy, Physiology and Occupational Health. A recent addition to these units is the ultra-modern Emergency Accident Department. As a tertiary hospital, it is also a referral health facility for other hospitals, health centres and clinics in five regions in the middle and northern parts of Ghana. Its central location in the country makes the hospital accessible to patients from neighbouring countries such as Burkina Faso and La Cote d'Ivoire.[7]

Komfo Anokye Teaching Hospital is host to other institutions attached to the Ministry of Health, and also has links to several autonomous institutions. These include: the Nurses Training School; the Midwifery Training School; the Medical School of Kwame Nkrumah University of Science and Technology, Kumasi; the Blood Bank and The Health Laboratory Services.

The VCT centre here is located within the same block as the postnatal care clinic and some of the hospital's administrative offices. Clients must pass through these places, facing mothers waiting for services or administrative personnel, in order to receive HIV counselling and testing. Unlike St. Patrick's Hospital and Suntreso Government Hospital, there are two separate rooms for counselling and testing in this hospital. That is, clients went for counselling in one room and walked about 25 metres to another room in the same block for testing. In other hospitals, I observed

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[5] The hospital is named after one 'fetish priest' of the Ashanti Kingdom called Komfo Anokye. Kumasi where the hospital is located is the capital town of the Ashanti Kingdom and the second capital city of Ghana after Accra.

[6] Korle Bu Teaching Hospital is the premier public health facility in Ghana. It is affiliated to the University of Ghana Medical School in Accra.

[7] Burkina Faso borders Ghana to the north while Cote d'Ivoire borders Ghana to the west.

that counsellors did counselling and testing in the same room. The ART clinic[8] was located on the ground floor of a five-storey building made up of offices for medical doctors, nurses and other health workers and admission wards. Adjacent to the clinic is the emergency accident department, which was built recently. The distance between the centre and the clinic is about 300 metres. From the centre, clients go through a number of units in the hospital to reach the clinic via the backyard of the storey building.

As indicated earlier in Chapter One, I also collected data in the VCT centre of the Suntreso Government Hospital. This hospital is located in Suntreso, a suburb of Kumasi. The centre in this hospital is located between the antenatal care and postnatal care clinics, and the maternity ward. Clients accessed services in the vicinity of the antenatal care and post-natal care units. I also visited a private clinic (Quality Care Clinic) in the Offinso municipality to observe some post-test counselling sessions. This became necessary when I found that a significant number of ART clients in St. Patrick's Hospital were referred from this private clinic. Only post-test counselling sessions were observed in this facility because all the tests were diagnostic or provider-initiated without pre-test counselling. The tests were usually done in the laboratory with the ELISA, a method of testing that will be explained later in this chapter.

Finally, I visited a counsellor at Nkenkasu Government Hospital in the Offinso-North District to participate in and observe counselling and testing because a number of positive persons were also referred from this facility to St. Patrick's Hospital for treatment. However, there was no case for the counsellor to attend to on the occasions that I visited the hospital. During this period, no one voluntarily walked in for counselling and testing and there was no provider-initiated testing. The majority of descriptions in this chapter and thesis are based on research in St. Patrick's and the Teaching Hospital and to some extent Suntreso Government Hospital since data were collected mainly in these facilities.

The services

Voluntary counselling and testing
The centres provide counselling and testing to people who want to know their HIV status or need information about HIV/AIDS and the services that the centres offer. As the name suggests, VCT is supposed to be voluntary, whereby clients walk into the centres and ask for the services. Information gathered from the facilities showed

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[8] The clinic is called the "Chest Clinic." The senior nursing officer in-charge of the clinic explained that the facility was originally meant for tuberculosis (TB) treatment. The clinic therefore derived its name from the disease's association with the chest. However, the decision to use the clinic for HIV treatment was based on the fact that the majority of TB patients were also HIV positive persons. This name has helped to prevent other people from knowing that the clinic is also used for HIV treatment.

that on the contrary, people rarely walked into centres to ask voluntarily for counselling and testing. Records in the centres indicated that voluntary counselling and testing represented less than 20 per cent of all clients counselled and tested. For instance, in one of the facilities, the number of people tested in 2009 was 1,686. Out of this figure, 310 clients were walk-ins for the service while 1,376 had been referred by medical doctors. Voluntary uptake was a little over 18 per cent of the total number of clients tested in that year. Both health workers and clients pointed out that many people were reluctant to undergo counselling and testing and to learn their status because of the persistent stigma associated with HIV/AIDS in Ghana. Health workers indicated that there had been cases of people who showed most of the signs and symptoms of the infection[9] but refused to walk-in for the service. According to counsellors who were involved in this study, the service was no longer voluntary counselling and testing (VCT), but rather counselling and testing (CT) since the voluntary aspect of the service was seemingly non-existent.

In response to the general public's reluctance to use the service voluntarily, health workers have resorted to diagnostic testing or provider-initiated testing to compel people to go for counselling and testing. This type of testing means that when a patient reports to the hospital or health centre with a general health problem and the doctor has cause to suspect him of the infection, he refers the patient to the centre for counselling and testing. The doctor's suspicion is often based on the illness history and some signs and symptoms of the infection presented by the patient.

With regard to pregnant women, the Ghana Health Service (GHS) has made HIV testing mandatory for those who attend the antenatal care clinic and deliver in government health facilities. In an interview, a medical doctor explained that this is intended to make testing routine for pregnant women, who are one of the groups most vulnerable to HIV/AIDS. Besides, if a pregnant woman has HIV/AIDS, it often puts her unborn baby at risk of infection. The doctor explained that routine testing for pregnant women is a policy termed 'Opt-Out', referring to the fact that all pregnant women attending ANC are eligible for testing (opt-in), but have the right to refuse the service if they do not want to undergo testing (opt out). If a pregnant woman refuses the test, she would not be able to access antenatal care and her baby would not be delivered in a government health facility.

The medical doctor further explained that the rationale behind the Opt-Out policy is to identify pregnant women who may be positive in order to put them on treatment before delivery since treatment could help to prevent the unborn babies from possible HIV infection. After delivery, their babies are also be put on ARV for one week to protect them from infection. The treatment for positive pregnant women

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[9] Some of the signs and symptoms of HIV infection mentioned by health workers include persistent coughing, diarrhoea and fever for one month or more, skin rashes and shingles, sores in the mouth and around the genitals, among others.

before delivery is called prevention of mother-to-child transmission (PMTCT).[10] A nurse also added that the opt-out policy helps health workers in the delivery wards know whether pregnant women are positive and to take the necessary precautions in delivering their babies.

Finally, the doctor said that unlike voluntary counselling and testing, most clients do indeed go for the services if it is provider-initiated. Most pregnant women also go for the test under the current policy. Counsellors agreed with the views of the doctor on the good aspects of diagnostic testing and opt-out policy. I also observed that most patients reported at the centres for provider-initiated testing possibly due to the fear that they would be denied treatment if they did not follow the instructions of the doctor. Similarly, many pregnant women also went for the routine testing under the opt-out policy.

Counselling

Counselling is core to HIV testing and treatment. "It is a confidential dialogue between a client and a counsellor which aims at enabling the client to cope with stress and take personal decisions related to HIV/AIDS" (IAE/UNFPA 2005:36). Counselling is often given before and after testing under the voluntary counselling and testing model, and involves a face-to-face session where a trained counsellor provides information about HIV/AIDS to a client. Information provided by the counsellor usually covers how to prevent transmission, what the test and its result mean, and treatment. The counselling which precedes testing is called pre-test counselling and is based on the premise that for many clients, the decision of whether to go for the test or not is often difficult and involves examining complex issues such as fear of the stigma associated with HIV/AIDS. Pre-test counselling therefore helps clients reflect on the wider and deeper implications of taking the test so that clients can make an informed decision. When the client reports to the centre for services, consent is often obtained before counselling and testing. The counsellor is required to give the client a minimum level of information as part of the consent-seeking process to explain what it means for him to agree to and go through counselling, which may lead to testing. If the client agrees to undergo the counselling process, he/she signs or thumb-prints a consent form and the counsellor also counter signs for purposes of reference whenever the need arises. In fact, the Ghana Draft Policy Document on HIV and AIDS (MOH/UG 2000) clearly states "informed consent for HIV testing must be the norm all the time…" (2000:6). After testing,

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[10] According to the doctor, under the PMTCT programme a pregnant woman is given ARV prophylaxis from 28 weeks till one week after delivery. The pregnant woman is also given a single dose of nevirapine at the onset of labour. In addition, the baby is given a single dose of nevirapine within 48 hours of delivery and a combination of some other ARV drugs every 12 hours for one week. The mother is also counselled not to breast feed the baby at all if she can afford to feed the baby with baby formula for six months, or she should do exclusive breast-feeding for six months.

another counselling session is often given to help clients accept the test results, either positive or negative. This type of counselling is called post-test counselling. When a client tests positive, the counsellor provides him/her with information about treatment and subsequently refers him/her to the clinic for treatment. The counsellor also discusses issues with clients including partner notification and behavioural changes to reduce the risk of infecting other people with the virus. In the case of a negative test result, the counsellor discusses with the clients how infections occur and how to avoid or reduce the risk of getting an infection. The counsellor also discusses the window period[11] with clients and asks them to come back for another test in three months' time to confirm the result of the first test (cf. IAE/UNFPA 2005).

Counsellors also provide couple counselling, although clients are supposed to be counselled individually to ensure confidentiality. They encourage people diagnosed as positive who have partners or spouses to disclose their status to them and also to invite the partners to sit in on their counselling sessions. The partners or couples do not have to be positive before they undergo couple counselling. That is, a discordant couple – one positive and the other negative – can go through couple counselling with the consent of the positive partner. The partners are often counselled together on psychosocial, reproductive and financial issues. The couple is also provided with information on available and accessible links, networks, referral systems and positive person associations within their communities. Couple counselling is also referred to as shared confidentiality (WHO 2007).

Testing

Two main methods were used to do testing in the centres where the study was carried out. These were called 'First Response' and 'Oral Quick' according to counsellors. They are also known as the 'Rapid HIV antibody test' and 'Oral mucosal transuadate test' respectively (see also UNAIDS 1997:3). The two methods are generally referred to as Simple or Rapid Tests.

Counsellors and laboratory technicians also mentioned a third testing method, – 'Determine', which they said is currently used only rarely in facilities. Another name for this method is the 'Standard blood test' or ELISA[12] (see also UNAIDS 1997:3). In an interview, a laboratory technician, Denis, said that ELISA was the first antibody test method developed and made available for use in many developing countries including Ghana. The ELISA, he said can only be used by skilled personnel and this makes its use less suitable for health facilities without trained laboratory personnel. Denis further explained that the ELISA is being used less

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[11] Window period is the time the HIV virus takes to show up in the antibody of an individual after infection. The period is between 4 and 12 weeks.
[12] ELISA means enzyme-linked immunosorbent assay (UNAIDS 1997)

because its results can take a day or more to process as the blood sample has to go through certain laboratory processes. He pointed out that the delay associated with the method deterred many people from coming back for their test results at the beginning of the epidemic in Ghana.

With regard to the rapid test method, the laboratory technician said that they could be used by anyone after a demonstration. More importantly, it only takes about 30 minutes for the test results of these methods to be ready. Denis added that the test results of all the methods are highly reliable and he commented about the rapid test methods as follows:

> I have used all methods before and I can say that unlike the ELISA, clients do not go through the trauma of waiting for days or weeks to get their test results with the rapid test methods. Now, the results are given within minutes after testing… This has also helped to stop the problem of clients not coming back for their test results which in the past made our work difficult. Besides, it has helped more people know their status and start treatment as early as possible…

Counsellors used the rapid methods in the centres for testing as follows. The Oral Quick test method uses a specially treated pad placed in a person's mouth and gently rubbed between the lower cheek and gum. The pad collects an oral fluid called oral mucosal transudate (OMT). The fluid contains HIV antibodies in an HIV-infected person. Oral Quick test does not test for HIV in saliva (UNAIDS 1997). To perform the test with the First Response method, a finger stick sample of blood is collected from an individual and transferred to a vial where it is mixed with a developing solution. This test device, which resembles a dipstick, is then inserted into a vial. In as little as 20 minutes, the test device will indicate if HIV-1 or HIV-2 antibodies are present in the solution (UNAIDS 1997).

Antiretroviral Therapy (ART)

The clinics provide antiretroviral therapy treatment to positive persons referred from the centres after post-test counselling. This makes counselling and testing the entry point for treatment in Ghana. Before treatment starts, clients go through certain procedures in the clinics to qualify to start on ARV medicines. The procedures are generally referred to as eligibility criteria[13] and have two parts: (i) clinical and biological and (ii) social criteria (NACP/GHS 2006). The treatment process follows a particular order.

The first step is registration. Positive persons who report to the clinics for treatment are first registered as new clients. The registration could be the same day the person reported to the clinic, a couple of days or sometimes even one week later.

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[13] Eligibility criteria are also referred to as Initiation criteria. They have two parts: Inclusion, and Exclusion criteria. If a client satisfies all the necessary requirements for ART initiation as explained in the main text of this chapter, it means that he/she would be included in ART treatment and this is referred to as Inclusion criteria. On the other hand, if a client is not able to satisfy all the necessary requirements for ART initiation, it means he/she would be excluded from ART treatment and this is referred to as Exclusion criteria.

For example, in one of the clinics, particular days have been set aside to register new clients for treatment. This means that if a positive person reports to the clinic on a day set aside for activities other than registration, he/se would have to wait till another registration day. According to the health workers, this strict regime became necessary in view of the heavy workload they have to contend with. They explained that although the number of clients accessing treatment continues to rise, the staffing situation in the clinics remains almost the same. As a coping mechanism for the heavy workload, they have assigned certain activities to particular days of the week.

Registration involves writing the name of the person in the client registration book[14] based on the referral notes from the centre and a client registration form filled for him/her. The registration form contains the client's basic data including the date he/she tested positive and was referred to the clinic to start treatment, socio-demographic characteristics, and contact address or phone number among other things. A clinic identity card is issued to the person and this will have to be presented to health workers any time the person reports to the clinic for treatment. This, known as the treatment folder, is always kept in the clinic. The treatment folder contains all the client's treatment records including laboratory tests done, monthly reviews of health status and re-supply of drugs. After registration, the client is given a laboratory form for a CD4 count test[15] and is expected to report back to the clinic for the test results at a later date.

The second procedure concerns clinical and biological criteria. These are the various laboratory tests a client needs to go through prior to treatment. The first in the series of these tests is the CD4 count test, which determines how soon a client will begin adherence counselling leading to treatment. In Ghana, until mid 2008, the CD4 count level for a client to be due for treatment was 250 and below. The National AIDS and STI Control Programme/Ghana Health Service changed it to 300 and below around June 2008. Presently, a client whose CD4 count is above 300 would not be put on treatment because it is assumed that the immune system will be strong enough to fight any opportunistic infections.[16] The client would instead be given another date, in one to six months, to come back to the clinic for another CD4 count test. If it happens that a client's count level is consistently high, he/she would not be put on treatment for many months or sometimes even years. During this study, I encountered a number of clients in the clinics who had not started treatment

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[14] The client registration book contains the names of all clients who take-up care and treatment in the ART clinics. The names are written in the book on monthly basis for each year starting from the date the clinic started providing services to positive persons. Some of the data often recorded in the registration book includes sex, age of client, place of residence and house number if available.

[15] According to NACP/GHS (2005), CD4 Count is a good indicator of the immune function in HIV infection. It is recommended that the CD4 count be done at ART initiation and once every six months.

[16] Opportunistic Infections (OIs) are clinical conditions that result from an individual's weakened immune system. They represent major causes of ill health and will lead to death in positive persons. Examples of OIs are diarrhoea, cough and TB. (NACP/ MOH 2006).

for more than one year after testing positive due to high count levels. Such clients were usually asked to come back to the clinics within three to six months for another test to check their CD4 count levels. They are often given some prophylaxis like Septrine when they report to the clinic for scheduled visits to help maintain the resistance of their immune system to opportunistic infections.

I asked a medical doctor why the level of CD4 count for treatment has been changed as mentioned earlier. He explained that the decision was based on recommendations of the World Health Organization (WHO) for ART initiation. According to the WHO, there are four different stages of HIV infection: Stages One, Two, Three and Four.[17] At Stages One and Two, the infection is considered to be in its initial phase and is therefore less threatening to the life of the positive person. Stages Three and Four are considered to be the AIDS stage and could lead to the death of the patient if treatment is not started early. According to the doctor, the count of 250 and below was eventually found to be too close to the AIDS stage and therefore the minimum count threshold needed to be increased to 300. The doctor said that at 250 and below, it was observed some of the clients died before they completed all the necessary procedures to start treatment. With a count of 300 and below, it was expected that most clients would be strong and healthy enough to be able to go through all the necessary procedures and stay alive for the treatment. In other words, the change was meant to prevent clients from dying before they could benefit from treatment. When a client's count has been established to be at the recommended level for treatment, he is given a date to start adherence counselling. The starting date could be one day, two days or one week after the CD4 count test result.

The client is also expected to undergo a number of laboratory tests ahead of adherence counselling. These tests include Tuberculosis (TB), Haemoglobin (HB), Hepatitis B, liver and kidney functioning among others. During my interactions with clients in the clinics, most of them expressed frustration with the many laboratory tests they had to undergo before treatment. Some clients in one of the clinics explained that they accessed these laboratory services at different locations and units throughout the hospital, which they said increased the risk of exposing their status to other patients because they use the same laboratory services as other departments' clients. A client cited an instance in which she met a relative at one of the laboratories and the relative insisted on knowing why she had come for health

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[17] Some of the descriptions for WHO Stages of HIV infection are as follows: Stage 1- Asymptomatic HIV infection, persistent generalized lymphadenopathy (PGL). Stage 2- Herpes Zoster (within the last 5 years), recurrent upper respiratory tract infections, and weight loss of more than of 10% of body weight. Stage 3- Severe bacterial infections (i.e. pneumonia), oral candidiasis (thrush), unexplained chronic diarrhoea (more than 1 month), unexplained prolonged fever (intermittent or constant for more than 1 month), Tuberculosis (TB), weight loss of more than 10% of body weight. Stage 4- Candidiasis, cryptococcosis with diarrhoea for more than 1 month, herpes simplex, HIV encephalopathy, HIV wasting syndrome, kaposis sarcoma (KS), TB among other things (NACP/GHS 2005).

services when she did not look sick. Another client also suggested that the hospital authorities should make all the necessary services that positive persons need for treatment available in the clinic. The client said this would enable very weak clients who often find it difficult to move around the hospital to use services more easily.

In response to clients' complaints about the many tests, a medical doctor explained that apart from the CD4 count level, the other tests are needed to assess clients' health in general before they are put on treatment. The doctor said that in view of the likely side effects that clients may suffer from taking antiretroviral drugs, it was important to undergo series of tests in order to know which drug combinations would be suitable for each client. He further explained that the chemical components of some of the drugs are not good for clients suffering from TB, Hepatitis B, low HB, liver or kidney functioning problems. The doctor cited for instance that clients suffering from TB are not put on treatment until the infection is cured. According to him, it is not medically advisable for a TB patient to be put on ARV drugs since that could compromise the client's health.

The third step concerns the social criteria. Clients must also satisfy the following social criteria in addition to the clinical and biological criteria before beginning ART. The first of these is the disclosure of one's positive status to a selected person as his Adherence Monitor. According to the National Guidelines for ART initiation (NACP/GHS 2005), every client is supposed to disclose his status to at least one person he trusts to keep knowledge of this a secret. Suzane, a senior nurse said that the adherence monitor could be a spouse, relative or friend of the client and should ideally live in the same house as the client or close to the client. The nurse further explained that if it happens that a client is too weak, due to opportunistic infections, to access treatment on his/her own, the adherence monitor would be the right person to escort the client to the clinic for treatment. The adherence monitor is also supposed to remind the client always to take his/her medicines at the right time and to support the client to cope psychologically with the infection. The monitor is also expected to join the client during adherence counselling sessions leading to treatment. A client who does not present a monitor is not allowed to undergo adherence counselling.

The second social criteria is the mandatory three weeks of adherence counselling. According to Suzane, this is obligatory for every client as a precondition for treatment. During this period, health workers comprehensively explain the treatment to clients and their monitors. It is meant to help them understand the condition, its treatment and the consequences of non-adherence to treatment before initiation. She also pointed out that misconceptions about HIV/AIDS and its treatment as a cure are discussed and corrected during adherence counselling. The adherence counselling

sessions basically provide information on the following: HIV infection, viral load[18] and the significance of CD4 count; drugs administration, mechanisms of action and side effects[19]; when to take medicines, the need for adherence and notion of drug resistance; storage of drugs, life long treatment, avoidance of sharing drugs, the effects of alcohol, smoking and herbal drugs; safe sex and good nutrition; date(s) for next clinical and pharmacy appointment(s). Issues such as financial problems, stigmatization and other social problems are discussed and addressed during these counselling sessions (WHO 2007).

Adherence counselling is re-enforced during every scheduled clinic visit and a mandatory pill count is done. The mandatory pill count is to assess client's self-reported adherence. Statistics on clients' vital signs are also taken during monthly clinic visits before treatment. The vital signs include blood pressure, pulse count, temperature, weight, and height, and these measurements enable health workers to monitor clients' progress on treatment.

After the three weeks of adherence counselling, health workers then decide when a client will start treatment, a decision that is often based on his performance during the counselling process. Clients are expected to recall most of the things learnt at every stage of the adherence counselling process before progressing to the next stage. Health workers explained that a client's ability to do this is an indication that he has adequately understood the treatment and he is most likely to adhere to the treatment if put on the drugs. Clients who are not able to recall things learnt during adherence counselling are often made to go over the process again till health workers are convinced that they have understood treatment.

It was observed in one of the clinics that adherence counselling was done on a one-on-one basis while in the other it was through group counselling. In one clinic[20], the counsellor, the client and the monitor were usually present in the counselling session. On the other hand, in the second clinic[21], those present in counselling sessions included the counsellors, about ten or more clients and their monitors.

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[18] According to NACP/GHS (2005), although viral load is important, it cannot be taken routinely due to financial and capacity constraints. The viral load at the initiation of therapy indicates the prognosis of HIV infection and during therapy it provides evidence of the virology response to therapy. Viral load monitoring is not critical if there is clinical improvement, good adherence and an increase in CD4 count. Though viral load is not accessible for management and follow up, it is recommended that where available and affordable it should be done in 0, 3, 6 month(s) and six-monthly. If the viral load is undetectable and there is good adherence to drugs, the frequency of viral load determination can be reduced unless there are clinical indicators of deterioration (NACP/GHS 2005).

[19] Some of the side effects of the ARV drugs are as follows: anaemia, peripheral neuropathy, diarrhoea, pregnancy nightmares, hypertensive reaction, and hepatitis.

[20] This is the clinic in St. Patrick's Hospital, Offinso. It is called "Special Clinic" and the clinic day for positive persons is every Wednesdays.

[21] This clinic is the one in Komfo Anokye Teaching Hospital, Kumasi. It is called "Chest Clinic" and the clinic days for positive persons are Mondays and Fridays. Wednesdays are for Adherence counselling sessions.

Health workers in the second clinic explained that they are doing adherence counselling through group counselling as a coping mechanism for the heavy workload although they are aware that this does not guarantee clients privacy. They explained that the number of clients for adherence counselling is always high and due to their limited number, the health workers cannot counsel individual clients and their monitors one after the other. Vera, a senior nurse opined: "If we do adherence counselling on a one-on-one basis in this clinic, it means we would not do any other work for the whole five working days."

Nurses, pharmacists/dispensary assistants and disease control officers trained in counselling skills were involved in adherence counselling in the two clinics. In the second clinic, however, peer educators, who are also positive persons and trained in counselling skills, often helped health workers counsel clients during group counselling sessions. The peer educators thus complement the work of care providers in adherence counselling by sharing their lived experiences of the disease and its treatment with clients.

The fourth procedure is consultation. After a client and a monitor have successfully gone through all the procedures described above, they would then see the medical doctor in the consulting room, who finally decides which combination of drugs the client will be put on. The doctor again assesses the client's knowledge of the treatment based on what was learnt during adherence counselling before recommending him for treatment; if he is unable to recall things learnt during adherence counselling, the doctor can recommend that a client go back for counselling again.

The last step in the treatment process takes place at the pharmacy. Clients who have been cleared by medical doctors to start treatment are supplied with their drugs at the clinic's pharmacy. The drugs are sold to clients at a government-subsidized cost of five Ghana cedis (about five US Dollars). They are re-supplied with the drugs at the same cost every month. At the end of the long process, pharmacy staff often re-emphasise some adherence counselling messages earlier given by nurses and other health workers. These include drug administration, mechanisms of action and side effects, when to take medicines, the need for adherence and the concept of drug resistance, storage of drugs, avoidance of sharing drugs and pharmacy dates.

Clients often go through some of these procedures during monthly visits to the clinic for a review of their health and re-supply of medicines. For instance, during monthly visits, they need to do a CD4 count test and sometimes also a haemoglobin test. In addition, the doctor can request a client to do other tests such as TB, Hepatitis B, liver or kidney function depending on the client's health. Records of clients' vital signs are also taken before medical doctors attend to them. After these procedures, clients can go to the pharmacy to receive new supplies. Health workers also continue counselling clients during monthly visits to help them adhere to

treatment. According to the health workers, clients who are treatment defaulters often develop resistance to the drug combinations they have been prescribed, and there are limited options available in Ghana for such clients to be put on second line drugs, which are very expensive.

General observations on services

This section is devoted to general observations regarding the provision of services at the study sites. These include attendance, cost of services, set-up of counselling rooms, duration of counselling, lack of counselling in diagnostic testing, reliability of test results, disclosure of test results, concerns about eligibility criteria and positive persons on ward admission.

Reviewing the centres' and clinics' service records spanning the past few years shows that there has been a gradual increase in the uptake of services. For instance, in one of the centres, the total number of clients tested for HIV in 2004 was 1,906 while the total for 2005 was 2,706. The 2005 figure represents an almost 30 per cent increase over the 2004 figure. The increase in the use of services in the centres was largely due to the increased availability of diagnostic testing, and to the mandatory testing of pregnant women under the Opt-Out policy. These factors have also led to an increase in the enrolment of positive persons in the clinics for treatment, as will be seen later below.

Counsellors explained that in most cases it is would-be couples that came in voluntarily to access counselling and testing services. Such people are often asked by their church authorities to submit a report on their HIV status as a requirement for the blessing of their marriage in the church. Counsellors also pointed out that people who wanted to travel abroad to certain countries also came to access services as walk-ins in order to obtain the personal HIV-status report required by those countries' embassies for travel visa applications. Finally, the counsellors said that few people who willingly came for counselling and testing were likely to have engaged in risky sexual behaviours or feared that they had been exposed to the virus.

In the clinics, the number of clients accessing treatment has been increasing over the years, partly due to the greater availability of diagnostic testing and its wider use due to the 'opt-out' policy for pregnant women. For instance, where the enrolment of clients in one of the clinics in 2005 was 634, by 2006 the total enrolment had reached 1,710, an increase of approximately 62 per cent. On clinic days, the facilities were always busy with a number of clients waiting in long queues to be attended to. Most of the clients (more than 60 per cent) who reported to the clinics for registration and treatment were women; of the total number of clients tested in a centre in 2004, females accounted for 61 per cent and 64 per cent in 2005.

One medical doctor explained in a conversation that the higher number of female clients using services, compared with males, is in line with the way Ghanaians generally access HIV/AIDS-related health care. According to him, records in his hospital (see also Chapter 3) and possibly other health facilities in Ghana show that women utilise HIV counselling, testing and treatment services more than men do. He further explained that apart from being tested through voluntary uptake and provider-initiated, the opt-out policy for pregnant women has also led to more women undergoing HIV-test. And, as a result of this, more women tested positive and started using treatment services. The observation by the medical doctor is similar to the finding by Ghana AIDS Commission (GAC) on the Progress of the United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS. Their report pointed out that the percentage of women on ART has been consistently higher than men and the gap between men and women has increased over time. It further noted that this may be due to entry points to care from prevention of mother-to-child transmission which links women to services (GAC 2000: 41).

However, Nurse Vera was of the view that most men who tested positive were reluctant to access treatment for fear that they would be identified and stigmatised or discriminated against. A client also said that her husband who had tested positive more than two years earlier had refused to access treatment for the same reason. According to the client, her husband said that because of his popularity in the community, he would prefer to die with the virus rather than access treatment in the clinic and be seen by other clients who could tell other people about his status.

Another nurse, Roseline, explained that some positive men thought that their peers who accessed treatment were cowards who feared that they might die due to the infection. According to the nurse, HIV-positive men who refused to access treatment considered themselves brave men (*mmarima akokodurofoɔ)* and were ready to die at anytime, regardless of the consequences. That is, some positive men saw their refusal to access treatment as a sign of bravery and a lack of a fear of death. Being fearless is seen as a masculine trait among most Ghanaian ethnic groups. Ohene, a male client, shared similar views on masculinity, citing it as the main reason why some positive men had refused to use care and treatment services. He said that such positive men even teased other male clients on treatment, calling them women (*mmaa)* because they feared HIV/AIDS might shorten their lives. This description of male clients as *mmaa* is in line with the way most Ghanaian ethnic groups generally perceive women, considering them cowards, and unlike men, not brave enough or lacking the courage to face difficulties and hardships in life or death. It is this perception of women that nurse Roseline and Ohene suggested that some HIV-positive men who are not on treatment may invoke when they disparage male clients.

Although the Ghanaian government subsidizes the cost of antiretroviral drugs, it was found that the majority of clients were unable to buy them at the end of each month due to poverty and unemployment. However, to encourage clients to continue coming to re-stock their medicine supplies every month, the health facilities have instituted a policy that allows clients to buy their medicine on credit. There is no limit to the number of months or times a client can buy drugs on credit, but some clients complained that they were unduly delayed at the pharmacy whenever they bought drugs on credit. That is, clients who bought and paid upfront were always served first in the queue contrary to the informal 'first come, first served' policy in the facilities. When questioned about this during an interview, a pharmacist denied this and explained that some of the clients are too impatient to wait their turns in the queue to get their re-supply of drugs. The pharmacist pointed out that staff always serve clients according to the order in which they are seated in the queue and do not favour those who make prompt payment. However, I observed on a number of occasions that some clients noted for buying drugs on credit were asked to wait while others who paid upfront were served first.

The cost of counselling and testing used to be one Ghana cedi (about one US Dollar) in Government health facilities including the hospitals where this study was carried out. In one centre, the cost was as low as 50 Ghana pesewas (about 50 US cents). Under the 'opt-out' policy, counselling and testing is free of charge for pregnant women. According to Bernard, a counsellor, the objective for making the services free or almost free of charge is to encourage more people to undergo counselling and testing, and to learn their status. This implies that costs should not be a barrier for anyone who wants to undergo counselling and testing in a government hospital or health centre. The costs of testing in some private health facilities and laboratories were relatively high because most of them were still using ELISA for testing. For instance, in Quality Care Clinic, clients paid four Ghana cedis (about four US Dollars) for testing. It was not surprising that some clients in this clinic found it difficult to meet the cost; in other hospitals I observed that some clients could not even pay the one Ghana cedi charge for counselling and testing. The medical doctor in charge of the clinic explained that the regimens they use for testing are expensive, hence the need to charge this amount to cover costs. However, during follow-up, I found that counselling and testing had been made free of charge in government facilities as of March 2009 (NACP/GHS 2009).

It was observed that the set-up of counselling rooms in the centres did not make them attractive enough to motivate people to access services voluntarily. For instance, the walls of the counselling rooms did not have information, education or communication materials with pictures to inform and educate visitors to the centres about the importance of voluntary counselling and testing and how they are provided. The seating arrangements in the counselling rooms were also not

conducive to interactive counselling. In one counselling room, for example, I observed that the counsellor was seated across the table (and rather far away) from the client. Over the years, this type of seating arrangement has been associated with the 'teacher-pupil' relationship, with the teacher seated at a table in one corner of the classroom and the pupil on the other side of the classroom. The teacher, as the one in-charge, gives instructions to the pupil who must carry them out without asking questions. This set-up does not encourage interactive discussion. During the course of this study, clients were observed during counselling sessions to sit listening attentively to the counsellors as if to a teacher, rarely asking questions, nodding their heads in agreement with whatever the counsellors said. After the clients had been through a few sessions I asked them why they did not ask questions for clarification during counselling. Most of them said that counsellors knew better and whatever they said was right. These observations on counselling show that there was little social interaction between counsellors and clients. It was not a conducive environment to encourage dialogue between two parties. However, in one centre I observed that Bernard, a counsellor, sometimes engaged in informal conversation with clients during counselling. Such conversations often helped put clients at ease before their test results were disclosed to them.

The time counsellors spent with clients during pre- and post-test counselling was inadequate. Most of the sessions took less than 10 minutes and in some cases only about five minutes, although, according to WHO (2007) a typical pre-test counselling session should take 30-45 minutes while post-test counselling should take 20-25 minutes. The duration for these two types of counselling is due to the number of topics that must be covered in each of the sessions. It can be presumed that counselling in the centres in particular did not cover all the recommended topics, as mentioned earlier ,which suggests that in most cases clients were not given adequate information to make informed decisions about testing and treatment. One counsellor explained that the high number of clients accessing services had made it difficult to do lengthy counselling. Spending a short time on counselling each client was thus a coping mechanism for the centre counsellors' heavy workload.

All indications pointed to the fact that counsellors were selective in the information they gave to clients in counselling sessions. Information given was largely dependent on a client's socio-demographic characteristics such as the level of education. Some counsellors did not seek clients' consent or clearly explain the consent process to them during pre-test counselling as required by the Ghana Draft Policy on HIV/AIDS (2000).[22] The counsellors said that most of the clients were illiterate and would not be able to understand the process and meaning of seeking

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[22] The Ghana Draft Policy on HIV/AIDS (2000) states that the consent of every client must be sought before pre-test counselling and the client has the right to refuse the counselling and testing whether it is voluntary or diagnostic.

consent. In some instances, counsellors did not explain to illiterate clients that they could undergo counselling and take their time to make a decision whether or not to go through with testing, which could be done on another day.

In fact, there was no pre-test counselling in most of the diagnostic testing cases I observed. In the few cases that such counselling was conducted, counsellors spent about five minutes with the clients. Seeking consent was also either not done at all or not properly done. Counsellors explained that there was no need to spend too much time on clients referred by doctors for testing because unlike voluntary counselling and testing, they have no choice to refuse testing. One important finding made about diagnostic testing was that in the majority of cases, clients were not explicitly told that they have been asked to go for HIV testing. They were often instead asked to go for a laboratory test, which could have been malaria, haemoglobin, or any other medical test. It was at the centres or at the point of the testing that those clients discovered that they had been asked to go for HIV testing. A counsellor explained that sometimes the doctors felt that if clients were told that they had been referred for HIV testing, like some voluntary counselling and testing clients, they might refuse to go for the service.

The methods used for testing were said to be very reliable. In most of the testing I observed, counsellors used the First Response test to determine the status of clients. After this, they used the Oral Quick test to confirm the results of the first test. However, the two methods sometimes gave different results. In the case of one client, her first test result was positive and the second was negative. She became confused and worried, as the counsellor could not decide which of the results he should take as the accurate indication of the woman's status. The counsellor had to refer the client to a private laboratory for another test in order to make a decision as to whether the client tested positive or negative. In the few cases where there was uncertainty about the test results, clients' facial expression showed their anxiety over what would the outcome of yet another test would be.

In an interview, a laboratory technician explained that this happens in a few cases irrespective of the high reliability of the testing methods. According to him, even with the advanced technology behind the kits, sometimes room must be given for such errors, although this should not happen often. He added that this does not mean that the test kits are not good or reliable.

Rapid test kits have made the disclosure of test results to clients easier. Counsellors often explained to clients that if two lines appeared on the First Response twenty minutes after the blood sample has been taken, the result was positive, whereas one line meant negative. Similarly, with Oral Quick, they told clients that if a line appeared on the test kit, it meant positive, but if nothing appeared, then the result was negative. This enabled clients to read the results themselves after counsellors showed the test kit to them. Some clients intentionally read the lines

wrong, particularly in cases of bad test results which meant that they had HIV. Yet, I observed that most of them were able to tell the counsellors the test results. The idea of involving clients in disclosure is to help reduce the suddenness with which clients receive positive results. Moreover, this has lessened the difficulty most counsellors faced in disclosing positive results to clients, which is considered bad news. This is a particularly important consideration in the Ghanaian context, as giving bad news presents particularly difficulties for the one who does the disclosure.

Conversely, there were instances in which some counsellors could not clearly communicate to clients that they had tested positive when they were compelled to do so. For example, some clients misread the number of lines that appeared on the test kits and counsellors had to disclose the results to them. Those counsellors alternatively communicated positive test results to clients in one of the following ways: "Some worms (*mmoaa*) have been found in your blood," "Some of the disease (*yareɛ no bi*) has been found in your blood," and that "their disease (*wɔn yareɛ no*) has been found in your blood."[23] Some clients either genuinely did not understand or pretended not to have understood the disclosure of test results. Any of these vernacularly phrased disclosures could be understood to mean that the client was suffering from a condition other than HIV. For instance, in the Twi language (*mmoaa*) could mean small worms or animals. So, if a counsellor tells a client that some *mmoaa* have been found in his/her blood, the client may intentionally or unintentionally think that he is suffering from a hook worm infection and not the HIV infection the counsellor intended. Perhaps such counsellors could have qualified *mmoaa* with AIDS, which most Ghanaians have heard of, and this would have differentiated HIV infection from other worm infections.

These ambiguous disclosures have led to problems between health workers and clients referred to the clinics for treatment on many occasions. According to health workers in the clinics, as a first step to treatment, clients referred from the centres are expected to clearly tell them that they tested positive and have been referred for treatment. However, some clients chose to say what the counsellors told them in ambiguous terms on their first visits to the clinics. For example, some clients said, "The man (counsellor) who asked me to come here for medicines said some worms (*mmoaa*) have been found in my blood." Health workers often responded to such statements as follows: "Which type of worms you were told have been found in your blood?" The health workers were of the view that some clients tended to deny their status with the claim that counsellors told them about some worm infection and not HIV. In such cases, they always insisted that until the clients admitted their positive status either in Twi or English language they would not be registered and treated in the clinic. In Twi, clients often said "*Yɛhunu* AIDS *anasɛ* HIV *yareɛ mmoaa no bi*

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[23]   Those counsellors said these in the Twi language as follows; '*Mmoaa bi aba wo mogya mu*', '*Yareɛ no bi aba wo mogya mu*', '*Yɛhunu wɔn yareɛ no bi wɔ wo mogya mu.*'

wɔ me mogya mu" which literally means "They have found some of the AIDS or HIV worms in my blood." This confusion in the clinics was the result of some counsellors lacking the skills to communicate bad news such as positive test results to clients.

The majority of clients I interacted with expressed their frustrations with the eligibility criteria for treatment, which they said was too long. They pointed out that the mandatory three weeks of adherence counselling was like school 'test' or 'examination' (*nsɔhwɛ)* which one must pass to be initiated onto treatment. I recall an instance after an adherence counselling session, about which a client openly remarked as follows:

> Today too they – health workers – said I did not do well during the counselling so I cannot start treatment next week. In fact, I am tired of this test (*nsɔwhɛ)* although I am not a schoolboy… I hope next week would be the last time for me to do this counselling and start the treatment which I came here for…

In another instance, a client could not recall what he learnt during adherence counselling for four weeks. On the next clinic day, I learnt this client died two days after he visited the clinic the last time for adherence counselling. The client's life probably could have been saved if he had been put on treatment irrespective of his inability to pass the test after three weeks of adherence counselling. A medical doctor explained that in few cases some clients are allowed to start treatment without the mandatory three weeks of adherence counselling. He pointed out that in such cases, it is the medical doctor who uses his discretion to decide which client urgently needs treatment without three weeks of adherence counselling. However, this rarely happens because adherence counselling is crucial for the treatment of the disease and before seeing the doctor in the first place.

The two hospitals, St Patrick's Hospital and Komfo Anokye Teaching Hospital, did not have separate wards for positive persons such as in Korle-Bu Teaching Hospital in Accra, the capital city of Ghana. This meant that on admission seriously ill clients were put in general wards with patients suffering from other diseases. It was observed in the hospitals that, compared with other patients, health workers in the wards did not give clients adequate nursing care. For instance, in one of the hospitals, they were put in the side wards, which were rather isolated from the other patients in the main ward. In an interview, a medical doctor in charge of one the wards explained that it was normal for patients to be put in the side wards. According to him, side wards are part of the main ward except that they are often reserved for patients who have infectious diseases such as tuberculosis. He was of the view that most positive persons are put in the side wards because they have tuberculosis and not because of the HIV/AIDS *per se*. A senior nurse who was in charge of the nurses in the ward agreed with the medical doctor and added that patients are often assigned beds based on availability and not according to their type

of disease. However, following some ward rounds with the health workers, I observed that positive persons were often put in the side wards. In one ward, for instance, it was observed that most of the clients on admission were put in the side ward compared with patients suffering from other diseases. On the other hand, health workers in the ART clinics said that positive persons were not treated well in the general wards and therefore called for a separate ward for them, staffed with nurses who have been trained in how to care for positive persons.

In conclusion, this chapter gave a general introduction to where the present study was carried out. It described the characteristics of the hospitals, voluntary counselling and testing centres and antiretroviral therapy treatment clinics that are relevant to this study. Next, it gave a detailed account of the procedures and processes of the services. It also presented general comments on how services were provided and used and what their impact was on the data collected. Finally, the chapter gave an idea of the topics that will be discussed in the subsequent empirical chapters.

The social risks of using services

> Yes, it is true; some people have cited lack of confidentiality on the part of health workers as a reason for not using HIV-related health care services. Some of our colleagues talk too much ... so they easily disclose the status of clients to other people forgetting that this could lead to stigmatization of the clients. Other clients have also complained about the open location of the clinic in this hospital because they find it difficult to sneak in and access services, and also sneak out after treatment… They fear that relatives may see them entering or coming out of the clinic and suspect them of the disease, and stigmatise them (Marie, a health assistant).

In making the decision to access HIV counselling, testing and treatment services, clients are often concerned about the possibility of their status being revealed and the negative repercussions that could follow. The repercussions are what I term social risks and they are mainly due to the persistent stigma associated with HIV/AIDS in Ghana. The social risks related to people's beliefs and perceptions about the disease are in the form of shame (*animguaseɛ*), loss of respect (*onni buo*) and honour (*onni animuonyam*). These could lead to divorce, rejection, ostracization, discrimination, and loss of job, as can be seen in more detail in the work of my colleague, Kwansa (2011) who followed these clients in the community. According to Mbonu *et al.* (2009), the fear of stigma and its repercussions negatively affects those seeking HIV testing and seeking treatment after diagnosis in Sub-Saharan African countries, including Ghana. This has been a matter of concern to stakeholders in the campaign to prevent the spread of HIV/AIDS. To encourage more people to go for counselling, testing and treatment, a scale up exercise was carried out in Ghana to make the services easily available and accessible to people in all parts of the country.

During interactions with health workers, they pointed out that the increased availability of counselling, testing and treatment sites had not led to the expected

increase in use of services. As can be seen from the quotation above, Marie, a health assistant, attributed this to the fear by clients that health workers could disclose people's status to others which could lead to stigmatisation. She added that clients were of the view that the open location of the clinic does not guarantee them the privacy to access services and conceal their status from others. It implies that people often take into consideration how health workers handle information obtained from clients during contacts and some characteristics of the facilities to decide on the use of services. These considerations relate to confidentiality and privacy in the health care setting. In Ghana, one can be suspected of having HIV/AIDS if he is found in a facility that provides HIV counselling, testing and treatment. This, in many cases leads to stigmatization because HIV/AIDS is often associated with pre-marital sex and commercial sex work. Nwintuo & Mill (2006) observe that such practices are perceived as immoral sexual behaviours and are socially unacceptable.

However, some people have acted and chosen to use these services despite the persistent stigma associated with HIV/AIDS. They might have been motivated to access services in view of the perceived benefits they will get from using counselling, testing and treatment services. Such people believe they will know their HIV status and if positive, they could start treatment early and live longer with the disease. The present chapter therefore shows how the events and activities in the hospital have implications from the point of view of the society. It further demonstrates the possible consequences one could suffer if he is found accessing HIV-related services in the hospital.

I begin the chapter with a presentation of the views and opinions of both health workers and clients on the confidentiality and privacy in the hospital set-up. The second part, a discussion of the issues, looks at four main issues. I argue that the deadly nature of the disease rather than the association with immoral sexual behaviour is the cause of the persistent stigma associated with it, leading to concealment of their status from others. It examines the ethical dilemma of health workers due to the need to maintain confidentiality about clients' status, even, in situations when they know that this could lead to the infection of others. A discussion of the implications of confidentiality on therapy management for the work of care providers follows. Finally, it looks at the debate for and against the provision of HIV-related care and treatment services separate from or integrated into other services in the hospitals.

Confidentiality

Confidentiality is core in the provision of counselling, testing and treatment services as seen in the definition of counselling in Chapter Three. Before counselling starts, counsellors always assured clients of confidentiality. They told clients that other

people would not know about any discussion or conversation between the two of them. Confidentiality thus establishes trust between the two parties. Clients expect that health workers keep to their word. By respecting this, clients are able to conceal their status from relatives and others and avoid the social costs associated with HIV/AIDS.

In some cases, clients allowed health workers to disclose their status to selected persons in the context of shared confidentiality or couple counselling. However, in conversations and interviews with clients, they said some health workers did not keep the status of clients confidential as promised during counselling. Interestingly, some health workers, including Marie quoted above, agreed with this assertion by clients. Health workers referred to this as a breach or lack of confidentiality, which takes two forms – unintentional and intentional disclosure. These are instances of enacted stigma since such disclosures by health workers led to discrimination or rejection of clients by spouses or relatives.

Openly talking about clients' status (Unintentional disclosure)
These are cases in which some health workers were said to have revealed the status of clients to other people or to their colleagues in other units of the hospitals. Both health workers and clients cited instances to support this point. Rebecca, a senior nurse, recalled how a colleague in conversation with another health worker openly referred to a client as 'HIV patient' to the hearing of some other patients waiting for laboratory services in a queue. The nurse said that in order to protect the identities of positive persons, those of them working in the clinics call them 'clients.'[1]

Furthermore, during this study, a health worker disclosed a client's status to some community members and the client threatened to stop accessing services. The client, Bruwaa, reported to the medical doctor in charge of the clinic that a health worker had gone public about her status by warning someone to stay away from her because she is HIV-positive. According to her, this made those community members gossip about her and point accusing fingers at her that she got HIV/AIDS through prostitution. The doctor had to take action about Bruwaa's case and summoned the health worker before a disciplinary committee of the hospital. She was warned to desist from that behaviour. The doctor later said that this was not the first time a health worker was reported to have talked about a client's status in the community. He further explained that the good thing about Bruwaa's case was that she identified the particular health worker, which enabled the hospital authorities to take action.

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[1] According to nurse Rebecca, positive persons who access services in the clinics preferred to be called clients instead of patients. She said the positive persons believe that after regaining their health through treatment, they are no longer patients. Besides, the nurse explained that because the treatment is life-long, these people would continue visiting the clinics for the rest of their lives and it would be proper to call them clients.

In an interview with Mike, a counsellor, he pointed out that the ethics of the health profession does not allow health workers to talk about a client's health problems, even in the case of 'common' malaria let alone HIV infection. Mike added that:

> But I have observed that some of our colleagues have not changed after all the professional training they have gone through … they are simply 'okro mouth.' So, they let out information about patients' health problems unnecessarily to people who are not health workers…

Mike's comment implies that the professional training health workers received should have equipped them to know how to keep information about client's status confidential. He gave an instance in which he personally intervened to solve a problem between a colleague health worker and a client. Mike said that a care provider disclosed a client's status to her boyfriend and this led to a sudden end of their marriage plans. The client later identified the health worker who leaked her status to the parents of her boyfriend. The parents also warned their son to end his relationship with her. The client had wanted to confront the health worker on the disclosure of her status to others. However, he convinced the client to leave the matter for him to investigate and find an amicable solution to it. The counsellor further explained that fortunately his colleague was transferred to a health facility in a different town and this ended the problem.

Awo, a client, also told of an instance in which a nurse openly described her and a colleague as patients referred to the AIDS clinic to the hearing of other patients. The client explained that after she tested positive and was referred to the clinic for treatment, together with a colleague, they could not find their way to the ART clinic. They asked a nurse to help them locate the facility. While the nurse was leading them to the clinic, another nurse met them and asked her colleague where she was going with them. The nurse responded by saying that they have been referred to the AIDS clinic but they cannot find their way to the place and so, she was leading them to the clinic for treatment. Awo said that the moment the nurse made this statement in the corridor of a unit in the hospital other patients waiting for treatment suddenly turned to look at them. This, according to her implied that the nurse had disclosed their positive status to those patients.

Similarly, Salifu, a client, said that in the attempt of a medical doctor to get a ward assistant to assist him to the clinic, he let other patients know that he is positive. The client explained that after the doctor had attended to him, he was referred to the clinic for treatment, but he told the doctor that he did not know where the clinic was located. The doctor called a ward assistant and openly asked her to take him to where HIV patients are treated. Salifu pointed out that the doctor said this to the hearing of other patients waiting for treatment at the Out Patients Department. He added:

> The moment I came out of the doctor's room with the ward assistant, everybody was looking at me. I observed that some of them were saying something about me. I did not hear what they said but I believe they were saying that I am HIV-positive based on what the doctor said earlier… You see, this happened because I was very sick and I could not walk on my own… else, I would have looked for the clinic myself…

These cases imply that health workers sometimes unintentionally breach confidentiality at work and as a result disclose clients' status to other people. Such disclosures can erode the trust clients have in health workers to keep information about their status confidential.

Informing relevant others without client's consent (Intentional)

It was also found that some health workers informed other people about clients' status without their consent. In most of such cases, clients did not want those people to know about their positive diagnosis. Health workers often considered such people as significant or relevant others of the clients and felt that they must be informed of their status. These significant others included spouses and some close relatives. Clients told of experiences of how health workers informed their spouses and relatives about their status without first seeking their approval for such disclosures. In particular, the intentional disclosure of the status of positive pregnant women came to the fore during this study. According to some female clients, nurses in the labour wards informed their spouses or relatives about their status while they were in labour. The clients explained that they did not understand why health workers chose to do this. They further explained that such disclosures have led to the divorce of some female clients by their spouses. Eno, one such client remarked in a conversation as follows:

> ... I do not really know why… but maybe they were trying to explain to my husband why I had prolonged labour which was probably due to this disease ... I do not know... But, I still think that they should have asked me whether I have informed my husband about this before doing that …because, now my husband has lost trust in me as a faithful wife and I fear that this would result in the break-up of our marriage one day.

Another female client said:

> They – health workers know why they did that because they told us (during group counselling) before testing that until we (pregnant women) allow them, they would not tell our husbands about this disease. I do not know why they did not follow what they said… or, maybe they wanted my husband to divorce me for having this disease. I have decided that next time I would not come here (hospital) and deliver. I am still asking myself why they did that to spoil my marriage… (Ramah).

Later, Ramah said that she has advised some of her peers not to deliver in the hospital because the nurses would inform their husbands about their status as they did to her. She told those peers that if they do not want to be divorced and face disgrace as happened to her, they should deliver in a hospital other than the one where they were diagnosed positive or accessed treatment.

In an interview with Kumah, a client, she said the disclosure of her status to a relative by nurses led to her rejection by family members. The client explained that nurses in the delivery ward revealed her status to her grandmother after she lost the baby some hours after delivery. The grandmother reacted by forcing her from the family house because she brought shame to their family for being infected with an immoral disease. Kumah pleaded with the grandmother to forgive her and allow her to continue living in the family house but the grandmother refused to accept her back to the family house. The worrying aspect of her case was that she could not go and live with the boyfriend who impregnated her because he had abandoned Kumah and married another woman. The client was living with a distant relative who was not aware of her status at the time of this conversation.

Amma, also a client, initially denied her status when the husband observed that she had been taking medicines morning and evening on a daily basis.[2] She lied to him that the medicines were for the treatment of high blood pressure but her husband was not convinced. One day he took Amma's medicines and treatment cards without her knowledge to the clinic and showed them to a health worker in the clinic that they belong to his sister. The husband asked the health worker what the medicines and cards were meant for. The health worker told Amma's husband that they were for AIDS treatment. According to Amma, the husband attacked her and threatened to divorce her for lying to him. After her husband explained how he got to know about her status she confessed that she has the disease. This led to the break up of the marriage because her husband told his family members that she was HIV-positive. The client blamed the health worker who disclosed her status without her consent for the break of her marriage. She opined in a conversation, "I did not inform him of my status because I feared that could lead to divorce but this has eventually happened through a health worker."

Another client, Hassan, also told of an instance which showed that word had gone ahead of him from the centre or somewhere in the hospital to the ward that he is a positive person who has been sent for admission. The moment he got to the ward, he realised that one nurse gave a sign to a colleague (which he demonstrated this with his hands) and she also did the same sign to another nurse. Hassan pointed out that following the signs, he was moved from one bed to another in the same ward.

After he was discharged, he told a fellow client about the behaviour of the nurses in the ward. His colleague explained that the signs by the nurses were meant to inform their peers that he was a positive person and therefore they should be careful when attending to him in order not to be infected. His colleague also told him that often when a doctor referred a positive person for admission, health workers quickly

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[2] The ARV medicines are supposed to be taken every morning and evening at certain specific times on a daily basis. Ideally, the client must never miss taking the medicines at the times he has chosen in a day.

revealed to their colleagues in the wards to warn them before the client got to the ward. Hassan ended his story with the following statement:

> If this is what some health workers are doing in the hospitals, then the assurance they usually give during counselling and testing that whatever goes on is between only the counsellor and the client and nobody will hear of it is not true…

Nurse Suzane, however, explained that health workers sometimes disclosed the status of clients to others in the interest of the clients or their spouses. She said that in some cases they could not just look on and allow infected female clients to breastfeed their babies since the children could be infected through breast milk. Suzane further explained that in some cases, they prevent this by involving spouses or relatives of clients in the counselling process in order for them to know why the mother has been asked not to breastfeed her baby. She was of the view that health workers do this with the belief that clients might have informed their husbands or relatives. According to her, they have been receiving complaints from spouses of female clients asking why health workers have instructed their wives not to breastfeed their newborn babies. Health workers thought that it was important to involve spouses or close relatives in counselling positive mothers on what they can do to prevent their babies from getting infected through breast-feeding. She commented:

> The truth of the matter is that as health workers sometimes we are compelled by circumstances to disclose client's status to others in order to save lives… although we know this is against the code of ethics of our profession. Clients should understand that we do not intentionally do this to expose them as positive persons or embarrass them before their husbands or family members…

It is for this reason that the nurse said they often encouraged clients during counselling that they should disclose their status to their spouses, so that they can be counselled together through couple counselling. They can also disclose their status to people they trust in the form of shared confidentiality as explained earlier in Chapter Three. In such cases, the client discloses his/her status to the spouse or partner and invites her to join him in the post-test counselling session. The two are then counselled together on how to practice safe sex, treatment and psychological implication of the positive test. Some clients I interacted with admitted that if not through couple counselling, they could not have disclosed their status to their spouses. This was due to the fear that their partners would divorce them for having HIV. Aba, a client who benefited from couple counselling stated:

> … Through this counselling, the counsellor informed my partner that I have the HIV disease in a very nice way. He accepted the news about my status without any problem. Following the advice of the counsellor, my partner also did the test that same day to know his status…

However, there were instances in which some clients wanted to disclose their status to spouses but they could not due to the fear of the possible repercussions that might follow. Health workers often help such clients to inform their spouses. They

ask the clients to bring their partners to the centre or clinic under the pretext that a doctor wants to discuss an issue related to their health problem with them in the hospital. Sometimes, health workers tell clients to explain to their spouses that they need to be given blood transfusion as part of their treatment and the doctor wants them to donate their blood for that purpose. It was observed that most of the clients were able to convince their partners this way and brought them to the centre or clinic for this arranged disclosure and couple counselling. The health workers would then explain to the two parties that they have to test their blood in order to know if the blood groups match each other before the transfusion. At this stage, an HIV test is done on their blood samples to find out whether the other party also has the disease. The health worker discloses the test results in the presence of the couple and counsels them together.

Through this 'arranged disclosure', clients often avoid being blamed by their spouses for infecting them with the disease, as often happens in cases where the clients do the disclosures by themselves. A client who benefited from such an arranged disclosure and counselling commented as follows:

> … It was this nurse (she mentions the name) who saved me by using an arranged meeting between me, my husband and her and told him that I have this disease. Else, I would have been divorced by now… The nurse's explanation that my husband has to donate his blood to be given to me as part of my treatment convinced him to do that. And after the blood was checked, he was also positive… The nurse then told the two of us that we have tested positive and my husband's blood cannot be used for the transfusion…This ended the matter and now the two of us are on treatment without any blame from my husband … (Fauzia, a client)

In a few cases, arranged disclosures by health workers led to problems between spouses. Anane, a client, explained how after a nurse helped to disclose his status to the wife, she subsequently packed her belongings and left the matrimonial home. The client explained that his wife tested negative after he took her to the hospital for an arranged disclosure and counselling by the nurse. Their marriage ended abruptly because the woman said she could not live with a man who has a dangerous disease (*yare bɔne*) like HIV. Anane stated:

> The reason why I refused to tell her about this sickness myself has happened now – divorce. The nurse did her best to help me but it was my wife who did not understand me… Now, I am asking myself, which is better in this case, to tell or not to tell your wife… May be, I should have kept it secret from her as many people in the clinic here are doing…

Yet, despite the risk of divorce associated with arranged disclosure, couple counselling or shared confidentiality, it has helped many clients to handle the disclosure to spouses. Health workers must therefore encourage married clients to opt for couple counselling. Other people can also be encouraged to share their status with people they trust and this can help them to cope with the psychological stress and other problems associated with HIV/AIDS.

Privacy in the use of services

Marie's comment at the beginning of this chapter also shows the importance clients attach to accessing care and treatment in privacy. Health workers said in interviews and conversations that due to the persistent stigma associated with the disease among members of the general public, clients preferred to use services in privacy in order to avoid being identified by relatives or acquaintances. Clients also said that using services in privacy enables them to conceal their status from other people. In this respect, health workers and clients mentioned some structural or institutional challenges in the health care setting, which do not guarantee privacy in the use of services. These, they said, were related to location of VCT and ART sites, how some services are provided and used, as well as to requirements for using services.

Location of centres and clinics
Most clients expressed concerns about the sites of some centres and clinics in the hospitals as seen earlier in Chapter Three. Clients explained that the open locations of some facilities do not guarantee them privacy while accessing care and treatment. They often feared that other people might see them entering or coming out of the facilities and suspect them of HIV infection. In Facility A for instance, the location of the centre made it possible for patients waiting for injection or X-Ray services to see people who used counselling and testing services. The open location of the clinic in this same facility also made it easy for food vendors at the main entrance of the hospital to see clients who entered or came out of the clinic during the first phase of data collection. A client remarked as follows about the location of the clinic and the presence of the food vendors:

> … I think that the doctors must move the clinic away from this place because the present location is not hidden. It is also close to the main gate of the hospital. Besides, the women selling at the gate can see every client entering or coming out of the clinic. So, they have been making some bad remarks about those of them they know in this town. Personally, whenever I am entering the clinic or coming out, I always look around and make sure that somebody I know does not see me… Else, the news would get to my community that I have the disease and face the rejection of my relatives… I think they should have built the clinic somewhere within the premises of the hospital so that we, the clients, can sneak in and out of the clinic without anyone seeing us... (Fauzia, a client)

The site of this clinic in the hospital can be seen as a constraint on the use of services. Clients therefore employed ways and means as indicated by Fauzia above to access services in such openly located facilities unnoticed. However, it was found during the second phase of fieldwork that the food vendors had been moved from the main entrance of the hospital. Yet other patients and visitors to the hospital could

see people who enter and come out of the clinic because everybody gets access to the hospital premises through the main entrance.[3]

In Facility B, the location of the centre is easily accessible to mothers attending postnatal care (PNC), administrative staff and visitors to some offices of the hospital. Clients said that the location of this centre made them feel insecure while accessing counselling and testing because mothers or visitors could see them and suspect them of the disease. They further explained that the location of the centre was rather far from the clinic within the hospital. Sometimes clients referred from the centre to the clinic for treatment went round the hospital from one unit to another with their referral notes asking health workers and other patients for direction to the clinic. This situation, as I observed, could expose the status of clients to people they do not want to know about their infection. Most of the clients, however, pointed out that the location of the clinic in this hospital is convenient. They always feel safe and secure to use services in the facility due to its discrete location within the hospital. According to them, the clinic's site makes it difficult for other people to see them openly entering or coming out of the clinic. Thus, the location of the clinic enables safe use of services. A client remarked:

> The place (clinic) we come for treatment in this hospital is in an obscure site. This is good for us clients because only those who also come for treatment here would see you. I do not know whether the doctors intentionally located it in a secret place like this. So, if you were not coming for treatment you would not easily know that there is a clinic here. I have even heard that some health workers in this very hospital do not know where this clinic is. This means that inquisitive people cannot see us in the clinic here and laugh at us.

Finally, the location of the centre in Facility C could also expose people who access services as positive persons to mothers and pregnant women waiting for postnatal and antenatal care respectively. On several occasions, the counsellor had to come out of the counselling room and appeal to women attending antenatal care to make less noise because the immediate precinct of the centre was often noisy. It was possible that the women sometimes heard the discussion which went on between the counsellor and clients during counselling sessions. The noisy atmosphere around the centre made a frustrated client comment as follows:

> Why did the doctors bring the place people check their blood for this disease here? The women are too many here and this can prevent shy people from coming to check their blood… because it is possible some of these women may see people they know in the centre. As you know women, they talk too much and they can send news about people coming to test their blood here outside. May be, the doctors have to move this place to where they check blood for other diseases (laboratory). That place, there are no many women like here…

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[3] It was also observed that a fence wall has been built around the hospital. I asked Marie, a health assistant in the clinic why these changes have been put in place at the entrance of the hospital. She explained that these were meant to improve security in the hospital. I also believe that the wall is to further address the concerns of ART clients who can be spotted from a distance close to the main gate entering or coming out of the clinic. Clients expressed satisfaction with the erection of the fence wall and the relocation of the food vendors from the main gate of the hospital.

However, in an interview with a medical doctor, he said that centres or clinics located in hidden or discrete places in the hospitals are not convenient for positive persons who are very sick and weak. He explained that sometimes it is difficult for such clients to locate the centres and clinics in the hospitals and this could delay the immediate treatment some of them might need. The doctor said that if, for instance, the clinic is located close to the hospital's main gate, positive persons do not have to walk over a long distance for treatment. He added that it is easier to direct somebody to the clinic if it is openly located. The doctor was of the view that although clients prefer to use services in privacy and conceal their status, they should also think about their peers who are very sick and can not walk round the hospitals looking for the clinic in an obscure or isolated place. In spite of the advantages of openly located facilities, most clients showed preference for those located in discrete places in the hospitals so that they could use services privately and hide their status. As a strategy, this would enable clients to manage the perceived stigma associated with the use of services in the centres and clinics.

Modes of using services
Clients had to access services in different locations or in other units of the hospitals besides the centres and clinics. They were also required to present an adherence monitor in the clinics before they were allowed to undergo adherence counselling and treatment. Positive persons were often put in the same wards as other patients while on admission in one of the hospitals. However, clients expressed concerns about these arrangements for provision of services because it meant they could easily be identified from other hospital patients.

Services in different locations and units: As noted in Chapter Three, counselling and testing were done in two different rooms in Facility B. Thus, pre and post-test counselling were done in one room while testing was done in another. After pre-test counselling, clients joined a queue for testing in another room adjacent to the counselling room. They came back to the counselling room after the test for the disclosure of the results and post-test counselling. This was different from what I observed in most facilities where counselling and testing were done in the same room. Some health workers and clients pointed out that the shuttling between the counselling and testing rooms could undermine clients' privacy. The movement between the counselling and testing rooms was in the full glare of mothers attending postnatal care and visitors to the offices. One client who looked weak and frail commented as follows on how counselling and testing was provided in two different rooms:

> I am already tired with this up and down walking from one end of the building to the other before knowing my results. The moment I came out of this room – testing room, all the women sitting there – mothers attending antenatal care clinic were looking at me as if going for the test is something bad (Maame, a client).

In this same hospital, clients accessed various laboratory services in different locations. The CD4 count test was done in one unit of the hospital, near the admission wards, while the haemoglobin test was done in another laboratory close to the outpatients department in a different building. Tuberculosis tests were however done in a laboratory in the ART clinic. Clients spoke of how the movement from one unit to another for services could possibly expose their status as positive persons to other patients. According to Boafo, a client, some laboratory technicians in other units often separated blood samples of positive persons from those of other patients. They kept the samples of positive persons in a particular place in the laboratory. This, Boafo said, has led some patients to suspect that the blood samples which were always kept at a particular corner were for positive persons. The client explained that on one occasion he confronted a laboratory technician and asked him why he always separated his blood sample from others. He also asked the technician why he always handled his sample in a manner, which suggested that the blood was contaminated. Boafo, who is also a peer educator, said the health worker did not respond to his questions but he observed that this helped to change the technician's negative behaviour towards his blood sample. The client pointed out that he does not experience any more such behaviour towards his blood sample and that in a laboratory in the ART clinic where they go for their tuberculosis test, the laboratory technician freely handles their blood samples. Boafo attributed this to the fact that the technician in this laboratory always interacts with clients in the clinic on daily basis and could not be infected from handling blood samples of clients. Boafo concluded his story by urging me to suggest to the hospital authorities to relocate all laboratory services for clients within the clinic. He added that clients have raised this issue on many occasions with health workers but the situation has persisted with negative implications for positive persons.

In a conversation, a health worker confirmed that some clients have complained about accessing laboratory services in different locations of the hospital and how this could expose their status to other patients. However, he said that due to limited space in the clinic's laboratory, it would not be possible for them to provide all the laboratory services clients need for their monthly visits. He added that the main hospital laboratory has a similar problem and the issue had been brought to the attention of the hospital authorities. I also observed that there was not enough space in the laboratory of the clinic to provide all the services that clients need. Boafo's submission and the health worker's response indicate that provision of care and treatment in different locations is a challenge that compromises a client's privacy in the use of services.

The adherence monitor: Health workers and clients expressed concerns about the lack of privacy regarding the required involvement of adherence monitors in adherence counselling. Health workers explained that although they are aware that

adherence monitors could reveal clients' status to others, they cannot do anything about the system. The adherence monitor is a mandatory inclusion criterion for starting treatment. It is also an aspect of shared confidentiality aimed at helping clients to adhere to ARV medicines. The client thus informs the monitor about his status and the monitor in turn helps him to adhere to treatment.

According to some clients, the requirement of adherence monitoring made it difficult for them to keep their status private. Brenya, a client, said that the difficulty of most clients was the fact that they had to reveal their status to the monitor before presenting for adherence counselling. This means that the monitor could tell other people about the client's status before they come to the clinic for counselling. He said that following the advice of health workers, clients often used people they trusted as monitors but some monitors revealed their status to relatives and friends. Brenya cited an instance in which a friend's adherence monitor spread news about his status and this made the client's life uncomfortable in the community. The client further explained that in his personal case, although he told the nurses that he was a stranger in town and did not have any relative or friend to function as his monitor; they insisted that he should bring someone before starting treatment. He was compelled to present somebody he did not know very well as a monitor before he was allowed to undergo three weeks of adherence counselling leading to treatment. Brenya added that he has always feared that his adherence monitor might have informed some people that he is HIV-positive.

Besiwaa, a client, was refused treatment for several weeks because she did not present an adherence monitor. I asked the client in a conversation why she was reluctant to bring a monitor for adherence counselling and she said:

> For this disease, you do not have to talk about it to your own relatives. The moment you tell one relative and bring him to the clinic, other relatives would hear that you have it. And they would start avoiding you for bringing shame (*animguaseɛ*) to the family… Now the problem I am facing is how to get a trusted person outside my family to accompany me to the clinic for treatment. This is what is delaying the start of my treatment but the nurses too will not understand and help me get the treatment without this person – monitor ...

I urged Besiwaa to try and get a monitor because without the monitor she would not be put on treatment. She simply responded: "It is true but I must get a good person who would not gossip about me to others that I have this disease." On another visit to the clinic two weeks later, I found out that the client had presented a monitor and she was undergoing adherence counselling together with the monitor.

In the attempt to keep his status hidden from his spouse and family members, a client also presented somebody he did not have any relationship with as an adherence monitor. The nurse counsellor suspected that the client had picked the person in the street and had presented him as a monitor. Health workers had earlier found that many clients used similar strategy to prevent their relatives and spouses from knowing about their status. She probed further to find out more about the

client's monitor and the supposed monitor confessed that the client met him at the lorry park and asked him to accompany him to the clinic. When the nurse asked the client why he brought somebody he did not know as a monitor, he said this:

> Madam, the problem is, I cannot trust any of my relatives to come with me for counselling. I do not want to bring my wife too because she does not know that I have this disease. My fear is that if I bring a relative and he gets to know that I have this disease, my wife and other family members would hear of it. This means that my wife would divorce me and I would lose the respect I have in the family as an immoral person. So, I felt that I should bring a stranger who does not know my wife or any of my relatives to reveal my status to them … (Kissiedu).

Not withstanding the advantages of the adherence monitor concept, the views of clients indicated that there are also serious risks associated with the use of monitors in adherence counselling. They fear that the monitors could disclose their status to others. Kissiedu's case is one of the ways some clients acted to take control over events that affected them in the facilities to avoid identification as positive persons.

Admission wards: Health workers and clients were not happy with the lack of admission wards for positive persons in the hospitals. In particular, those in the clinics said that putting positive persons in the same wards as other patients has been the cause for the poor nursing care and treatment they received while on admission. They said that most of the time nurses in the wards gave less nursing care to HIV clients than to other patients. Besides, in one of the hospitals some nurses put these clients at the side wards in order to have less contact with them. This, according to the health workers has often exposed the clients as positive persons in the wards. They further explained that some patients already on admission in the wards have assumed that any new patient put at the side ward must be HIV-positive. Vera, a senior nurse, took the researcher round a ward where some clients were on admission to prove this assertion. I counted about five clients in the ward who had their beds in places the nurse described as side wards.

Later in an interview, nurse Vera said that staff in the clinic had suggested to the hospital authorities to allocate one particular ward to their clients who go on admission like in Korle-Bu Teaching Hospital in Accra. They also suggested that such a ward should be staffed with health workers who have been trained to provide care and treatment to positive persons like those of them working in the VCT centres and ART clinics. They were of the view that this would help clients to receive good nursing care on admission. During the second phase of fieldwork, it was observed that the hospital authorities have not allocated a separate ward to positive persons as suggested by the health workers.

Carolina, another senior nurse, agreed with Vera's concerns about positive persons in the admission wards. She pointed out that in her hospital for instance, the status of most HIV-positive mothers at the maternity ward was known to other mothers. Carolina said that health workers in the maternity ward sometimes openly discussed the status of such mothers to the hearing of other mothers during

conversations. In some cases, when some of the patients in the ward observe that health workers are avoiding a particular mother or she is taking medicines different from theirs, they conclude that she has the disease. However, the nurse said that she does not think allocating a separate ward to positive persons would help them to conceal their status or avoid all the problems associated with the disease. Carolina continued, saying:

> … The moment a particular ward is given to these patients, most health workers would be reluctant to go and work there. This would even worsen the situation because many people would get to know that nurses are refusing to work in that ward because it is for HIV patients… I am a nurse and I know what I am talking about… I think we should leave the situation as it is now… But some of the health workers particularly the non-professionals in the wards and the hospitals in general need special training on how to care for HIV patients because they are the problem…

Carolina added that experience has shown that when the unit for a chronic disease is sited within or close to another unit of the hospital, it helps to prevent the facility from being stigmatised by both health workers and patients. She pointed out that this makes it difficult for a patient sitting next to a colleague to know which type of service the other is in the hospital to access. Positive persons should also be admitted to the general wards of admission so that people cannot easily know who is suffering from which sickness. The nurse said that if health workers in the wards do not talk about people's sicknesses, other patients or visitors in the ward would not know what type of disease a particular patient is suffering from.

In relation to the issue of putting clients at side wards, I asked a medical doctor during a ward round why positive persons are often put in those parts of the wards. The doctor, whose response was the same as that of the doctor referred to in Chapter Three, said that nurses do not deliberately put these patients at the side wards. He explained that the side wards are meant for patients who have infectious diseases like tuberculosis and diarrhoea. Such patients are often put at the side wards so that other patients in the ward would not be infected with their diseases. According to the doctor, positive persons are also put there when they come on admission with chronic cough suspected to be tuberculosis or with persistent diarrhoea. He added that in some cases, when clients come on admission, the beds in the main ward might be occupied with other patients while those at the side wards are free. Nurses have no choice but to put them on those beds. The doctor saw nothing wrong with putting positive persons or any other patients at the side wards because they are part of the admission ward.

Clients on their part narrated many instances of what happened in the admission wards that exposed their status to other patients. Kantanka, a client, said that after nurses in the ward where he was on admission realized that he was positive, they refused to come closer to his bed located in a far corner, which is often referred to as the side ward. The client said that one day he was too weak to get up from his bed

and take medicines and he tried to call some of the nurses to come to his aid but all of them refused, saying that they were busy attending to other clients. Kantanka said one nurse later came to attend to him but he realized that she was wearing double pair of hand gloves although she was not wearing gloves while attending to other patients close to his bed. According to the client, after the nurse left his bed, he heard two other patients discussing that they believe he has HIV and that was why the nurse wore double gloves. Kantanka stated:

> The strange behaviour of the nurse towards me suddenly exposed me as a positive person to other patients in the ward. In fact, that day, if I had my own way, I would have asked the nurse why he was wearing double gloves to attend to me but ... I could not … even in the first place the nurse was reluctant to come to my rescue…

Another client, Dufie, also said that when she went on admission in a ward, the nurses mostly spent very little time with her compared to other clients. At one point, she felt abandoned because the nurses were not coming close to her bed after ward rounds. On one occasion, she heard an elderly neighbour whose bed was close to hers telling another patient that she suspected that she, Dufie, was suffering from AIDS because the nurses often spent so little time with her. The elderly patient observed that it was only patients who have the disease that nurses often spent less time with. The client added that although she behaved as if she did not hear what the elderly patient told the other patient, she felt that the negative behaviour of the nurses towards her led other patients in the ward to think that she was HIV-positive.

The cases of Dufie and others show how the provision of some services and the need to satisfy certain requirements do not guarantee clients' privacy in the hospitals. It appears that individual, structural and institutional factors served as constraint to the uptake of services by clients. Yet some clients devised strategies to overcome some of the constraints to avoid identification as positive persons.

Discussion

This discussion looks at four main issues. Firstly, I argue that the deadly nature of the disease rather than the association with immoral sexual behaviour is the cause of the persistent stigma associated with it, leading to concealment of client status from others. Secondly, it examines the ethical dilemma of health workers due to the need to maintain confidentiality about clients' status, even in situations in which they know it could lead to the infection of others. A discussion of the implications of confidentiality on what we may call therapy management and the work of care providers follows. Finally, it looks at the debate for and against the provision of HIV-related care and treatment services in isolation of or integrated into other services in the hospitals.

From the discussion so far, stigma is the underlying reason for the reluctance of many people to take up voluntary counselling and testing leading to antiretroviral therapy treatment. According to Niehaus (2007), the main cause of stigma is the association of the disease with death rather than sexual promiscuity. Writing about South Africa, he acknowledges that this assertion is not entirely new but it shifts the emphasis for the cause of HIV-related stigma from immoral sexual behaviour or unprotected sex to fear of death. He observes that although immoral sexual behaviour is frowned upon by society, the sentiments against it are not strong enough to lead to the persistent stigma related to the disease and positive persons. In some African cultures, men are allowed to marry more than one woman and teenage pregnancies due to pre-marital sex are also common. The association of the disease with death and the subsequent stigma have also been reported in other studies. For instance, studies by Ashforth (2002:116) and Viljoen (2005) report that respondents in South Africa described AIDS as 'a waiting room for death' and positive persons as 'dead before dying.' According to Niehaus, this perception of HIV infection illuminates many aspects of people's responses to the disease, including the (non) use of health care services. It also helps to explain why most clients preferred to use services in privacy and hide their status from relatives and others.

These views about the disease are common in Ghana. In a study on the disease among the Akan in Ghana, Crentsil (2007) observes that positive persons are often stigmatised because the disease is believed to be incurable and the fear that the infected person is likely to die of it. Likewise, the pain and suffering the person goes through before HIV-related death is generally considered as shameful and disgraceful, and in some cases leads to perfunctory funerary rites. This is often due to the fear of contagion associated with the corpse of persons who die of HIV infection. Such death is described as 'bad death.' The concerns of clients in this study on the social risks associated with the disease resonate Niehaus' and Crentsil's findings that HIV is a deadly disease. The fear of death associated with the disease and the shame that often characterises HIV-related death could make relatives and others distance themselves from its sufferers. It is therefore not surprising that most clients in this study said that their relatives would reject or ostracise them if they got to know of their status.

In some Ghanaian communities, people refer to HIV/AIDS as 'sickness of the dead but alive' (*Yareɛ- teasea-wuo*) or 'sickness of death' (*Owuo yareɛ)*, terms also used by some local FM radio stations. In this respect, Hertz's well-known concepts of 'Biological Death' and 'Social Death,' are helpful to explain what people imply by such descriptions of the disease, as Niehaus makes clear. According to Hertz (1960), biological death ends the human organism and social death extinguishes the persons' social identity. These need not to coincide. Biological death usually precedes social death, but there are also circumstances that social death precedes

biological death. In the study area, it can be argued that social death often comes before AIDS-related biological death. For example, if somebody gets infected, in the eyes of members of the general public, he/she is assumed to be already dead (*yareε-teasea-wuo*) since the disease is incurable. The strong stigma associated with social death is sometimes more severe than biological death. It is the shame and disgrace associated with death that has made it necessary for clients in the present study to employ various strategies and use services in privacy to avoid identification and hide their status from relatives or spouses. With regard to social death, it is common to see people pointing accusing fingers at the individual or gossiping about him/her, eroding the person's respect and honour. Clients often suggested that this could be prevented if health workers maintain confidentiality about their status. Maintaining confidentiality enables them to avoid identification as positive persons. It would encourage more clients and potential clients to access services.

Confidentiality is central in the communication between health workers and clients in the provision of counselling, testing and treatment services. The professional ethics of health workers obliges them to respect confidentiality, as stipulated in the Ghana Draft Policy Document on HIV/IDS (MOH/UG 2000). Maintaining confidentiality by health workers in matters relating to HIV infection, care and treatment is about trust. However, the trust clients have in health workers may be eroded where it is promised and not fulfilled. The possible lack of confidentiality in the health care setting, on the other hand, is a constraint on the use of services and discourages clients and potential clients from accessing counselling testing and treatment services.

Although health workers acknowledge that confidentiality is core to the provision of counselling, testing and treatment, they acknowledge the possible harm of strictly enforcing confidentiality with unintended risks for others. It places them in a dilemma: should they maintain confidentiality when they know that a client is likely to infect others? Nuwagaba-Biribonwoha *et al*. (2007) also point out the dilemma of nurses regarding patients who feel unable to disclose their test results and who may go home to infect partners and unborn children. These nurses struggle with their obligation to maintain confidentiality. In this study, health workers encountered the same problem. They faced the dilemma of either maintaining confidentiality as required or breaching confidentiality. Maintaining confidentiality becomes more complicated when health workers are expected to help prevent the spread of HIV/AIDS by providing information on behaviour change among the infected and uninfected.

Some studies have suggested that the advantages of revealing someone's status outweigh maintaining confidentiality. There is the view that in most cases, informal care is provided by family members and therefore health workers should inform them about the type of disease the patient is suffering from (Colledge & Maddison

1992). They argue that maintaining confidentiality deprives family members of positive persons of pertinent information about the illness while they assume the bulk of the responsibility for the patient's wellbeing. Evans & Ndirangu (2009) contend that in many clinical settings, it may be very difficult for health workers to send patients' relatives away in order to discuss HIV testing in private in order to maintain confidentiality. Indeed, the mere act of doing so may raise suspicion amongst attending family members anyway. With regard to other serious illnesses like cancer, research suggests that family members often act as gatekeepers of information. It is considered normal practice for nurses to disclose 'bad news' to family members prior to informing patient (Mulemi 2008:122). Similarly, in Ghana, HIV infection is considered a serious sickness and 'bad news' due to its association with death. This suggests that clients should be informed of their status through family members in cases that they accompany clients to access services in the centre or clinic.

Some health workers in this study disclosed clients' status to others such as spouses or relatives without their consent. Health workers did that ostensibly in the interest of clients, particularly in the case of positive mothers. The spouses or relatives of these mothers may be involved in counselling on the need not to breastfeed their newborn babies. Such disclosures were motivated by the belief that those relevant others would help clients to adhere to treatment or also present for counselling and testing. It is also possible that the disclosures were meant to let spouses or relatives know about the illness of clients and help them to access the appropriate services whenever necessary. The difficulty, however, was with the way and manner health workers chose to breach confidentiality. For instance, in the case of positive pregnant women, their status was disclosed to others while they were in labour, a stressful moment. Some of them held the view that the nurses did that to embarrass them for not voluntarily disclosing their status to relevant others like spouses or relatives who were their informal caregivers. Others also blamed the nurses for making such disclosures which led their spouses to divorce them. However, in most of the cases, health workers disclosed the status of clients to save lives and to prevent the spread of the disease as part of their responsibilities.

The dilemma about maintaining confidentiality is not a hopeless situation in which both health workers and clients have taken an uncompromising stance. It is not the case that health workers are bent on disclosing the status of clients to their spouses for example, or that clients are completely opposed to such disclosures. On the contrary, health workers generally understand the predicament of clients very well and emphatize with them. They often give clients the opportunity to disclose their status to their spouses. Likewise, health workers allow clients to decide whom they want to share information about their infection with. In both cases, clients are encouraged to invite such people to join them in post-test counselling. In cases

where clients expressed the willingness to disclose their status to others but feared the possible negative consequences like divorce, health workers helped them to do the disclosure. In particular, health workers took certain actions to get the spouses of clients to the facility for arranged disclosure and counselling in the hope that there will not be unfavourable repercussions. Health workers used this arranged disclosure and counselling to also encourage other partners of clients or relevant others who have not undergone testing to do so. Couple counselling or arranged disclosure by health workers helped some clients to inform their spouses and relevant others about their status without problems such as divorce.

Studies in other countries have also found that couple counselling reduced the negative repercussions associated with positive test results in the case of women and led to increase use of treatment services. One study in Kenya showed that pregnant women who were offered couple counselling with partners were three times more likely to report using ART for prevention of mother-to-child transmission and five times more likely to avoid breastfeeding (Farquhar *et al*. 2005). Another study by the South India AIDS Action Group in Tamil Naadu reported that couple counselling schemes have shown success in reducing levels of violence and the numbers of women abandoned after diagnosis (SIAAP 2002).

Some of these disclosures by health workers did create problems for clients. The spouses of some clients who tested negative after the arranged disclosure later divorced their wives or husbands. This shows that there are no simple solutions to these complex issues clients and health workers face. Nevertheless, couple counselling or shared confidentiality seems the best choice to break the deadlock regarding maintaining confidentiality.

The policy of maintaining confidentiality also has wider implications for a client's therapy management group and the health worker-patient relationship. In most cases relatives and sometimes neighbours often play a significant role in the care and treatment of a sick person. In some cases, these individuals come together as a group and take decisions regarding care and treatment on behalf of the patient. The group's responsibility goes beyond the popular and folk medicine and extends to the hospital setting. It is for this reason that Gruskin *et al*. (2008) report that in many sub-Saharan African countries, patients are often accompanied to health care settings by family members. Ward environments and clinics tend to be characterized by over-crowding and lack of space for private discussions (see also Mulemi 2010). In his study on the search for therapy in Zaire, Janzen (1978) refers to these people as the 'therapy management group' of the patient. He characterises the group as mainly a set of close kin members who help with the management of illness or therapy. Members of the group know the type of sickness or disease the patient is suffering from in order to take appropriate decisions on cure and treatment, either in the hospital or in the folk system. This implies that health workers cannot maintain

confidentiality about the patient's health problem since some relatives, as therapy managers of the patient, must always be present during consultations

Similarly, Bossart (2003) who also studied the help relatives and others give to sick people in Abidjan observed that in certain situations sick individuals prefer not to decide on treatment by themselves or are unable to take care of themselves, and therefore defer decisions to relatives, neighbours, friends and others. Bossart also points out that the help these people often give to the sick person, almost in the same way as Janzen observed about the therapy management group, includes illness identification, treatment choice, treatment evaluation and financial support. From these perspectives, any attempt on the part of health workers or the client to maintain confidentiality could have negative implications for the wellbeing of the client. The therapy management group could for example withdraw its support or assistance to the client for lack of information about his/her health condition to decide on how he/she can be helped. It may be for this reason that Janzen (1987) points out that Mellvray and MacClean exhort clinicians working in hospitals and medical centres in Africa to be sensitive to their patients' therapy managers and to share information with them. Sharing information is likely to enlist the full support of the group towards the effort to find a treatment for patients' sickness. The advice by Mellvray and MacClean also shows that in sub-Saharan Africa, it takes the combined effort of health workers and a client's therapy management group to successfully treat a patient of his sickness. The assumption is that when information about the patient's health problem or sickness is shared with the group, rather than maintaining confidentiality, the patient gets a decent treatment beyond a clinical decision. The present study suggests that maintaining confidentiality in the care and treatment of HIV could complicate the work of care providers and also create problems for clients due to the crucial role of the therapy management group.

The sensitive nature of HIV/AIDS brings a new dimension to the concept of therapy management group and the work of health workers, as it is imperative for health workers not to disclose a client's status to relatives, friends or neighbours who are his therapy managers. They must also exclude relatives from clinical consultations and other decisions in relation to the client's care and treatment so that his/her status will not be disclosed. These are contrary to the basic principles of therapy management, which according to Janzen is a negotiated process that provides a way of perceiving the sickness phenomenon in its social context. In this process, relatives, friends and neighbours assist in lending support, solace or aid in treatment to the sick person. The role of the therapy management group is therefore more critical in the situation of positive persons who cannot work for a living or have lost their jobs while others continue to spend a lot of money on treatment of opportunistic infections. I argue that in as much as health workers are enjoined by their professional ethics to maintain confidentiality, it is difficult for them to apply

this to positive persons who often depend on their therapy management groups for treatment among other things.

Another issue emerging from the data presented in this chapter has to do with the debate of either providing HIV-related care and treatment services in isolation of or integrated with other services in the hospitals. The debate has been necessitated by the obvious preference of clients for centres and clinics sited in discrete or obscure locations in the hospitals due to the persistent stigma associated with HIV/AIDS. Moreover, clients showed a preference for the provision of all the services they need during scheduled monthly visits within the clinics. In essence, clients think that the provision of HIV-related care and treatment services should be isolated from other services in the hospitals. Some nurses in the clinics were also in support of isolation of services for positive persons, particularly in the wards of admission. The nurses in the general wards may tend to devote more of their attention to other patients to the neglect of positive persons. In that case, if clients were isolated from other patients in a different ward, it would encourage nurses in that ward to give their fullest attention to them. On the other hand, some health workers were of the view that isolating these services from the rest would actually increase the stigma already associated with HIV/AIDS and the facilities where services for infected persons are provided. Thus, these health workers suggest that the provision of HIV-related care and treatment services should be integrated into other services instead of isolating them.

The debate for and against integration or isolation by health workers is basically aimed at conveniently providing services to clients so they could use services in privacy and conceal their status from relatives and friends. Both arguments have merits and demerits which call for critical examination by health workers. If they choose integration should it be partial or complete? In the case of partial integration, health workers would have to make it clear which aspects of counselling, testing and treatment need to be provided alongside other services, and in which specific units. With regard to total integration, it is important for health workers to identify which particular unit or units such services could be conveniently provided for clients to feel secure and to continue to access services. If isolation is chosen, which locations in the hospitals would be appropriate for such services: tucked away from open places to prevent other patients from identifying clients while they use services? Does this mean that new facilities should be built within the hospitals at obscure locations in spite of the perennial lack of funds?

Whichever option health workers or planners decide to go for, one important thing that they must not forget is the interest and welfare of clients who are the ultimate beneficiaries of health care services. Integration or isolation of the services must ensure that clients are guaranteed privacy in the use of services to avoid identification in the health care setting and prevent stigmatisation. This is likely to

encourage clients to continue accessing services and also motivate potential clients to use services.

Conclusion

This chapter has shown that clients tend to be more concerned about the social risks of treatment than about the medical outcomes of accessing counselling, testing and treatment services. The concern is largely due to some perceived individual and institutional or structural-level gaps in the health care setting. Under normal circumstances, patients accessing health care services are interested in getting the required cure or treatment for their health problems, with little interest in whether someone they know may see them in the hospital. However, the same cannot be said of HIV care and treatment because of the disease's peculiar status. It has therefore become necessary for its sufferers to use services in confidentiality and privacy to hide their status from relatives, spouses and others, and avoid stigmatisation. HIV/AIDS is here to stay with the people and the health care delivery system, which calls for a comprehensive look at the way its services are provided and used. The concerns of clients must be taken into consideration in whichever way the services are provided or would be provided in the future, to ensure success when the system is made more widespread. The inability of health care authorities to effectively do this could be a missed opportunity for encouraging more clients and potential clients to access counselling, testing and treatment services in an effort to reduce the spread of the virus.

How do health workers deal with HIV patients?

> I have observed that most of the health workers in this clinic treat clients well by showing courtesy towards them. For instance, this nurse [she mentions her name] is friendly and talks nicely to clients. That is why I always go to her with problems related to my treatment and she readily helps me... I saw that some clients even consult her for advice on their personal problems… In fact, she is kind to clients… (Abrefi, a client).

> Some of the health workers do not know how to talk to patients with respect… They sometimes shout at clients like one nurse did a moment ago for doing something wrong with his treatment. I saw that the man felt embarrassed because other clients were looking on. Probably, they sometimes talk to us [clients] this way because of the type of disease we are suffering from… (Manu, a client)

The comment by Manu was common in the centres and the clinics. It is one of the ways many clients expressed their disapproval of the manner in which some health workers related to and communicated with them while accessing care and treatment. The client's comment is consistent with the general perception in sub-Saharan Africa that health workers, particularly nurses, often do not treat patients or clients well.[1] They abuse patients; nurses are rude and harsh towards patients; and health workers often give immediate and high quality treatment to patients they know. Jewkes *et al.* (1998), in their study on nurses in South Africa, observed that some pregnant women expressed reservations of delivering in the hospital due to previous experiences of being shouted at, beaten or neglected by nurses. According to the study findings, although some nurses agreed with the reservations of the pregnant women, they attributed the practices to many factors. These were organizational

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[1]   Health workers referred to here include medical doctors, nurses, counsellors, disease control officers and health assistants working in the voluntary counselling and testing (VCT) centres and antiretroviral therapy (ART) clinics. Nurses, who are in daily contact with clients in the facilities, are the focus in this study.

issues, professional concerns, including perceptions that staff were themselves abused by patients, a perceived need to assert control over the environment and patients, social sanctioning of coercive strategies including punitive actions, and an underpinning ideology of patient ignorance and inferiority. In another study, Andersen (2004) argued that health workers in a Ghanaian hospital used education level to distance themselves from certain patient groups. In this regard, they distinguished between those patients who are entitled to high quality services and those who are not. Some patients, especially the uneducated, disparagingly called 'villagers', were treated with impatience and discourtesy, given less information and accorded less time. They were ordered around, yelled at and accused of lying.

In Ghana today there is a widespread popular discourse that health workers are harsh and frequently treat patients without respect. Critical media report about the poor quality of services provided in the country's health facilities can be found in press. An example is a feature article that appeared on Ghanaweb (Tuesday, 2nd June 2009), in which the writer deplored the use of abusive and foul language on clients by nurses in a public hospital. The writer further pointed out that some nurses were violent and aggressive towards patients to vent their frustration. The instances cited above suggest that the image of health workers, especially nurses, in Ghana and some sub-Saharan African countries is not good (see also Böhmig 2010:219). Their practices are contrary to the popular and professional discourses that characterise nursing as a profession of dedicated staff, exhibiting qualities of care, nurturing, comfort and concern and motivated by desires to help people that one sees in the United Kingdom (Davies 1994:1-2). In many developing countries, the professional discourse is similar although health workers in the public sector work in harsh and often squalid conditions (Jewkes *et al.* 1998).

Contrary to this stereotyping of nurses, this study observed that some nurses demonstrated professional ideals in their interactions with patients or clients during service provision. Some nurses were kind and respectful to clients, acting as advisors for clients on a wide range of issues besides treatment and care. These practices are worth looking at critically because they suggest that there are health workers, especially nurses, who are patient and show respect towards clients while others are impatient and become irritated with clients who do not follow their treatment regimen.

This chapter deals with the practices of health workers during the provision of care and treatment, and their influence on the use of services. To shed more light on these, I refer to the practices as 'attitudes' and 'behaviours'. I use attitudes and behaviours as convenient terms to describe how health workers deal with clients in their interactions during clinical encounters and not as theoretical concepts. The attitudes and behaviours that are consistent with the previously mentioned professional ideals of nursing will be labelled positive while those that are

unprofessional will be labelled negative. I start the chapter with a description of clients' views on positive and negative attitudes and behaviours of health workers in the centres and clinics. The second part discusses why some health workers treat HIV patients or clients well, in contrast to the widely held view that they do not. It examines three main reasons that account for these professional attitudes and behaviours: the additional training they have received in the provision of care and treatment for HIV patients, the life-long nature of the treatment and the knowledge of health workers about the neglect of clients due to the stigma associated with HIV infection. I conclude that the good attitudes and behaviours of health workers have a positive influence on the use of services.

Positive attitudes and behaviours

Much of the literature suggests that health workers in sub-Saharan Africa, especially nurses, rarely show positive attitudes and behaviours towards clients who access HIV counselling, testing and treatment services. In the few studies where health workers were reported to have shown positive attitudes towards clients, no mention was made of the specific type of attitudes or behaviours. Adebajo *et al.* (2003), for instance, reported in their study that 90 per cent of care providers in Nigeria agreed to treat persons with HIV/AIDS. Fusilier *et al.* (1998) also indicated that 81 per cent of health care workers they interviewed were willing to provide AIDS care. Quach *et al.* (2005) observed in their study that a third of physicians they interviewed had positive attitudes about providing care to HIV/AIDS patients. In essence, the good attitude these studies found was the willingness of care providers to treat positive persons. The present study also found that most health workers had good perception of clients and showed positive attitudes and behaviours towards them during interactions.

Warm reception
It was observed at the centres and clinics that health workers often gave clients a warm reception. Nurses embraced or hugged clients who have not visited the clinics for a long time.[2] Medical doctors and counsellors in the clinics and centres also welcomed clients with a smile and readily offered them a seat. They asked clients about their health and sometimes that of their families, before they were treated or counselling started. A client, Owusua, who had just gone through counselling and testing, gave me her impressions of the way the counsellor received her:

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[2] I refer to clients who have adhered to ART treatment for at least one year. Health workers describe them as 'trusted clients' and most of them have good relationships with health workers. As a result, their visits to the clinics for a review of their CD4 count and other tests are often scheduled between three to six months. Also, unlike new clients, they are allowed to buy ARV drugs for three to six months in advance.

> Oh… The counsellor received me very well… by first asking about my health and that of my husband and children. He even offered me some water to drink when I tried to clear my throat in order to speak out clearly. Though the test showed that I do not have the disease, the way the counsellor nicely talked to me has encouraged me to come back in three months time for another test as he has requested.

Health workers for their part explained that they gave clients a warm reception to motivate them to continue accessing care and treatment. According to them, some clients have strictly adhered to the treatment and survived HIV/AIDS. Such clients have become role models for other clients who have persistently defaulted in their treatment regimen. They hugged or embraced these clients to motivate defaulters to adhere to treatment and feel appreciated by health workers. The health workers pointed out that experience in the facilities has shown that warm reception towards clients has encouraged many of them to continue accessing treatment.

Clients also explained that they were motivated to continue doing the right things about their treatment whenever care providers gave them positive compliments like a hug in the presence of their peers. For instance, a client who received a warm reception from nurses a couple of times in the clinic said the following in a conversation:

> I always feel happy whenever I come to the clinic and hear one health worker after another saying that I am looking good. Anytime they embrace me, it makes me feel that after all somebody loves and appreciates me. I have even been used as an example [role model] to counsel some clients who had lost hope that they would not survive the disease. The good reception I always receive from this doctor [she mentions his name] and the nurses here has encouraged me to regularly take my medicines and visit the clinic on appointed dates. (Asampana, a client)

From the views of health workers and clients, it can be said that the warm reception health workers give to clients has led to some kind of bond and affection between them and this has subsequently encouraged some clients to adhere to treatment.

Courtesy

Another way health workers behaved favourably towards clients was how they addressed them during consultations or conversations. I closely followed the way that care providers addressed clients to find out whether the perceived stigma associated with HIV/AIDS had negatively influenced the respect and patience they have for them. Observations in the facilities showed that most of the health workers addressed clients politely. For instance, I heard doctors, nurses, counsellors and other staff addressing clients with traditionally accepted phrases and honorific titles such as 'please' (*mepa wo kyɛw), *'elder' *(ɔpanyin),* 'madam' (*maame),* 'my friend' *(m'adamfo),* 'lady' *(awuraa)* and 'young man' *(abrpanteɛ)* before they talked to them. The titles showed that these health workers respected clients irrespective of their status.

Two particular health workers, one in a clinic and the other in a centre, were noted for addressing almost every client they came into contact with in one of the traditionally accepted ways as described above. One of these two health care providers was Martinson and I observed that many clients always wanted him to attend to them on clinic days. Addae, an elderly client in a conversation, confirmed this assertion and added that unlike some of his colleagues, Martinson addressed clients with courtesy. According to him, the health worker always addressed him as 'father' (*agya)* before he talked to him. Addae pointed out that this was a sign of respect Martinson had for him as someone who could be his biological father, and not as an irresponsible old man who presumably got the infection through immoral sex [the client laughed].

Another client mentioned a nurse called Benedicta as a health worker who also addressed both old and young clients politely in one of the clinics. The client pointed out that she usually addressed male clients as brother (*me nuabarima),* and female clients as sister or (*me nuabaa).* Besides, she always prefixed her communication with clients in clinical encounters with "please".

Financial support

A study of records in the centres and clinics with regard to the socio-demographic characteristics of clients showed that over 85 percent of them were relatively poor. Most of these clients faced financial difficulties in making out-of-pocket payment for certain health care services not covered by the National Health Insurance Scheme (NHIS).[3] The majority of them were unemployed and they attributed this to different social and economic factors. Some of the clients explained that they became unemployed after they got the infection. Others said that before they were diagnosed positive, they had taken their prolonged health problems to many places including hospitals, prayer camps, traditional healers, herbalists and fetish priests for solution or cure. At each of these places, they spent large sums of money to get treatment, although they never succeeded. A few of them pointed out that they lost their jobs because their employers thought they were spending too many working hours in hospitals accessing treatment. It was obvious that it was difficult for most of them to make a living. The following comment made by Benewa, a client, captures the poor financial situation of most of the clients.

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[3] The Government of Ghana introduced the NHIS in 2003 to replace the Cash and Carry system. Under the old system, citizens made out-of-pocket payment for all health care services. But with the NHIS, Ghanaians are supposed to pay a yearly premium which entitles them to access most health care services free of charge. However, the scheme does not cover certain health care expenses including the cost of ARVmedicines for treating HIV/AIDS. As a result, PLWHA are supposed to make out-of-pocket payment for the supply of ARV medicines every month. During this study the cost of these heavily subsidized medicines by the Ghana government was five Ghana cedis (almost five US Dollars). However, over 85% of PLWHA who are on these medicines are not able to buy them because they are either poor or unemployed. In order to enable every PLWHA to have access to these medicines, the ART clinics have a policy which allows clients to buy the medicines on credit.

As I am speaking with you now, I do not know how I am going back home after treatment let alone think of the food I must provide for my two children this evening. Take a look inside my purse – she opened her purse for me to see but I refused to look inside – there is not even one Ghana cedi – almost one US Dollar – for me to take transport back home. At least for the medicines, I know I can buy on credit but then, after taking the drugs, I have to eat; my children too have to eat before I can think of other things I need money to take care of. In fact, it is financially hard for some of us (throwing her hands in despair)

It was such dire financial difficulties among clients that led some nurses in the clinics to give financial support. The support from health workers to clients helped them to take transport back home after accessing treatment, as seen in the case of Serwaa in Chapter One, or buy food. For instance, Marie, a health assistant, used her own money on many occasions to buy food for clients who reported to the clinic in a weak condition and almost out of breath because they did not have money to buy food. Clients were always grateful to health workers for supporting them financially.

Counsellors in the centres sometimes paid the cost of counselling and testing for some clients who could not afford the service. The cost of counselling used to be one Ghana cedi (almost one US Dollar) in government health facilities, but the service was made free from March 2009 (NACP/GHS 2009) to encourage more people to undergo counselling and testing. The financial support health workers gave to clients not only helped them buy food or pay their transportation cost, but also to pay for the cost of care and treatment.

Advice

The favourable attitudes of health workers went beyond their official roles as counsellors and providers of health care. Some clients had taken health workers as their personal advisors on a wide range of issues beyond care and treatment, as is made clear in the comments by Abrefi at the beginning of this chapter. Health workers willingly accepted this role and acted it with enthusiasm. Clients were seen in the centres and clinics discussing their health, marital and family problems with health workers.

On one occasion, Naa, a client, approached a senior nurse, Suzane, for advice on a marital problem. According to the client, she lost interest in sex when she started taking the ARV drugs but her HIV-negative husband was not happy with her reluctance to have sex with him. Naa said her husband started coming home late after close of work and this gave her cause to suspect that he was in love with another woman. So, she asked nurse Suzane to advise her on what she should do to solve the problem with her husband because the man's change of attitude towards her was giving her sleepless nights. Suzane, who the client had adopted as an elder sister, invited the couple to the clinic for a discussion on this issue.

Two months later, I met Naa in the clinic full of smiles and asked her whether she was able to come with her husband to see the nurse. She answered in the affirmative and explained how the nurse's advice helped to save her marriage. According to her,

the nurse explained that loss of interest in sex was not one of the known side effects of the drugs. She should therefore do away with the idea that the drugs had made her to lose interest in sex. The nurse told her to psychologically tune her mind onto sex whenever she was going to bed, which could help her to regain interest in sex. Naa admitted that Suzane's advice helped to bring her marriage back on track and she was grateful to Suzane for her intervention.

A male client called Bempa also recounted how he followed the advice of a nurse and went for a bank loan to start a small business on his own. According to Bempa, he mentioned to the nurse in a conversation that he had been unemployed for more than one year after he tested positive. His health had improved considerably following treatment and he felt that he could engage in some meaningful business to make a living. The nurse advised him to go for a bank loan and start selling used clothing in the market, which he did. The client explained that he never regretted taking the nurse's advice because his business was going well. Bempa stated that "because of the motherly advice the nurse gave me to start the business, I would never forget her in my life." It is important to mention that through their advisory role, clients have adopted some health workers as their parents or relatives. They consult them when taking decisions such as those about their treatment and finances. The use of health workers as advisors enables clients to exclude their actual family members from taking decisions in relation to their status and helped clients to hide their status from relatives as a coping strategy against stigmatisation associated with the infection.

Working overtime

It was also observed that health workers in the centres and clinics sometimes worked beyond official working hours of 8 a.m. to 5 p.m. to attend to every client who reported for care and treatment. On clinic days, care providers worked throughout the day without a lunch break. In a conversation with a medical doctor, I asked why they hardly take their lunch break whenever they worked in the clinic. He responded as follows:

> Whether I go for lunch break or not, I am the very person who would attend to the clients. Assuming I leave the clients for break of one hour, I would come back and meet them waiting for me. So, I prefer to sacrifice the lunch break time and finish treating them. In that case, if I leave the clinic here for lunch I would not come back again till the following morning. The problem is… only a few of us medical doctors in this hospital here have shown the willingness to work with this type of clients. That is why when some of us come to the clinic here we spend all our time to attend to clients although we are not given any incentives…

Rebecca, a nurse, also explained that although officially they have times that they start work, take lunch break and finish, sometimes health workers in the clinics do not work according to those times. She said that in view of the poor health of some of the clients, they thought it would be inhumane on their part to leave them waiting

while they go for lunch. They usually sacrificed their lunch break time to attend to all the clients as early as possible so that those who came from far away places could return home early enough. Rebecca also explained that if they do not sacrifice a little to help the clients, most of them would spend long hours of waiting in the clinic which means that they would also not close early. She pointed out that it was rather unfortunate that the hospital authorities have refused to give them incentives for working work overtime, yet they were not discouraged. According to nurse Rebecca, they had taken the clients as their brothers and sisters, or even their children who needed their help to live positively with HIV/AIDS. "This is the reason why we have decided to work overtime on clinic days to attend to all clients," she added.

Similarly, counsellors in the centres attended to clients before 8 a.m. and after 5 p.m. These are the normal working hours for most Ghanaian workers. A counsellor, Prince, said in a conversation that there were occasions he was called to the hospital on weekends to provide counselling and testing to clients. Prince was of the view that as a counsellor, one must always be ready to provide the services at anytime so that clients would not use the absence of the counsellor as an excuse not to access counselling and testing.

What is even more, clients could call health workers on their cell phones at any time of the day to talk about their health problems. These health workers willingly gave their mobile phone numbers to clients to call them whenever they needed counselling or advice on their health and other problems. Martinson pointed out in a conversation that it was common for clients to call them in the middle of the night to talk about their health problems. Martinson gave an instance in which a client called him around 2 a.m. and complained about headache. The health worker said that after he advised the client on what he should do to stop the headache, he asked himself "Oh! Is it because of common headache this client woke me up around this time of the night?" This shows that health workers do not only work overtime in the clinic but also outside the clinic and at odd hours.

Interacting comfortably

On the whole health workers openly interacted with clients without hesitation. In the clinics for instance, they were found holding the hands of positive persons or touching them with ease during conversations. Furthermore, health workers often engaged in private conversations with clients and their relatives who accompanied them to the access treatment outside the clinic premises. I eavesdropped in the conversation of two clients and one of them, Fosua, described the way nurses in a clinic easily interacted with clients as follows:

> I feel encouraged by the behaviour of the doctors and nurses in this clinic because they freely interact with clients. Unlike the other hospital where I first went on admission … before I was referred here for treatment, the nurses there were not friendly at all. But the doctors, nurses and

other health workers here easily converse with clients and their relatives, shake hands with clients. The nurses even accompany some clients to the outskirts of the clinic after they have been treated…

Aba, the other client in the conversation, agreed and said that the health workers knew that one way they could encourage clients to continue accessing treatment is to be sociable with them. Aba said that news had reached the health workers that some clients stopped accessing care and treatment due to the unfriendly behaviour of some of their colleagues.

Similarly, in the centres, counsellors were seen holding the hands of clients, particularly those who tested positive and were too frail to walk out of the counselling rooms. They also interacted with clients and their relatives after counselling and testing to further address their concerns. Such interactions by counsellors were often used to encourage clients who tested positive to accept their status in good faith and access treatment. There was an instance in a counselling centre when a counsellor stopped what he was doing and accompanied a client to the bus stop outside the hospital premises to take transport back home. The client was completely devastated with the positive test result and could not move out of the counselling centre for about one hour before the counsellor helped her to leave the hospital premises.

Health workers attended outreach programmes in churches, schools and other social gatherings with peer educators who are also HIV-positive. During such outreach programmes, it was observed that health workers and peer educators usually sat together and freely conversed with each other. Until the clients were formally introduced to the audience, they could be taken as health workers due to the way health workers related to and interacted with them. In other words, the comfortable interaction between health workers and clients was not limited to the hospital premises; it was extended into the community and social gatherings.

As a concluding remark, it was observed that clients appreciated the good attitudes and behaviours of health workers towards them, which they said had encouraged them to continue accessing care and treatment. In other words, the good practices of health workers acted as enablers and increased the use of services by clients. In the next section I describe the negative attitudes and behaviours of health workers.

Negative attitudes and behaviours

This section describes the practices of health workers in the centres and clinics which were found to be contrary to the ideals of the health care profession. Some of these findings on negative attitudes and behaviours are in line with those reported in earlier studies, as will be seen in the ethnographic data presented below.

Poor communication

As can be seen from Manu's comment at the beginning of this chapter, some health workers in the centres and clinics lacked the skills to communicate well with clients. Medical doctors and nurses in the clinics sometimes talked harshly to clients at the least provocation. They easily became angry with clients they considered to be troublesome or irritating and talked to or yelled at them angrily. This description fits the observations made by Jewkes *et al.* (1998) on the way nurses communicated with patients during the provision of obstetric services in South Africa. Jewkes *et al.* found that some nurses communicated poorly with pregnant women and spoke to them as if they were children. They also cited an instance in which a midwife shouted at all the patients one day, complaining that they were careless about their health and that they would all have stillborn babies because they were stupid, like one who had given birth to a dead baby the week before.

In the present study, I also observed a case in the clinic that a nurse became angry and shouted at a client to go out of her presence within hearing of other clients. This was during an adherence counselling session and I saw that the client wanted to explain something to the nurse. Before he could talk to her, the nurse burst out and angrily said:

> Hei! Don't tell me any story this morning. We health workers are fed up with your stories. You clients always come here to tell us stories as if we are jokers. I don't know what is wrong with some of you, may be you are not able to think and accordingly to do the right things for your own health. Get away from my presence and allow other clients in the queue who are ready to do the right things to be attended to…

The client left the nurse without a word. One week later, the client, Anane, came back to the clinic for counselling. He explained that he had wanted to tell the nurse that his adherence monitor suddenly fell sick and could not come with him for the counselling and he would make sure to come with the monitor for the next session. The nurse should therefore have allowed him to start the counselling. Anane added that, "This was all that I wanted to explain to her when she called my name but before I could speak, she poured her anger on me and, spoke to me like a small boy."

The nurse on the other hand explained that Anane had on many occasions complained that he could not get anyone to be his monitor and the health workers had insisted that if he does not present a monitor for counselling, he would not be put on treatment. When she saw that he wanted to tell her something, she knew Anane was about to give another excuse for not bringing the adherence monitor. According to the nurse, this was the reason why she did not allow Anane, whom she described as a difficult client, to talk to her.

There was also an instance in the consulting room when a medical doctor made uncomplimentary remarks about a client, Abiba, who could not recall any of the

things she had learnt during adherence counselling.[4] The client had finished the mandatory three weeks of adherence counselling and she was supposed to see the doctor for recommendation to start treatment. The doctor's recommendation is usually based on the ability of a client to recall some of the things learned during the three weeks of adherence counselling.[5] If a client is not able to do this, he is not recommended for treatment. The client would have to go through the adherence counselling again and be able to satisfy this requirement. When Abiba could not recall any of the things she learnt during adherence counselling process, the medical doctor said:

> So, you are not ashamed of yourself for not being able to recall even one thing you learnt in the three weeks of counselling? You are block-headed and do not deserve to be put on treatment now… I would recommend that you go back and do the three weeks of counselling again… Get up and go away!

The client left the consulting room with her husband who accompanied her as adherence monitor. As the couple walked out of the consulting room, the facial expression of the client showed that she felt ridiculed by the doctor's remarks about her.

During one of my visits to a centre, I met about six or more clients, two of whom looked very sick waiting to be counselled and tested. The counsellor suddenly came out of the counselling room and banged the door behind him without speaking to the clients. One of the clients realized that the counsellor was going out and she told him that they were waiting for him to attend to them. The counsellor stood at a distance and responded that he was going out to attend to something important. Those who would not mind waiting for him until he returned were free to do so, he said, but others who could not wait for him could go and come back for the service later in the day. The counsellor's behaviour towards the clients suggested that the service they came to access was less important than what he went out to do. He could have asked the clients to give him some time to quickly solve an urgent problem and come back to attend to them.

In all the cases mentioned here, the health workers could have talked to clients in a polite and cordial manner. The situations of the pregnant women in the study by Jewkes *et al*. and that of the positive persons in this study may be different, but the cases show that some health workers lack the requisite communication skills to talk to non-compliant clients with respect.

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4 Adherence counselling is usually for a period of three weeks during which clients who are yet to be put on ART treatment are taken through the dos and don'ts of the treatment by the nurses or counsellors. Every client is expected to attend all the counselling sessions with his/her Adherence Monitor. If a client fails to bring an Adherence Monitor he would not be allowed to go through the adherence counselling.

5 Some of the things a client is suppose to recall to the medical doctor to be recommended for ART initiation include the objective of taking ARV drugs, the dos and don'ts of ART treatment. Clients are thought these during the three weeks of adherence counselling.

Condemnation and abuse

In some instances, health workers in the clinics used abusive language with clients they considered to be irresponsible with regard to their treatment. Clients who defaulted treatment were often verbally abused or condemned. According to health workers, treatment defaulters are clients who have stopped taking their drugs for one or both of the following reasons: either because they have recovered from the signs and symptoms of the infection or they have resorted to alternative treatment such as taking herbal concoctions or preparations, spiritual treatment at prayer camps. Such clients do not take their drugs regularly as prescribed or stop coming to the clinic for their monthly re-supply of drugs. Some medical doctors and nurses in particular condemned defaulters and sometimes told them that they would die from non-compliance to treatment. For instance, Roseline, a nurse, openly said the following to a client, whom she described as a persistent defaulter, when he was brought to the clinic in a wheel chair looking weak and lean: "You do not deserve any mercy from us for not taking your medicines once again. Clients like you should be left to die."

Health workers also condemned some clients as immoral people because they believed those clients got the infection through commercial sex work. In one instance, I eavesdropped in a conversation among some health workers and one of them, Thelma, gossiped about a client who was in pain:

> … Look at her; she has been doing 'night business' in a hotel and whenever her health deterio-rates she rushes to the clinic as if we health workers are magicians to solve all her health problems for her… If she does not stop this night business she would eventually die of the disease…

There were also cases in which doctors unreservedly expressed their displeasure with clients who defaulted in their treatment regimen and condemned them for lack of seriousness towards treatment. A medical doctor told a client who had defaulted treatment for three months that he would die for not taking his medicines. The client complained to the doctor that he stopped taking the medicines because he vomited anytime he took them. The doctor was not convinced by the client's explanation and angrily said, "If you do not care about your health get up and leave the consulting room, and allow clients who are serious with their treatment to come in." The client shut up and allowed the doctor to continue with the consultation.

Nurse Suzane, however, explained that health workers do not take delight in abusing clients who default treatment. As people with feelings, they often get frustrated with clients who do not adhere to treatment after all the effort put into three weeks of adherence counselling. So health workers sometimes expressed such disappointments in harsh words to compel the clients to comply with treatment requirements. They scolded clients to improve compliance. Comparing what happened in the present study with the literature brings out certain parallels. Brown (2010), for instance, found in a study in the labour ward of a Kenyan hospital that

midwives used physical abuse and restraint such as tying non-compliant patients to their beds so they would be still for examination during labour and deliver their babies safely. This, she pointed out was in line with local cultural beliefs that physical reprimands were acceptable within relationships if such discipline taught people to 'behave properly.' The parallels in this study and that of Brown relate to how condemnation, scolding and verbal or physical abuse were applied on clients and patients. Whether these strategies are acceptable or not, the important thing is that they were employed by nurses to improve compliance. Nurse Roseline and the medical doctor's scolding of defaulting clients could be seen in that same light.

Controlling clients

During interactions with health workers and clients in the health facilities, I observed that clients often accepted the decisions and orders of health workers without questions or suggestions, which may be due to the hierarchical relationship that existed between them. The health worker-client relationships in the facilities were ordered in a hierarchy of authority based on level of knowledge and technical competence. With their monopoly of medical knowledge, health workers have competence while patients by definition are incompetent because they need intervention of professional health workers to cure their ailments (Andersen 2004). Consequently, health workers have control over decisions and actions of clients in respect of their care and treatment. Patients must subject to the authority of the health worker and follow prescriptions in order to be regarded as a good patient (Jewkes *et al*. 1998). Good clients in the present study were often praised by health workers for being compliant and serious with their treatment. It was observed that health workers in this study sometimes imposed decisions on clients in terms of where they should access care and treatment.

For instance, in some centres counsellors often referred clients who tested positive to particular clinics for treatment and did not allow them to decide which facility to go to for services. I asked a counsellor, Prince, why he always referred clients to a particular clinic although he had a list of other facilities in the region where clients could have decided to access treatment.[6] He explained that he referred clients to that facility because he always received testing kits from that hospital. After this conversation, I observed that he allowed clients who tested positive to choose which clinic they wanted to go to for care and treatment.

The question to Prince was prompted by the decision of a client not to access care and treatment in a hospital she was referred to by the counsellor. I met the client, Biyaa, in a different hospital and asked why she did not access treatment in the facility the counsellor originally referred her to, Biyaa responded:

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[6] There were 23 ART clinics and 145 VCT centres in the Ashanti Region as of December 2010.

> Oh!... That hospital was not the place I wanted to go for treatment. So, after I left the place… I decided to come for treatment in this hospital which I believe would be convenient for me because the other hospital is close to where my paternal relatives live. From what I know about my relatives in relation to this disease, it would be better for me to access treatment in this hospital which is far away and where nobody knows me. I believe this is the only way I can keep my status to myself…

In the clinics, clients who refused to take the orders or instructions of health workers were labelled uncooperative or irresponsible. Such clients were sometimes sanctioned or punished by health workers for objecting to their professional instructions or advice. Elsewhere, this type of client is referred to as 'bad patient', 'troublesome patient' or 'disobedient' (Andersen 2004: 2009-10). According to Andersen, the bad patient is the one who does not accept staff authority, recognise their monopoly on medical knowledge or take their advice. Uncooperative, irresponsible or bad clients were often threatened with non-provision of service or sidelined when it was their turn in the queue to be attended to.

In one instance, a client challenged the decision of a nurse to first attend to another client who reported late to the clinic before attending to him. The nurse therefore refused to attend to the client when it was his turn in the queue because he challenged her authority. The 'uncooperative' client, as the nurse described him, had to wait for more than an hour until a senior nurse intervened on his behalf to get another nurse to attend to him. The nurse later explained that her decision was meant to let him know that he could not dictate to health workers how they should go about their work. "As a client, he must patiently wait in the queue until it is his turn for the health worker to attend to him," she pointed out. This suggests that sometimes health workers use their power over clients to control them and make them comply. Likewise, Jewkes *et al.* found that in the face of perceived insubordination, some midwives used punishment as strategy to enhance or enforce control during delivery. These included giving patients a 'mouthful' or beating them to gain compliance during delivery (1998: 1789). The difficulty, however, with this strategy is how to determine the boundaries between control and punishment. Denial of services as a control strategy or punishment, such as a nurse was seen to employ on a client in this study, could lead to dire consequences.

Discriminatory treatment

Health workers in the clinics often allowed elderly clients and others who were very sick and weak to get immediate treatment without joining long queues. They explained that this practice was due to the specific circumstances of such clients. It was however against hospital rules which stipulate that patients must wait for their turn to see a health worker. The rule was informally referred to as *first-come-first-served* by both health workers and clients. During interactions and interviews with clients, they said that under the guise of helping elderly clients and others who were seriously sick, health workers rather gave immediate treatment to their favourites

and friends who reported late to the clinic. They added that this has been one of the causes for many confrontations between health workers and clients on clinic days. They urged me to be more observant in the clinics to check on the veracity of their claim.

Another client in an interview stated that health workers sometimes ignored clients in the queues and provided immediate treatment to rich clients who gave them bribes in return. Although Ohene, the client, did not give any evidence to prove this allegation, he insisted that it was a practice in the clinics and that many clients were aware of this. Andersen (2004) described this as differential treatment. She observed that in a Ghanaian hospital, health workers practiced differential treatment based on patients' education and ability to communicate in English. Thus, patients were categorised into the educated and the uneducated, which in large measure influenced the quality of care a patient was provided. This provided a criterion for social inclusion and exclusion casting the educated as insiders or modern and the uneducated as outsiders or villagers. The patients who are educated received immediate and high quality treatment in the hospital due to the personal relation or connections they have with medical doctors and nurses. The uneducated patients on the other hand often waited in long queues before receiving treatment, and in most cases they were not treated well by health workers during clinical encounters. The rich clients and friends or favourites of health workers could be considered as the 'insiders' in Andersen's terms. As a result, they were given discriminatory treatment, especially in the clinics.

To get the views of health workers on these issues, nurse Rebecca denied the allegation and said that clients who were given immediate treatment were those who genuinely needed help from health workers to access treatment without delay or difficulty. Rebecca further gave instances of some particular cases in which health workers had no choice and gave discriminatory treatment to those clients concerned. According to her, such clients, for various reasons, cannot join long queues in the clinic to access care and treatment. She mentioned a queen mother and a pastor who were clients and said it would not be proper for them to join the queues. The nurse further explained that should the queen mother be seen by some of her subjects in a queue accessing treatment, she might be destooled for being positive. Rebecca also said it was possible that if the pastor were found in the queue waiting to be attended to it would undermine his authority in the church as a man of God. The nurse added, "It was important that clients like the pastor and queen mother who are respected in society be helped to conveniently access care and treatment in whatever way possible without problems."

Besides, I saw in the clinics that some clients often brought foodstuffs and other items to the nurses and other staffs. I thought that such items were given to health workers in appreciation of support they might have given to those clients or because

they behaved favourably towards them. Some clients instead believed that those items were given to health workers in return for immediate treatment.

Asabea, a client, who is also a peer educator, pointed out that what the clients said was true to some extent. She said she was aware that because of these gifts some health workers in a clinic were reluctant to go on annual leave and preferred to work throughout the year. According to her, this implied that a client who was not in a position to give foodstuffs and other gifts to health workers would often spend more time in the clinic while those who offered gifts were given immediate treatment. She described this situation as unfair and could discourage some clients from accessing care and treatment. Asabea who was one of the first clients to access treatment in the clinic quickly added:

> My brother [meaning the researcher], but do you know something? Now, I can say that generally the incidence of unfavourable behaviours of health workers towards clients is going down compared to the time some of us started treatment here… I remember those days we had to accept anything health workers did to us. But these days, some people can complain about wrong things going on here… things are gradually changing here for the good of clients…

Several health workers and clients confirmed the observation by Asabea. Her comment suggests that as the years go by the negative attitudes and behaviours of health care providers are changing for the better. With regard to the foodstuffs and gifts, nurse Vera defended the idea of health workers accepting foodstuffs and other gifts from clients. She pointed out that the foodstuffs and gifts were in appreciation for help a health worker might have given to the client in the past. According to her, if, for instance, a health worker helped a client to pay for the transport fare and the client brought some farm produce in appreciation, it does not mean the client did that because he/she was given preferential treatment. It was common she said, for Ghanaians to show appreciation for some favour or good done to them by giving gifts. "These gifts are not bribes from clients so that they would be given immediate treatment in return," she said. The fact still remains that the issue of gifts had different meanings for clients and health workers. Clients felt that discriminatory treatment on the part of health workers often gave unfair advantage to some of their peers during care and treatment.

Delaying treatment

Observation in the clinics showed that sometimes health workers were slow in attending to clients referred from the centres to start treatment. Most clients who tested positive and were referred to the clinics for the first time looked very sick and weak. Whenever they reported in the clinics, they expected that they would be given some form of treatment as a first step. This was not the case in most instances as clients were made to go through many procedures taking days or weeks before they were put on antiretroviral drugs. In their poor state of health, these clients were usually asked by the nurses to go home and come back for registration as a prelude

to the long process leading to treatment. The registration alone, depending on the day of the week, could be the same day, a few days later, or in some cases one week later. It implied that clients had to go home and manage their conditions till they were due for registration to start the process for treatment.

As a researcher and a non-health professional, I often experienced emotional difficulties with the decision of health workers to send these seriously sick clients home without any first aid. In fact, these clients were most of the time simply told by health workers: "We cannot register you today because registration for new clients is on specific days of the week. So, go home and come back to the clinic on this date for registration." I observed that whenever the clients were asked to go home and come back at a later date, their facial expression changed from that of hope of receiving some form of immediate medical attention to that of disappointment. During a conversation with nurse Vera, I asked her why they asked clients to go home and come back for registration at a later date without any medical attention. She explained that due to the increasing numbers of clients and the limited staff, they have allocated particular days for various activities in the clinics to cope with the heavy workload. She explained that if a client was referred to the clinic on a day set aside for other activities other than registration of new clients, they could not attend to him on that day. They would have to ask the client to go home and come back at a later date for registration and subsequent start of treatment.

One medical doctor explained that delayed treatment was not a serious problem. He indicated that the core responsibility of the clinic is the provision of ART treatment to positive persons. Health workers in the clinics are not supposed to give first aid to clients but refer them to the appropriate unit in the hospital. He added:

> ... The HIV disease itself does not necessarily kill the victims but it is rather the opportunistic infections that usually kill them. So, whenever a client reports to the ART clinic with such infections, the ARV medicines in the clinic here can not be given to the client immediately to boost the immune system as the case may be without the required adherence counselling. In this light, it is expected that any seriously sick client would have to go for treatment through the out patients department of the hospital and later on report in the clinic to be registered and initiated onto ARVs, after the mandatory three weeks adherence counselling…

In some other instances, health workers were observed talking on their mobile phones for a long time while clients waited in long queues. This often created the impression that health workers did not attach urgency to clients' treatment. A couple of times clients confronted health workers for talking too long on the phone while they waited in queues.

As a concluding remark on the unfavourable practices of health workers, these have in many cases discouraged clients and potential clients from using counselling, testing and treatment services. People sometimes felt that health workers would not accord them good reception if they came to access VCT and ART, yet some of them

chose to use the services due to the perceived benefit of living longer through ART treatment.

Discussion

The discussion looks at three main reasons that account for the professional attitudes and behaviours of health workers towards clients. These are the additional training they have received in the provision of care and treatment for HIV patients, the life-long nature of the HIV treatment and the fact health workers know that these clients do not have people to help them take decisions on treatment due to the persistent stigma associated with HIV infection. It concludes that the professional attitudes and behaviours of health workers have a positive influence on the use of services.

The positive attitudes and behaviours described in this chapter raise the question of whether the practices of health workers in other units of the hospitals are as patient-friendly as those in the centres and clinics. An example in this respect was the financial support nurses gave to some clients. The positive attitudes and behaviours as reported in this study are striking against the backdrop of the assertion by Van der Geest & Sarkodie (1998) that in Ghana, people generally feel nurses in hospitals are often unfriendly and rude, as previously indicated. Experience showed that nurses in the antenatal clinics, for instance, do not normally give mothers who accessed services money to take transport or buy food. However, it is not uncommon in Ghanaian hospitals to find a few nurses who behave positively towards patients like those in this study. Such practices could be based on compassion, which according to Armstrong (2010) is the moral foundation of helping relationship between nurse and patient. This suggests that compassion in nursing practice strongly influences the nurse-patient relationship through which a nurse may support a patient or client in an unusual way. In their study, Van der Geest & Sarkodie (1998) found that nurses in a Ghanaian hospital ward sometimes spent their own money to buy food or drugs for patients. Compassion, which may have motivated these nurses to do this, could also be the reason for the financial support some health workers gave to clients in this study. The difference between health workers in the centres and clinics and those in other units may be how far they are prepared to support clients.

Unlike their colleagues in other units, health workers in this study went beyond duty in their care for clients. For instance, warmly receiving clients with a hug was not common among health workers in other departments of the hospitals. Likewise, the advisory role of health workers in the clinics in relation to treatment, marital and family issues was a behaviour their colleagues in other units rarely showed towards patients. In other units, health workers usually advised clients on matters related to care and treatment, but not marital or family problems. These instances illustrate

that care providers in the centres and clinics made a conscious effort to treat clients well during interactions to encourage them to continue using services. Health workers' good practices in effect were enablers which facilitated clients' use of services.

The conscious effort of health workers to behave favourably towards clients suggests that their attitudes and behaviours were meant to create the impression that they related to and treated clients well. According to Turner & Stets (2006), social actors' behaviour is self-directed (2006:9). This implies that social actors sometimes adjust their behaviour to make things work in certain situations, achieve an objective or even win the gratitude of others. Similarly, it could be that the good attitudes and behaviours of health workers were not genuine but 'self-directed', to convince the researcher or visitors to the facilities that they were friendly and nice to clients contrary to the negative feeling Ghanaians have about nurses. To a certain extent, this view could be true, but the situation as was observed in the centres and clinics showed that the positive practices of health workers were mostly real and not acted. Some of the positive attitudes and behaviours clients talked about happened before this study was carried out and there was no reason for them to describe these to please the researcher. Besides, clients spontaneously talked about some of the favourable and unfavourable practices of care providers during informal conversations with the researcher. Furthermore, these observation were made over fifteen months of fieldwork in the centres and clinics.[7] In this period, the researcher had a continuous presence in the facilities to observe the daily interactions between health workers and clients, and participated in some of those interactions. Thus, health workers in the centres and clinics could not have continuously acted these positive attitudes and behaviours for a period of fifteen months without exposing themselves if they were not used to them.

Various reasons account for the positive attitudes and behaviours of health workers in this study. HIV/AIDS prevention and treatment is a relatively new service area in the health care delivery system of Ghana. This made it necessary for health workers directly providing HIV/AIDS-related health care services to be given additional training in counselling, testing and treatment. The training, which is regular, has equipped them with the requisite skills to relate to and treat clients in a more professional manner than other health workers who have not received such training. Besides, it has helped these care providers to understand better the level of risks associated with caring for positive persons and also how to handle such risks. The special training has led to a greater willingness by these health workers to care for positive persons with less negative attitudes and behaviours towards them. Other studies also found that HIV training equips health workers to behave well towards

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[7] The fifteen-month fieldwork was in two parts. I first spent twelve months in the field to collect data for the first part. The second part also took three months.

clients during service provision. For instance, a USAID (2007) study on health care providers in Tanzania observed that providers with HIV training had a significantly higher knowledge scores than those without it, a result that is consistent with the possibility that HIV training can significantly improve such knowledge regarding HIV transmission and prevention. The study further noted that AIDS education among health workers, particularly nurses led to significant improvement in attitudes towards patients (see also Horizons Program 2006:29). In the present study, the training and the refresher courses the health workers attended might have contributed to the good perception they had about positive persons and to their subsequent good treatment of them during interactions.

The friendly attitude and behaviour could also be due to the life-long nature of the ART treatment. The fact is that when a client starts the treatment, he will continue to access the services until death. It implies that the client will visit the clinic frequently for health status reassessment and re-supply of antiretroviral drugs for the rest of his/her life. Clinic visits are normally scheduled on monthly basis during which the client goes through various procedures for a health status review and get a refill for his/her drugs. However, in the case of some old clients who have adhered to treatment for many years, they are often given three to six months to visit the clinics for the review of their health and re-supply of drugs. Having realised that the clients will need their care and treatment indefinitely, health workers deemed it appropriate to establish a longer-lasting relationship with them. Unlike other patients who visited the hospitals when they were sick, positive persons would keep on visiting the clinics, at least every month, three months or six months for many years. If care providers treat clients with distaste, they may feel uncomfortable interacting with them during their visits to the clinics to access treatment. To avoid this situation, they behave nicely and in a friendly manner towards clients to establish good relationships with them and help keep them on treatment.

Clients for their part expressed satisfaction with the positive attitudes and behaviours of health workers towards them. It follows that clients developed good relationships with some health workers and individual nurses were selected for praise and often spoken warmly about by clients. The relationship clients established with health workers helped them to adopt some care providers as their parents or siblings and consulted them for advice. They used their capacity to control events about their status and often sought the advice of such health workers on a wide range of issues including treatment, marital, family and business problems. This way, the good behaviour of health workers encouraged the use of services, helping clients to avoid identification as positive persons by relatives and prevent stigmatisation.

Health workers have observed that clients find it difficult to discuss issues about their status with relatives due to the fear of stigma. As I mentioned earlier, in the

communities served by the hospitals where this study was carried out, positive persons are often rejected, ostracised or discriminated against by relatives for suffering from HIV/AIDS. Clients in those cases could not disclose their status to relatives and let alone enlist their help in managing their state. This is contrary to the normal practice that a patient's relatives fulfil their responsibility to help the patient find a diagnosis and treatment. When someone is sick, it is the family members who normally take decisions on care and treatment on behalf of the sick person. Some of them would accompany the sick person to seek treatment and also assist with certain aspects of patient care in case of hospital admission. The patient who is deemed incapable of taking such decisions independenlty has to rely on relatives for treatment and other necessary support. This implies that relatives have to know what type of sickness the patient is suffering from to enable them to look for appropriate treatment, either in biomedicine or the folk system. It is these people in charge of the decision-making process for the patient that Janzen (1978, 1987) refers to as the therapy management group, a 'special-purpose group', "a set of individuals involved with a sufferer to lend assistance or assume authority in diagnosis and therapy" (1987: 77). He points out that the therapy management group is often made up of close relatives of a patient and in some cases neighbours or friends. The group basically takes decisions on care and treatment on behalf of the sick person. In his study on social networks in times of illness in Abidjan, Bossart (2003) points out that sometimes such close relatives also contribute financially towards cost of treatment for the patient. Some members of the therapy management group accompany the sick person to the hospital to assist him with care in the ward.

Health workers have realised that this traditional form of shared care is not suitable for positive persons who do not want their status to be known. They therefore found it necessary to do something more than the routine provision of services to encourage clients to seek their advice on matters relating to their status. This enabled clients to choose non-relatives as members of their therapy management group. This seems to have motivated health workers to get closer to clients and become quasi-members of their therapy management group. They managed the fear of stigma by choosing health workers as their therapy managers and conveniently used them to take crucial decisions related to their positive status, especially treatment.

Conclusion

In conclusion, the way and manner health workers in the centres and clinics related to and behaved towards clients, particularly positive persons, was unusual in most Ghanaian health facilities. Unlike in other units of the hospitals, these health workers often went out of their way to help clients and to encourage them to

continue accessing counselling, testing and treatment. In other words, this category of clients were given 'special treatment' in the facilities during service provision in view of the persistent stigma associated with HIV/AIDS and the need to do everything possible to motivate them and other people to take-up these services. The good practices of health workers in the facilities seems to have positively influenced the use of services and they stood in contrast to the often-reported negative attitudes and behaviours in earlier studies. The positive attitude and behaviour of health workers should therefore be taken up in educational campaigns to motivate more people to access counselling and testing and, if positive, to continue using treatment services.

Regaining self-respect as peer educators

... Personally, I do not have any regrets working in the clinic here as a peer educator. Whether we are recognised or not... for me the training and the work here has been useful. For instance, the training has helped me to understand the disease and its treatment better than most of my peers. As a result, I am able to take good care of myself and always look healthy as you [researcher] can see for yourself. More importantly, my work as a volunteer in the clinic is to help my own people [clients] to also benefit from the treatment like myself... And I believe this is the same for my colleagues [peer educators]. So, I think it is good for us to continue working in the clinic here... (Boafo, a peer educator).

Following the increased availability of antiretroviral drugs in Ghana, it became obvious that many positive persons would access care and treatment despite the limited number of health workers providing services. There was therefore a need to tap the skills of non-professionals to help health workers provide care and treatment, at least in the interim. This led to the training of some positive persons who had successfully undergone treatment as peer educators. The peer educators work in the clinic as volunteers to complement the work of care providers and often spend most of their time during the week working in the facility. This chapter is about these peer educators.

Boafo's comment quoted above was in response to a question on how he evaluates the peer educators' work in the clinic. It shows that although peer educators face problems such as lack of recognition in the facility, they are not discouraged from the work they have been trained to do. The comment also suggests that apart from their personal gains, peer educators feel their peers are the ultimate beneficiaries of the work they do in the clinic. The seeming lack of recognition Boafo referred to perhaps has something to do with the general perceptions people have about HIV and positive persons in Ghana. The disease is often portrayed as a result of socially

disapproved behaviour such as extra-marital sex or commercial sex work. The link between HIV and immoral sex behaviour causes loss of respect (*onni buo*) for infected persons and when one is not respected, one's identity is spoiled. It was against this background of 'spoiled identity' that some positive persons were trained as peer educators to work in the clinic where they are also clients. Their role and work in the clinic was characterised by frustrations and benefits, as this chapter seeks to analyse.

Through their training and work in the clinic, peer educators have changed their misfortune of HIV infection into making a decent living. The chapter establishes that it has raised their self-esteem in spite of the lack of recognition for their work, particularly by the hospital management and some health workers. It argues that the peer educators exercised their ability to manage the challenges and difficulties they faced and continued to work in the clinic to transform their stigmatised status into a relatively respectable one. The chapter describes the training of peer educators and the work they are supposed to do in the clinic. I follow with a description of the work they were observed doing. I also look at the views of peer educators on the changes in their duties and the views of health workers and clients on their work. These throw light on their work situation in the clinic with regard to the contradictions between their ideal and real roles. The discussion finally considers four main issues: the frustrations and challenges of peer educators in the clinic; the benefits of their training and work in the clinic in spite of the frustrations and challenges they face; and the concept of 'experience experts' with regard to the work of peer educators in the clinic. Finally, the discussion examines peer educators' status in the clinic as role models to their peers.

Training of peer educators

The peer educators were formally trained in adherence counselling skills and basic knowledge in health to eable them to work in the clinic. However, observation in the clinic showed that there were two types of peer educators – formal and informal ones. The formal peer educators were those who had been purposively chosen and trained. They were selected based on the condition that they were clients of the clinic and had successfully adhered to treatment to become healthy. In addition, they must be prepared to work as volunteers. The peer educators explained that nine clients satisfied these criteria and had been selected to undergo training. The training was sponsored by an international non-governmental organization called START in collaboration with the hospital authorities. Two of the peer educators stopped

working at the clinic when the START project, which used to support them financially, ended.[1]

The informal peer educators are also positive persons who have many years experience of antiretroviral therapy treatment and use their experience of the treatment to counsel their peers. They are termed 'informal' because they are not formally trained, and also not recognised as such by health workers or their peers. Though this chapter is about formal peer educators, the role of the informal peer educators in the clinic deserves to be mentioned as well since they also help their peers.

According to peer educators, they were trained to complement the work of health care providers. They are supposed to help health workers counsel new clients who have been referred to the clinic for treatment. They also counsel their peers already in the clinic on treatment. Peer educators are to assist their seriously sick and weak fellow patients who cannot get to the admission wards or access services in other parts of the hospital on their own. With their training in basic health knowledge, they are supposed to give health talks to their fellows on nutrition and personal hygiene while on treatment. Finally, they maintain contact with their colleagues who have stopped treatment in the communities and counsel them to restart accessing care and treatment. They sometimes undertake home visits with health workers. In this respect, they are the link between health workers and clients.

The peer educators explained that immediately after their two weeks of training they carry out the activities stated above. They said that for more than one year after their training, the support they received from the START project (in cash and in kind) gave them the motivation needed to be present in the clinic on every working day. For instance, the project gave them a monthly allowance for transport to and from the clinic. They were also given t-shirts with the inscription 'Peer Educator' written at the back, which they often wore to work in the clinic. In an interview, a peer educator said the following about the rationale behind their training:

> The START project, which brought the idea of training us to complement the work of nurses in the clinic here, had very good plans for us… I believe the project expected the hospital authorities to continue supporting us after it ended. But the authorities have refused to do so. We have been working here for almost two years now without any support, even in kind… In fact, we are disappointed in the hospital management for their lack of interest in the work we are doing here…. (Menka)

Health workers gave similar information about the training of peer educators, saying that the training of peer educators became necessary due to the lack of staff and the gradual increase in the number of clients accessing services during the early

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[1] START stands for Support and Treatment for Antiretroviral Therapy. It was a project which first piloted antiretroviral therapy treatment in some selected health facilities in Ghana between 2001 and 2004. The project was sponsored by an international non-governmental organization called Family Health International under USAID.

days of the clinic. They attributed this to the fact that most health workers were reluctant to treat positive persons for fear of HIV infection.

The work of peer educators during a day

The daily activities of peer educators were mostly different from the work they had been trained for. Their routine task in the clinic involves retrieving clients' folders from the shelves for health workers. The folders were kept in the records unit of the clinic and they contained the treatment records of each client. On every clinic day, nurses have to first get access to these folders before they start attending to clients. They relied on peer educators to get the folders of all clients who reported to the clinic for treatment.

They also distributed laboratory tests results to clients before health workers attended to them. These tests results included those for CD4 count, haemoglobin, and Hepatitis B which clients need for treatment during monthly clinic visits. Some of the peer educators distributed the tests results while others took the folders from the shelves on most clinic days. They sometimes helped the pharmacy staff to dispense drug prescriptions to clients after the nurses and the doctors have attended to them. Peer educators reinforced messages on how clients are supposed to take the drugs. In addition to these tasks, health workers referred new clients who have been traumatised by the news about the infection to them for further counselling. Old clients also approached them for counselling on their treatment or advice on personal problems.

The work of peer educators took place not only at the clinic but also in the community and other places. Health workers went out with them for outreach programmes in the community, churches or schools, and on radio talk shows. During such programmes, peer educators shared their experiences of the infection and the treatment to educate the audience on the need to undergo counselling and testing to know their status. They also used such programmes to assure people that if they test positive there are medicines to help them live with the virus for many years.

At the end of the day's work in the clinic, peer educators who are leaders of positive persons' associations sometimes visited their members at home. They used such visits to find out from members how they were doing on treatment and discussed any other issues of interest to the association. These visits were also used to reach out to members who had stopped treatment and did not visit the clinic for refill of drugs. They counselled and encouraged such clients to restart treatment.

Peer educators attended meetings of their associations and facilitated the meetings to find solutions to members' health and other problems. The meetings were on a monthly basis and were avenues for members to fraternise and deliberate on issues

of interest. Through a peer educator, one association used to hold its meetings in the clinic, which according to clients was a convenient place.

They were often invited by governmental and non-governmental organizations to participate in programmes aimed at educating people on how to prevent the spread of the infection. They always introduced themselves as positive persons and shared their experiences with participants. In most cases, peer educators were given allowances or appearance fees for participating in such programmes. Some of them were also invited to attend workshops, seminars and conferences in and outside Ghana. During such programmes, peer educators were accommodated in expensive hotels and were also paid per diems and allowances for travel and transport.

With regard to informal peer educators, they were mostly involved in counselling their peers by sharing their experiences of the infection and its treatment with them in the clinic. Some of them also visited their peers in their homes to discuss issues of common interest with them. Unlike the trained peer educators, they were not invited to attend programmes, workshops and conferences because they were not formally recognised as peer educators.

Change of duties

Peer educators explained that health workers suddenly stopped them from undertaking adherence counselling and health talks. According to health workers, peer educators were stopped because formal adherence counselling, as described in Chapter Three, was not part of their duties. They were rather trained to counsel their peers referred to them by health workers in the clinic. Before this sudden change, peer educators often joined health workers in adherence counselling sessions to help counsel new clients before treatment started. This was usually done through group counselling and each group, made up of about ten clients, had at least a health worker and a peer educator as counsellors. Peer educators also sometimes gave health talks to clients on nutrition and personal hygiene. Thus, peer educators were relegated to doing counselling and health talks in an informal way, as described earlier in the case of the informal peer educators. In reaction to these decisions by the health workers, the peer educators also asked them not to mention their treatment success as examples in counselling sessions and health talks in which they were not involved.

According to peer educators, they were told later that the decision to exclude them from counselling and health talks was based on allegations that some of them were performing tasks reserved for health workers. They denied this and said that at least health workers should have given them the opportunity to tell their side of the story. Misaa, a peer educator, argued that the decision of the health workers was motivated by the fear that they were becoming too popular with the clients.

According to her, health workers think their involvement in these activities had brought the clients closer to them and that most of the clients preferred to deal with them instead of with health workers.

The peer educators pointed out that although health workers stopped them from undertaking the two core duties, this has not discouraged them from coming to the clinic. They said that their role in the clinic was mainly for the benefit of their peers and their absence would negatively affect clients' use of services. Boafo articulated this opinion as well. In the interest of their peers, they were prepared to continue working in the clinic by carrying out any tasks assigned to them. Kwaa, a peer educator, summed up their response to the change in their duties in the clinic with the following words:

> We have decided to continue coming to the clinic as peer educators in spite of these problems. But we cannot come and sit idle in the clinic everyday while we can do something little to help our peers to access services smoothly… The little things we are doing now are better than staying at home doing almost nothing… So, we continue to be here…

Kwaa contended that the decision of the health workers was informed by the view that their training as peer educators did not change their status as clients of the clinic and that they should therefore be seen as clients and not as peer educators with special skills. He thinks that this has led the hospital authorities not to support them either in kind or in cash. Kwaa said that instead of finding ways to motivate them for the good work they were doing in the clinic, health workers were interested in stopping them from performing adherence counselling and health talks. According to him, the only benefit they got from the clinic was the fact that they did not join queues to access care and treatment. Likewise, their spouses and children did not join queues whenever they visited the clinic for treatment. He said that as volunteers in the clinic, they expected to be re-supplied with medicines every month free-of-charge, but this was the not case. They are supposed to make out-of-pocket payment for their drugs rations like other clients, but they were not discouraged from the peer educator work. The peer educator contended that the most important thing is that they are able to meet their peers in the clinic and counsel them to adhere to treatment.

To Pokua, also a peer educator, the decision of health workers to sideline them in adherence counselling had not changed her determination to continue helping her fellow patients. Pokua said that before she was trained as a peer educator, she had been unemployed for more than two years. She indicated that staying at home without work to do had been a boring and frustrating experience. Following the training, the work she did in the clinic has often given her satisfaction. She explained that every day she came to the clinic to meet her peers some of who had become 'relatives' and friends to freely chat with them. Besides, whenever she saw that most of her fellow patients she counselled were doing very well on the

treatment, she felt she had done something good to save lives. Pokua added that sometimes she did not have money to pay for transport to and from the clinic but she borrowed money just to come and see her friends. The mere fact that she got up every morning, dressed up and told people in her house that she was going to work gave her a mental boost and the feeling that she was also employed. Pokua ended her views on their work in the clinic with the following comment:

> … For me, whether we join health workers to do counselling or not … I think that as people who have benefited from the treatment, we owe it as a duty to help educate our peers to adhere to treatment as well as others who do not know much about the disease… I believe that by sharing our experiences of the disease with other clients, they would be encouraged to continue with the treatment …

Another peer educator, Menka, expressed his surprise about the decision of the health workers to restrict them to peripheral duties in the clinic. He argued that the decision of the health workers was due to the relative increase in the number of health workers providing services in the clinic: when there were not many health workers, they recognised the important role of peer educators in the clinic. He recalled with some nostalgia their work in the clinic in the early days, after their training:

> During that time, we were very happy with the peer educator work. The t-shirts we used to wear gave us a presence in the whole hospital. This made patients and some health workers to give us respect... In fact, we were well motivated at the time to work and help our peers who do not understand the disease and the treatment… Those were the good days of the peer educator work…

Nimo, another peer educator, said in a conversation that the work had enabled him to acquire some skills to manage his positive persons association very well. Through various training programmes and workshops, he had learnt how to efficiently manage his positive persons association. The Ghana AIDS Commission and other non-governmental organizations, which often support positive persons associations financially, organized some of these programmes. Nimo explained that the per diem, allowances, appearance fees, the honorarium he received for attending workshops, conferences and seminars had served as a source of income for him. He also said that he was sometimes overwhelmed with the number of invitations he received for such programmes, conferences and workshops in a week or a month. Whenever he was not able to attend some of the programmes, he gave the opportunity to some of his association members to participate and earn some money, too. He added that the peer educator work had exposed him to politicians, policy makers and influential people in the fight against the spread of the disease, locally and internationally. It is for these reasons that Nimo said that he would continue to work in the clinic notwithstanding the lack of recognition for their work, because he receives recognition from others outside the clinic.

Finally, Asabea, a peer educator said that apart from using the clinic to meet most of her colleagues to counsel them and talk about issues of interest, the place served as a market for her to sell doughnuts. In reaction to the seeming lack of interest in their welfare by the hospital management, she said:

> These days, I would not spend much of my time doing this peer education work like before. Even now, I only give out the CD4 count test results to clients … What worries me is that some of our peers, positive persons, think that we are being paid like health workers for the work we are doing here... In fact, I need to concentrate more on my small business to make a living. I think this is the benefit I would also get from the clinic ...

The observations of peer educators on the change of their duties show that they are not really happy in the clinic. They are however willing to continue with the work in the clinic because they still benefit from it.

Views of health workers and clients on peer educators' work

Health workers explained that officially they are supposed to do adherence counselling and health talks, but they often allowed peer educators to join them in the counselling sessions to share their experiences of the treatment with clients. However, it came to their notice that some of the peer educators were not performing counselling according to the procedure laid down. The health workers explained that during the three weeks of adherence counselling, every client is expected to recall some of the things learnt before initiation onto treatment, as explained in Chapter Three. They also said that peer educators allowed some clients to go through the counselling without recalling things learnt in the previous session. This allowed those clients to finish the counselling process with little or no knowledge of adherence. However, the involvement of peer educators in adherence counselling also made them think that they could carry out duties solely meant for health workers. For instance, they found that some of the peer educators filled laboratory test request forms for clients. Similarly, some of them were said to be driving away clients who reported late for care and treatment on clinic days. It was for these reasons that health workers decided to clearly define the work of peer educators by stopping them from adherence counselling and giving health talks. A health worker remarked:

> … We are in charge here and we have to tell them what they can do and what they cannot do in the clinic. They cannot do whatever they want... They are volunteers and they are here to help us... but not to take over our professional duties as some of them are trying to do…

Yet most of the health workers acknowledged that the peer educators played a useful role in the clinic. They explained that in spite of a few problems they had caused, they had generally shown the spirit of voluntarism by willingly performing any task assigned to them. For instance, nurse Vera mentioned their role in the records unit, which she said had often helped them to attend to clients without much

delay on clinic days. Likewise, whenever health workers were busy they referred clients to peer educators for counselling and this has helped to reduce their workload. Nurse Suzane also commented on the counselling skills of peer educators:

> The peer educators have been helping us in many ways. In most cases, we refer clients who are traumatised by the infection to them for counselling… In fact, such clients often report to the clinic here looking worried and fearing that the disease will kill them… But through their personal experience of the disease, peer educators are able to calm down the fears of these new clients to accept their status and take advantage of the treatment in the clinic…

According to Suzane, the clinic management has been unhappy with the lack of support for the peer educators after the end of the START project. They have tried at the clinic level to convince the hospital management to support them but the authorities said there were no funds.

Some clients also said that the counselling they received from peer educators on their first visit to the clinic helped them to understand that HIV/AIDS is not as deadly as it has been portrayed in the media. Attawa, a client, for instance said that before she was diagnosed positive, she never thought that somebody with the virus could live a 'normal life' and would surely die within a short period of time. This perception about the disease changed when a peer educator used her personal experience of the treatment to counsel her on how she could also live with the disease for many years. Attawa explained that she first reported to the clinic for treatment in tears because she feared she was near to death. The nurses in the clinic tried to console her and assured her that she could be helped through treatment to live longer with the disease. She was not convinced because it was normal of doctors and nurses to try and lessen the fears of patients that they would survive whatever disease they were suffering from. Attawa said that a nurse then referred her to one of the peer educators for a discussion. The client explained that although she listened attentively to the peer educator during the discussion, she was still not convinced that there was hope for her to live longer. When the peer educator mentioned that she is also living with the disease; she thought it was a joke. She said:

> When the peer educator shared her personal experiences, I adjusted my seat and sat well to listen to her because the sister was looking very healthy and well dressed… I was really touched by her story about the disease and based on what she told me I became convinced that it is possible for me to also live longer with the disease. Since that time, I have taken the sister as my relative because through her advice I started treatment and survived this disease. As of now, I have been living with the disease for almost three years.

Another client acknowledged the useful role of peer educators on a clinic day that all the seven peer educators were absent. She observed that whenever peer educators were not present to help with the picking of folders from the shelves, work slowed down in the clinic. Clients often spent much time in the clinic in long queues before getting treatment. The client said that she has heard that the peer educators were not

paid for the work they were doing. According to her, this might be the reason for their absence from the clinic sometimes. She added that the doctors should do something for them financially, so they would continue to work and help clients in the clinic.

The relative of a client was also full of praise for a peer educator who gave her hope that the positive diagnosis was not the end of her daughter's life. The relative, an old woman of about 80 years old, said that the first day her daughter was referred to the clinic for treatment she suggested that they should rather go home and look for some herbal treatment. She had heard that doctors do not have a cure for the 'bad disease' (*yareɛ bɔne*) and therefore they should not waste their time in the clinic to look for treatment. One of the nurses in the clinic who registered her daughter observed that she and her daughter were looking sad. The nurse asked them to talk to a peer educator for further advice on the disease. The old woman pointed out that they never regretted talking to the peer educator, whom she described as a health worker. She said that the peer educator spent his time to convince them that her daughter would not die of the disease if she sought treatment. To their surprise, the peer educator told them that he was also an infected person and he had been taking medicines in the clinic for many years. The woman continued:

> … In fact, after listening to this man (she points at the peer educator) I wiped the tears from my eyes and had the belief that my daughter will not die if she is given the medicines as this man told us. Since then, I have often brought him some foodstuffs from my farm whenever I accompany my daughter to the clinic… because he was the one who restored our hope at a time we thought all was lost. He has even given his phone number to my daughter to call him anytime she needs his advice on the treatment… In fact, he is a good person (*ɔyɛ nipa pa*)...

The old woman pointed out that the peer educator helped her to understand her situation better which convinced her to become the adherence monitor for her daughter.

Conversely, some clients also expressed misgivings about the work of peer educators in the clinic. They stated that some of them behaved as if they were health workers and therefore distanced themselves from their peers. Clients explained that they expected the peer educators to act as intermediaries between them and health workers. This way, they could pursue the interest of clients in their dealings with health workers. To their surprise, some of them sided with health workers against their peers whenever there was a problem between them. Others also accused peer educators of behaving negatively towards them just like health workers, as explained in Chapter Five. For instance, some clients said some peer educators shouted at them for doing something wrong in relation to their treatment. They also gave discriminatory treatment to their friends and favourites by picking their folders first whatever time they reported to the clinic for treatment.

These comments and remarks by health workers, clients and their relatives show the significant but contradictory role peer educators played in the clinic following

their training. Indeed, it could be said that peer educators were complementing the work of health workers in the clinic, particularly, in the area of adherence counselling and retention of clients on treatment.

Discussion

The discussion examines four main issues. It looks at the frustrations and challenges of peer educators in the clinic. Next, it examines the benefits of their training and work in the clinic in spite of the frustrations and challenges. It then analyses the concept of 'experience experts' in relation to the work of peer educators in the clinic. Finally, it considers peer educators' status in the clinic as role models to their peers.

The ethnographic data shows that peer educators were facing some frustrations and challenges in the clinic. Prominent among these was the lack of recognition for their work by the hospital management and to some extent also the staff in the clinic. The underlying reason for the lack of recognition may be due to the fact that their training was not the decision of the hospital or clinic management. Explanations by peer educators indicated that their training and deployment to work in the clinic was the proposal of the START project. Their welfare as volunteers in the clinic was the sole responsibility of the START project. When the project ended, the hospital authorities did not have a plan to financially sustain their activities. They probably did not see the need to spend their limited resources on peer educators who are not health professionals. Schneider *et al.* (2008) made a similar observation in their study on community health workers in South Africa. They found that the health workers often looked down upon the community health workers, who were volunteers like the peer educators in this study. Besides, the community health workers did not receive adequate financial support for their voluntary work in the facility. Another study by Hermann *et al.* (2009) on community health workers in some sub-Saharan Africa countries also observed that the role of community health workers in the provision of ART treatment lacked recognition by health authorities in Uganda. The authors explained that although these community health workers, some of who were positive persons, had been working in government health facilities for years, they were not recognised in the occupational structure of the Ugandan Ministry of Health. It can thus be concluded that health authorities or health workers in this study did not recognise peer educators' contribution in the health facility, however skilled they were.

The challenges facing peer educators' also relate to the lack of clarity of their role. Health workers and peer educators may be uncertain about what exactly it is that they should be doing (see also Shiner 1999). While peer educators thought that based on their training, their core tasks in the clinic were adherence counselling and

giving of health talks, health workers thought otherwise. There was some confusion about their role, which subsequently contributed to the latent tension between the health workers and peer educators. As professionals, health workers sought to assert their authority over peer educators, who are first and foremost clients of the clinic as positive persons as well as volunteers. They restricted them to certain peripheral activities such as picking of clients' folders from the shelves. Likewise, Tantchou & Gruenais (2009) attributed tensions and confusion between health professionals and new actors like HIV-positive volunteers in a Cameroon hospital to the absence of precise roles redefinitions and task-shifting procedures which lead to frustrations. Patton (1999) on the other hand, contended that there is often a natural tension between the roles of professionals and volunteers who consider themselves as experts in their own right. In the present study, some peer educators indicated that health workers felt that through adherence counselling, they were becoming 'experts' and more prominent to clients, which led to their exclusion from adherence counselling sessions and health talks. The lack of recognition for the work of peer educators by health workers was a constraint that did not allow them to carry out the duties they were trained to perform in the clinic.

There is also the view that the lack of recognition of care providers for the work of peer educators might have been influenced by the recent improvement in the staffing situation of the clinic. This view may be true to some extent, but the issue needs to be looked at in a broader context. Activities and events in the clinic showed that the role of the peer educators is still crucial for the smooth running of the clinic irrespective of the increase in staff. For instance, sharing their experiences of living with HIV/AIDS and its treatment with clients during counselling sessions has often encouraged many clients to access treatment. Moreover, the follow-up visits of peer educators in the communities to counsel clients who stopped accessing treatment to restart helped to keep many clients on treatment. This implies that peer educators are largely responsible to the increased attendance in the clinic, one important role of peer educators which health workers are not aware of.

Some of the challenges peer educators faced came from clients, in whose interest they were working in the clinic. Some clients said that they had failed to act as intermediaries between them and health workers. Other clients accused the peer educators of behaving as if they were health workers and forgetting that they are also positive persons and clients like them. These suggest that like some health workers, clients too did not always appreciate the work of peer educators in the clinic.

Notwithstanding these frustrations and challenges, the peer educators' training and work has brought them important benefits which to a large extent enabled them to regain some respect which they had lost after their positive diagnose. With regard to health, their personal experience in addition to their training has given them a

better insight into the infection and its treatment. This has obviously made them better adherents to the treatment. Unlike other clients, they do not often get sick. Their relatively good health has enabled them to work throughout the day in the clinic and also visit clients in the communities after they closed in the clinic.

The peer educators are formally recognised as stakeholders in the fight against the infection but that recognition, as we have seen, is not always confirmed in their actual working situation. The formal recognition does connect them to influential people in policy-making circles and in society. Their training has built their capacities to advocate on issues related to the infection and the use of services. They feel confident to talk openly about the infection at public forums, their status and how the treatment has changed their bleak destinies for the better. Peer educators sometimes get the rare opportunity to sit around the same table with policy makers and people in authority at meetings, conferences, seminars and workshops to discuss issues related to the disease. One such opportunity was a workshop which the research team organized as part of activities for the multi-level perspective project. A one-day workshop took place in Kumasi and was used by the researchers to present the interim findings of the project to stakeholders. It was also meant to give an opportunity to those who were involved in the research project to add their views to the final report. Participants included policy makers, health workers, peer educators, positive persons, NGOs, and academic research scholars. Peer educators used the workshop to make a strong case for their formal recognition and integration into the provision of care and treatment in the centres and clinics. They argued that as positive persons, they have a better understanding of the infection and its treatment, and should be employed to counsel or educate their peers on adherence and other related issues. Their views on the efforts to combat the spread of the infection are sometimes taken on board by policy makers.

The work of peer educators has also helped them to develop their leadership capacities. Those who are leaders of positive persons' associations have attended workshops and training programmes to acquire managerial and entrepreneurial skills to efficiently manage their associations. Some of them know how to write project proposals to look for funding from governmental and non-governmental organizations to support members of their associations. Most of them have successfully managed the finances of their organizations to the satisfaction of their financiers or donors. Unlike some community-based organizations run by non-positive persons, those led by the peer educators often get funding from the Ghana AIDS Commission. The commission has trust in peer educators as managers who effectively use funds given to them to support their colleagues.

What is more, peer educators get some financial benefits from their work within and outside the clinic. Tantchou & Gruenais (2009) found that positive persons benefited financially from their involvement in the provision of services in a

counselling and testing centre in Cameroon. According to the authors, some positive persons continued to work in the centre after their contract had ended because of the money they got from the sale of drugs and other items to positive persons. It implies that like peer educators in this study, the positive persons who worked in the centre in Cameroon were not paid, yet their association with the facility brought them financial benefits. Peer educators' leadership positions in the associations for positive persons have become a source of salaried employment. Besides, they earn income from their participation in various workshops, conferences and other programmes on the disease locally and abroad. Further, they have become consultants in their own right to both governmental and non-governmental organizations. Peer educators are often invited by various organizations to serve as resource persons for the training of HIV-related care providers or educational campaigns on the disease. They are sometimes hired by non-governmental organizations to work in health facilities that have started providing treatment. In such cases, they help to train new peer educators on the job by sharing their working experiences in the clinic with them. During the follow-up fieldwork, two peer educators were hired by a French non-governmental organization called ESTHER to work in another facility, which had started treatment.[2] In all these instances, peer educators were paid appearance fees, allowances or given incentives in kind.

Peer educators derive psychological benefits from the work they do in the clinic. Most of the clients have been unemployed since their diagnoses because they were too weak to engage in hard work while others lost their jobs due to many hours they spent in accessing care and treatment. They had to endure the challenges of unemployment such as lack of money, idleness and boredom alongside stigmatisa-tion by relatives. Their work as peer educators has to some extent taken away these problems. The daily visits to the clinic have kept them busy throughout the week and this has helped to reduce the stress they were going through when unemployed. They also get satisfaction from working in the clinic to help their peers adhere to treatment and live longer with the disease. The mere fact that clients approach them with their problems for counselling or advice gives them the feeling that they are useful. This has often encouraged them to be present in the clinic most of the time. Similarly in their Cameroon study, Tantchou & Gruenais (2009) reported that some positive persons explained that they could not stop working in the counselling and testing centre as volunteers after their contract ended because they had become attached to patients. One volunteer said the following to explain why she was still working in the centre although her contract had ended; "I am still here because of the patients…" Another volunteer said, "I really like this job… When I talk to them

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[2]   ESTHER stands for Network for Therapeutic Solidarity in Hospitals (*Ensemble pour une Solidarité Therapeutique Hospitalière en Réseau*). Besides working in the new ART clinic, the NGO also sponsored the training of the peer educators in psychosocial counselling.

[patients], I can see that they are really touched and that makes me proud" (2009:54). These instances show the satisfaction peer educators get from helping their people to access treatment and live longer with the disease. Whenever the peer educators observe that their peers are doing well on the treatment they get some inner satisfaction that their counselling or advice has helped to save lives.

The positive status of peer educators combined with their training in counselling skills make them more effective in the work they do in the clinic. They have personal experience of the disease and do not need anyone to explain to them how it feels to be infected with HIV. Peer educators have been receiving treatment for many years and have personal experience of how the ARV medicines work. Moreover, the training they received has equipped them with counselling skills and basic medical knowledge to effectively educate others on the disease and its treatment. Their long association with the clinic as clients, volunteers and peer educators has also given them the opportunity to get on-the-job training on some basic aspects of the treatment. These put them in a better position to counsel or educate clients and others on the disease and its treatment compared with non-positive health workers.

It is in this context that De Bruyn & Paxton (2005:148) point out that people living with HIV as peer educators may be seen as 'experience experts.'[3] They empathise with clients and may be more effective, trustworthy and able to protect and promote the rights of positive persons. Elsewhere, experience experts are referred to as 'expert patients' (Kober & Van Damme 2006). These authors advocate for the inclusion of positive persons as 'expert patients' in HIV/AIDS prevention and treatment programmes, particularly in resource-poor settings where there is lack of health care providers. According to them, the concept of expert patient is based on the premise that if trained, their first-hand knowledge as people directly affected by the disease is enhanced by physiological and medical background knowledge. These people are therefore able to understand the patients under their care medically, emotionally and socially. They observe that the concept of expert patient has worked well in some developed countries for chronic diseases such as diabetes and this can be adopted in sub-Saharan Africa which has high HIV prevalence rate but lacks adequate numbers of health staff to provide services. Kober & Van Damme point out that the notion of the expert patient could potentially improve outcomes for the positive persons in terms of adherence to treatment and reduce the workload of the limited health workers providing services.

In the present study, counselling given by peer educators as experience experts or expert patients helped to reduce the workload of care providers in the clinic. Most clients approached them first with problems related to care and treatment. They believed that peer educators face similar challenges and difficulties as them as

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[3]   'Experience expert' is a Dutch term. Its Dutch origin is *ervaringsdeskundige*.

positive persons and are more likely to give them the support and counselling needed. Peer educators also show more sympathy and compassion towards their fellow patients by spending time to address their problems and challenges in the clinic and sometimes in their homes. Peer educators as experience experts put a human face to the infection, which encouraged many people to accept their positive status and access treatment services. Peer educators' work in the clinic as experience experts has gained them recognition as 'informal health workers' within and outside the clinic. Health workers often used their expertise by attending outreach programmes with them and allowing peer educators to share their experiences of the disease with the audience. Their ability to clearly explain issues about the disease and its treatment might have convinced some clients and others to think that they are health workers. On the whole, peer educator's recognition as informal health workers had a positive effect on the use of services by clients. Similarly, informal peer educators can also be referred to as experience experts because their work in the clinic helped their colleagues to adhere to treatment. These instances show that peer educators used their capacity to take control over events that affect their lives and stayed on to work in the clinic irrespective of the lack of recognition for their role by health workers. Peer educators subsequently used their creativity and engaged in various activities and programmes to improve themselves.

Peer educators have become role models for their colleagues following their successful treatment and surviving the disease. Before the advent of ARV medicines in sub-Sahara Africa, HIV was generally considered to be untreatable and its sufferers faced eminent death. Some people even doubted the efficacy of the medicines at the early stages and continued to hold onto the belief that they could not help positive persons to live longer. However, this perception began to change when the peer educators became healthy and started living 'normal lives.' The significant improvement in their health through treatment became a living testimony of the efficacy of the medicines. It is for this reason that health workers in this study always refer to the peer educators as success stories of the treatment in their effort to encourage clients to adhere to treatment during adherence counselling sessions. This makes them role models for their colleagues to emulate and also survive the 'deadly disease.' Turner & Shepherd (1999:328) for instance argue that, "the role of peer educator is to serve as a positive role model and to provide social information rather than merely providing facts… peer leaders enhance the programme's applicability by modelling appropriate behaviours."

During interactions with their colleagues, peer educators often used their own treatment experiences to advise them to access services and adhere to treatment. The information they give to their peers in such interactions was in most cases valued as coming from someone who has been successful in terms of HIV treatment. Most clients were therefore motivated to act upon what they told them to become healthy

and survive the disease. Their status as role models in the clinic inspired many clients to take their treatment serious and not to default on treatment. Peer educators modelled appropriate behaviour by accessing services like any other clients on scheduled dates. They were seen in the clinic going for re-supply of medicines when their rations run out, which suggests that they take their medicines regularly according to prescription. Peer educators always look healthy and generally comported themselves well in their interactions with health workers and clients. Indeed, peer educators were found practising what they counsel their peers to do. Their lives were exemplary for clients to emulate and live longer on treatment.

The disclosure of their status likely served as an appropriate behaviour for their colleagues to learn from. It is common knowledge that many clients do not want to inform other people about their status due to the fear of stigma. Radstake (2000) for example reported that Ghanaian HIV-positive persons used secrecy about their status as a strategy to minimize stigma. The non-disclosure of status to others thus helped them to maximize their ability to receive care and support (see also Crentsil 2007). However, peer educators have defied the persistent stigma associated with the disease and gone public about their status. This bold decision has contributed to the national campaign to de-stigmatise HIV and encourage more people to use counselling and testing services. It is possible that their open disclosure might have encouraged some of their peers to also disclose their status to others like their spouses. Clients see the peer educators as selfless people who are volunteering their time and energy to help them to smoothly access services. Their volunteering spirit might have motivated some other clients to work in the clinic as informal peer educators and, also became role models for their fellow patients.

Conclusion

In spite of the lack of recognition for the peer educators by some health workers, their case is a rare occurrence in relation to what I know about ill health and biomedical treatment in Ghana. Ill health and HIV/AIDS in particular is generally seen as a misfortune, which makes people to attribute their sickness to spiritual causes as is shown in the study of Kwansa (2011). Peer educators changed their ill health into an asset, both financially and morally. They did not only look for treatment in the clinic to become healthy. They transformed their misfortune of HIV infection into a venture to make a living. In addition, most of their peers and some influential people in society respect them thereby raising their social esteem. The peer educators generally have positive self-esteem and see themselves as stake-holders in the effort to combat the HIV/AIDS epidemic. Unlike other positive persons, they are able to interact freely with people who do not have the disease without fear of being discriminated against. Their case is important because it defies

the often-held view that the effects of stigma on the individual are specific to the negative dimensions of his self-esteem (cf. Wright *et al.* 2000). This rare event in the biomedical setting has allowed patients to live 'normal lives' as well as improving their health.

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When the clinic becomes
a home

> … It would be better if we [clients] meet here in the clinic to discuss this problem and find a solution… You are aware that matters concerning this disease cannot be talked about in our family homes for obvious reasons… But in the clinic, which has now become our second home we can freely talk about this problem without any fear that somebody would hear what we are discussing and know about our status with the possible negative implications for you and me… I think here in the clinic we can get the views of the health workers in the discussion because now they are our trusted family members (*abusuafoɔ*) when it comes to matters relating to this disease… (Nimo, a peer educator)

This chapter is about how clients go about their everyday life in the ART clinic. Its main purpose is to show the way positive persons have created a private place out of a public space and use it for various activities to keep their status hidden. Clients have adopted the clinic as a home with health workers as their 'family members' in parallel with their real homes in the community, as indicated in Nimo's comment above. This use of the clinic is largely due to the persistent stigma associated with HIV/AIDS and the need for clients to find ways and means to keep their HIV-positive status private. The comment by Nimo suggests that clients have found the clinic a convenient place to discuss issues concerning their status and conceal it from other people. He is of the view that it is unsafe for positive persons to discuss an issue related to their status in their family homes. Nimo feared that their houses do not guarantee the necessary privacy and other people such as spouses, relatives or neighbours could discover their status and stigmatise them. Through their capacity to act and take control over issues which affect them, clients therefore chose the clinic as a suitable place outside their real homes for carrying out certain activities and avoiding identification as positive persons by others.

The peer educator made above comment when a client approached him for advice on a problem between her and the authorities of her church. Nimo is a leader of an association for positive persons. According to the client, she and her partner had informed the church authorities about their positive status with the hope that the church would be sympathetic and supportive. Their decision was based on the church's messages of love. However, the church authorities instead stigmatised and discriminated against them as immoral and sinful people. The church leaders refused to share the same drinking cups with the couple. The church also withdrew its financial support to her husband as a pastor. She consulted the peer educator for advice on her plans to seek redress from the appropriate authority.

To illustrate how clients used the clinics as a home for various activities, I first describe what a home is and relate it to clients' ideas of the clinic as a home. I will describe how actors of a fictive kinship in the clinic carry out their activities like they do in their family homes. The discussion looks at four main issues. It starts with the analysis of why the family homes of clients are no longer experienced as homes, followed by a discussion of what makes the clinic a home for clients. It also examines the fictive kinship in the clinic as an alternative to the therapy management group. Finally, the discussion looks at the threat other actors pose to clients in the public space of the clinic.

The clinic as a home

A home is simply the place where one lives. It could also be an institution for people needing professional care like a nursing home for the aged. This basic definition of a home implies that it is a place where a family lives and carries out most of its activities on a daily basis. As well as being a physical home it is also a social space. In a typical Ghanaian home, the family is often made up of parent(s), children and in many cases other relatives such as grandparents, uncles, aunties, nieces or nephews. Crentsil (2006) notes that among the Akan in Ghana, children ideally live and spend as much time as possible with their parents in the house (see also Kallinen 2004). The parents are responsible for their children's welfare and training in the formative years. The home is thus a place for family togetherness. Relating these characteristics of a home to the clinic and how clients in this study use it, the clinic could be regarded as their second home. Clients meet in the clinic almost every month to access services. Peer educators are in the clinic to complement the work of health workers. Food vendors, newspapers vendors and other traders visit the clinic to sell their items or pursue their interests. The presence of these people in the clinic has led to enduring relations as in family homes. The relations in the clinic can be seen as fictive kinship. The close bond between health workers and clients resembles the one between parents and children. Peer educators can be seen as uncles and aunties

of this family. Likewise, food and newspapers vendors and traders who visit the clinic can be referred to as 'distant relatives.'

Clients use the clinic as a private place to go about some aspects of their lives instead of doing so in their family homes. The belief maybe that unlike their personal homes, the clinic guarantees them the privacy they need to carry out certain activities as positive persons. In effect, they are able to prevent people in their family homes from knowing their status. This helps clients to keep the respect and honour they have in their families and in the community.

Their use of the clinic as a home might have also been based on how they experienced and perceived it as a place they could conveniently use for private and public purposes. To personally experience and perceive a place could make one to relate to the place as a home (McColgan 2005). In its private sense, clients use the clinic as a venue to undertake some activities, which they could not perform in their personal homes, for fear of being identified as positive persons. On the other hand, the public context of the clinic is for clients to access care and treatment every month. Both ways of using the clinic has helped clients to keep their status secret from spouses, relatives and friends. They have also enabled clients to live 'normal lives' in their family homes and in the community like uninfected persons.

Clients' intimate relationship with the clinic might have influenced them to perceive the place as a home. This observation finds meaning in Bachelard's (1994) suggestion that one can call a place home if one finds intimacy in it. In the case of clients for the present study, some of them had strong attachment to the clinic through the use of services over more than three years. Over that period, they had been visiting the clinic either on monthly basis, every three months or at most every six months for a review of their health and re-supply of medicines. The relationship clients have with the clinic will not end since the treatment they receive is life-long. They are likely to continue visiting the clinic frequently for the rest of their lives. Clients could therefore perceive the clinic as a home because, like their personal private homes where they would live till they die, clients would continue using services there till they die. The next section describes the various activities that members of this fictive kinship carry out in the clinic.

Activities of actors in the clinic as a home

The main actors in this home are health workers as providers of care and treatment, and HIV-positive persons who use the services that are provided. Peer educators who are also clients are another category. Other actors include people such as visitors, food and newspapers vendors and traders. As fictive relatives, each of these actors relate to the clinic according to their interests. I put them into four main groups and analyse their activities in the facility as a private and public space. The

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groups are: clients, health workers, peer educators and others, which include food and newspapers vendors and traders.

Clients

Clients are the main actors in the clinic as a home. For many clients the clinic has become the place to meet their fellow patients, to fraternise and to share common problems they face as positive persons. According to most of the clients I interacted with, when they come to the clinic for scheduled visits, they are able to converse with peers on a wide range of issues, such as treatment outcomes and family problems. Asana, a client, said that it is in the clinic that she gets someone to engage in lengthy conversation with. She pointed out that in her family home she hardly converses with members of her extended family because they believe she is suffering from a curse (*dua bɔ*). She explained that when the infection started, she fell ill seriously and all attempts to cure her failed. Her relatives concluded that she had committed a sin against someone and the person had cursed her with a terrible sickness. Most of them rejected her as a sinner and declined to associate themselves with her. Asana said they believed that when they come closer to her, the curse from which she got the bad disease (*yareɛ bɔne*) would spiritually infect them too. Whenever she comes to the clinic for scheduled visits, she feels welcome and gets the opportunity to converse with her fellow clients, some of whom she considered as her 'family members.' She added:

> … It is in the clinic here that I find some happiness which makes me see this place as my home. Anytime I come to the clinic, I leave here late even if I get treatment early... If I go back home early, I am most of the time alone without anyone to converse with like here in the clinic. Hmm! This disease has made life difficult for some of us even in our own families…

Baah, another client said that because he had not been able to disclose his status to his wife and family members, he found it difficult to even have a lengthy conversation with them. He feared that he might mistakenly say something about his status if he did so. During Baah's visits to the clinic for treatment, he meets people some of who he described as 'sickness family members' (*yareɛ abusuafoɔ*).[1] He freely interacted and conversed with them to release some of the stress he has being going through in his own home. He further explained that he has HIV-positive friends who also have similar problems and they normally meet in the clinic to share how they were managing their various situations in their family homes. Baah: "For some of us, now the clinic has become another home besides our original homes where we can find some happiness by laughing over our problems."

One client, Aba, said that sometimes she comes to the clinic just to hang around and chat with her fellow patients. She pointed out that before she got the disease, she was a trader travelling from one town to the other on market days with her wares.

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[1] It means family members of this disease.

She fell sick for a long time and spent all her money on treatment until she was diagnosed positive. Although she was doing very well following treatment, she did not have capital to start her trading again. Aba is at home most of the time doing virtually nothing and has become fed-up with her unemployed situation. On non-clinic days, she visits some nurses she has taken as her parents and friends. Besides, Aba sometimes comes to the clinic to converse with her peers and know the challenges they were going through following the infection. She uses such visits to also share her experiences with them because she cannot do the same at home. Aba, who is an example of an informal peer educator as described in Chapter Six, explained that she does not take delight in listening to the stories of fellow clients but that:

> Some of the cases they tell me are worse than what I went through before I started treatment here in the clinic. These, sometimes serve as encouragement for me to feel that in my case things were a little better and there is still hope for me in life… (*anidasoɔ wɔ hɔ ma me)*

Some clients said the way some of the health workers related to them made the place a 'home away from home'. This, they said sometimes helped them to forget for a moment the difficulties they go through. Unlike some of their relatives, most of the health workers showed love towards them whenever they visited the clinic. Abrefi, a client, said that some clients have even adopted particular nurses as their mothers because they made them feel good by relating to them well in the clinic. She further commented about the health workers:

> ... They welcome us and listened to whatever problems we come to them with, which is not the same with our relatives who in most cases we can not even talk to about this disease. I always make sure that I do not miss my scheduled visits so I can see friends and nurse [she mentions her name] I have adopted as my mother to talk to over issues of interest…

Among the clients themselves, the way and manner they addressed each other whenever they meet in the clinic further strengthens the fictive kinship relationship between them. I heard clients calling each other brother/sister (*me nua*) or relative (*abusua*). I became curious to know why they addressed each other this way since among most Ghanaian ethnic groups, it is people who come from the same biological parents or from the same extended family who refer to each other in such terms. Naa, a client, explained that in view of their positive status and the fact that they have been meeting in the clinic every month, they see themselves as people belonging to 'one family' with a common problem.

According to Misaa, they always address each other as 'church member' (*as-ɔreba*) outside the clinic. Misaa, who is also a peer educator, said whenever they call each other *asɔreba* in public, other people do not understand what they mean by the term. Calling each other 'church member' enables clients to talk about themselves without making any reference to HIV/AIDS, which could expose them as positive

persons. It also meant that as members of one church, they often showed solidarity by relating to each other as brothers and sisters.

The clinic as a home was also an avenue for clients to find a partner and get married. This makes sense against the backdrop of the reluctance of many positive persons to disclose their status to their spouses, let alone inform other people that they do not know. Asiedua, a client, told of how she met her partner in the clinic and later got married to him. After she tested positive, her then boyfriend abruptly ended the relationship. She decided not to enter into any love relationship again for the fear that she may infect an innocent person. The client changed her mind because she felt that she was too young (in her mid twenties) not to engage in a love relationship any longer. She thought that it would be better to look for a partner who is also positive like her so she does not infect a lover who is negative. The following was what Asiedua said about how she finally met her lover in the clinic:

> … It happened that I boarded the same vehicle with him a couple of times to the clinic. On all those occasions, the two of us dropped at the same place and walked to the clinic separately... But on two other visits we were following each other in the queue in the clinic and subsequently identified each other as having bordered the same vehicle to the clinic. So, we conversed briefly in the clinic and got to know each other's name… On another occasion, when the two of us finished treatment and we were walking to the lorry park, he spoke to me and then fell in love with me. Now, we are happily married as husband and wife. This is my love story in the clinic…

Another client met her husband at the clinic. The client said during an interview that she did not have peace in her previous marriage because her former husband accused her of being an unfaithful and promiscuous woman and getting the disease in that way. The couple were discordant – the woman was positive and the man was negative. According to Fremaa, the client, her former husband later divorced her and married another woman. The client summed up her narration as follows:

> By God's grace, I met my husband I am living with now in this clinic while we were all getting treatment. Since we are both positive, we understand each other… In fact, with this man, I have the peace that was missing…

Some clients were less successful in their attempts to get a partner in the clinic. One client told his colleague that a female client was stalking him after he had rejected her love. On one clinic day, I was seated among the clients in the clinic observing activities and also eavesdropping in the conversations of clients. Suddenly, a male client moved out of the queue and came to sit close to where I was seated. Then, a fellow client asked him why he left the queue. He responded:

> It is because of a lady who came to sit close to me. I got to know her in the clinic here and we became casual friends… because the two of us have been meeting here on scheduled clinic visits. Later, she fell in love with me and I turned her down. Yet, she would not understand that I do not love her… Whenever she sees me in the clinic, she behaves in the presence of others as if I am her lover. This made another female client ask me whether I am in love with her… Just now, she came to sit where I was seated in the queue… To avoid any contact with her and also prevent her from acting as my lover, I decided to leave the queue to come and sit here till she leaves the place…

Clients fell in love not only with fellow clients but also with health workers. Nurses gave instances in which some female clients wanted to have a relationship with male health workers in one of the clinics of this study, but the health workers refused. The nurses expressed surprise about the boldness of such clients to sexual liaison with care providers who knew their positive status.

Like peer educators, some clients also traded at the clinic as they do around their family homes. Some of the clients brought some of their wares to the clinic to sell on clinic and non-clinic days. Abrefi, a client, who sells second hand clothes, explained that the health workers in the clinic are some of her most reliable customers. According to her, sometimes when she is coming to the clinic for treatment, she selects the best of the wares and brings them to the health workers and clients to buy. She added that because some of the health workers and clients know her shop in the market, they sometimes come there to buy things.

Health workers
Through their daily caring interactions with clients, health workers could be referred to as the parents of the fictive kinship system in the clinic. Female health workers, especially nurses, were like mothers while male health workers such as doctors were like fathers. In their role as parents, they were often observed settling disputes between clients and their spouses, and sometimes between clients and their relatives. Some of these spouses and relatives were not clients but they accepted the mediating role of the health workers.

In most cases, it was a client who adopted a health worker as a parent. For instance, a client takes a nurse as a mother after the latter has treated him/her well in interactions in the clinic. The client as a result tells the nurse a problem or dispute he may be having with his/her spouse or a relative. The client subsequently asks the health worker for advice on how to solve the problem. Health workers usually responded with advice. There were cases in which they invited the parties involved in the conflict to the clinic for a discussion to find a solution. On such occasions, they meet on the clinic premises or in their offices.

I observed an instance in the clinic in which nurse Suzane who a client adopted as a mother helped to solve a problem she had with her husband and her mother-in-law. Asempa, the client asked Suzane to advice her on how to respond to her mother-in-law who had been harassing her for being infertile. The mother-in-law also threatened that she would let her son (Asempa's husband who is also a positive person) to divorce her for not being able to give birth to a child. The client further explained that she had asked her husband to talk to his mother to stop harassing her but he had failed to do that. Nurse Suzane invited Asempa and her husband to the clinic for a discussion. She advised the couple to move out of the family house where they lived with the mother-in-law. Besides, the husband should explain to his

mother that the doctor who was treating Asempa following her prolonged sickness had advised her not to give birth within the next two years. They were simply, following the doctor's advice to ensure that his wife fully recovers from her health problem. The next time I met Asempa in the clinic, she said that nurse Suzane's advice helped to solve the dispute between her and the mother-in-law. She further said that they had moved from the family house and were living far away from the mother-in-law. She added, "Now, I am free from all the insinuations and threats from that old woman."

Commenting on the role of health workers in settling disputes and the clinic as the convenient venue for this purpose, nurse Benedicta said the following:

> Apart from our work as care providers, we also have the additional responsibility of settling disputes in the clinic here because most of the clients are not sincere in disclosing their status to their spouses… When their spouses get to know of their status, they run to us to help them out by talking to their spouses to accept their positive status and continue to live with them. We often try our best to help the clients here in the clinic… because they cannot send such problems to their real parents or family members to settle. They do not want them to know about their status and be branded as immoral people, and subsequently lose respect in the family...

I also overhead a conversation between some clients in the clinic and one of them said:

> ... I have always imagined how difficult it would have been for me to solve the problem I had with my husband if this nurse had not mediated… In fact, she saved me from a possible disclosure of my status to my in-laws if I had taken the problem to them for a solution. Luckily, we got the problem solved here in the clinic quietly without the knowledge of any family member. Now, I share all problems with that nurse for advice as a mother….

Nimo's comment quoted at the beginning of this chapter also underscores the important role of the clinic and health workers in settling disputes of positive persons, as they would have done in their families and private homes. The clinic is thus seen as a home for members to conveniently discuss issues concerning the infection, without the knowledge of their relatives or spouses.

In a similar way as it is done in many Ghanaian household, health workers often prayed with clients in the clinic before starting the day's work. They led clients to sing songs and thank the Lord for taking good care of them. Both health workers and clients prayed that God should protect positive persons from opportunistic infections and provide for their needs.

Christians as well as Muslims and other believers were actively involved in these prayers, which rarely happens in the larger society. On such occasions, the atmosphere in the clinic becomes charged and lively with clients and their relatives and health workers singing songs of praise to God and clapping their hands in happiness. I remember one particular gospel song that nurse Benedicta used to start the morning devotion with in one of the clinics.[2] The song is paraphrased as follows

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[2]   The song paraphrased in Twi language is by Pastor Joe Beccham, a Ghanaian gospel musician.

in Twi: *Enti me paa ni na woayɛ me sɛ yi, Awurade wo ho yɛ hu…Woasesa me hyɛbrɛ,* which literally means, "Am I the one you have made like this? God you are wonderful. You have changed my destiny." According to the nurse, for the clients the song means "They cannot believe that they are still alive because as positive persons, they would have been dead by now. If they are still alive, then it is by the grace of God who has made this possible through ART treatment." She explained that with this gospel song, she was encouraging the clients that in the name of God there was hope for them to live longer lives on treatment. They should not despair.

Health workers were also trading at the clinic. They sold medicines to clients outside the clinic's pharmacy like drug peddlers do in the community. Buying and selling in people's homes is a common feature in Ghanaian society. Petty traders often carry their wares round the community and enter houses to advertise their items for people to buy. The items that are often sold or bought range from clothes, drugs to vegetables and other food stuffs.

From my inquiries as to why health workers were not selling those medicines through the clinic's pharmacy, I found that some health workers were in alliance with pharmacists in town who supplied them the medicines to be sold to clients directly. Those health workers were often given a percentage of the sales as commission.

Most of the medicines sold to clients outside the pharmacy were multivitamins, which according to care providers are good for positive persons because they boost their appetite. Health workers explained that clients needed to take them in addition to the ARV drugs so they could eat very well and look healthy. Besides, a health worker was selling soft drinks such as coca cola, Fanta, Sprite and malt to her colleague health workers, clients and their relatives and visitors in the clinic.

Health workers not only sell to clients in the clinics, they also buy items from them. I saw clients selling their personal belongings to health workers in order to either buy drugs, pay for their transport to and from the clinic or to solve other financial problems. I recall one case in which a client sold her new and expensive wax print to a health worker at a cheap price simply because she was broke and needed money badly. Later in a conversation, the client explained that she was an unemployed mother with three children. Her husband had travelled without informing her where he was going, leaving her with the three children. She was finding it difficult to get money for a living and therefore needs to sell the wax print at a cheap price. She further explained that she could have sold it for a higher price but it would have taken a bit of time for her to get a buyer. She urgently needed money to take care of her children; and had no choice than to sell the wax print at a give away price.

Peer educators

Peers educators can be seen as uncles or aunties of clients. They helped health workers to settle clients' disputes. They resolved differences between clients and their spouses or between two clients. Some peer educators had formed HIV-positive persons associations to support their members socially, psychologically and economically.[3] The associations often used the clinic as a venue to settle disputes between their members like families do in their homes. They chose the clinic because all the members are receiving care and treatment in the clinic and can be easily reached there on clinic days. A peer educator pointed out that most of the clients have not been able to disclose their status to their spouses and relatives for fear of being divorced or losing respect. Marital disputes among members for example can not be settled in people's family homes for fear that one may mistakenly make mention of the infection. One of them said:

> ... But in the clinic here, now all of us – health workers, clients, peer educators, adherence monitors and even you who is a student [researcher] – have become one family. So, there is nothing to worry about using the clinic here to talk about problems or disputes that have something to do with this disease we are suffering from… But we cannot do the same in our homes because family members would reject us or would not respect us again if they get to know that we have this disease…

The suggestion by Nimo at the beginning of the chapter also emphasises the role of peer educators in settling disputes or helping their members to find solutions to their problems. The meeting Nimo talked about in the comment took place at the clinic. According to him, another peer educator, a client, a nurse and himself, who were present at the meeting, advised the client not to confront her church authorities about the unfair treatment meted out to her and her husband. They warned the client that such an action could let many people know of their positive status with even wider negative implications. Nimo said that they suggested to the couple to leave the church, which was the only way they could avoid further stigmatisation and discrimination. I talked to the client involved in this case and she confirmed that they had followed the advice of the peer educator and had left the church.

As 'uncles' and 'aunts', peer educators were concerned about the possible exposure of clients' status if they held meetings at places where other people could identify them as positive persons. Kwaa, a peer educator, explained that the clinic has become central to the activities of the various associations because it is the home for every client who wants to live longer with the disease. He said even association members who had stopped attending meetings could not stay away from the clinic forever because they would come to the clinic for the re-supply of their drugs. According to him, peer educators always used the clinic to see clients who have

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3   One can read more positive persons associations in the study of my colleague Kwansa (2011) who studied HIV/AIDS in the community.

stopped attending association meetings and find out their reasons for not attending. They often meet association members in the clinic and book appointments for home visits in the community with them or colleagues who stay in the same neighbourhood as them. "The truth is that the clinic has simply become the home for all of us clients in many respects, except that we do not sleep here," he stated.

Some of the peer educators were also engaged in their private business in the clinic alongside the peer education work as indicated in Chapter Six. In a kind of a partnership, a peer educator was selling pastries to match with the soft drinks a health worker was also selling in the clinic. The peer educator explained that she was unemployed and the hospital authorities have refused to support peer educators either in kind or cash. This has made life difficult for her and her three children. Through the sale of the pastries in the clinic, she gets some income to take care of herself and the children. She remarked:

> I think that the idea of selling in the clinic here as a peer educator is not popular with some of the health workers… but my brother [researcher] without this small business I am doing in the clinic, my children and I would not eat. So far as we are all working in the clinic, we have to make a living from here…

Finally, on one occasion, I observed that a peer educator was sharing rice and cooking oil with clients in the clinic. These items had been given to some of the associations by an international organization to support positive persons. I enquired why he was sharing the items in the clinic at the time some of his fellow patients were still accessing treatment. He said that in the past they gave out such items to clients in their communities. Family and community members started probing to know the source of the items and why only some selected people were been given those items. Later, it came to their notice that some community members had found out that people who usually received such items in the community are positive persons. They as a result moved the distribution of such relief items to clients to the clinic where only association members and other positive persons are always present. The clinic, he said was their second home and had helped them to give out those items to clients in privacy instead of doing that in their family homes.

In sum, as 'uncles' and aunts', peer educators use the clinic to carry out many activities to help clients conceal their status from relatives and community members.

Other actors
Other actors were non-positive persons who used the clinic for various activities. They could be considered as 'distant members' of the fictive kinship system. Most of these people were food vendors who freely moved in and out to sell to health workers, clients and their relatives and peer educators. It was common to see these food vendors in one of the clinics going round and verbally advertising the items they were selling such as pastries and fruits – apples, bananas, and oranges. They also entered the offices of health workers to sell their food items. Sometimes, when

health workers were busy attending to clients, they went outside the clinic to order for food and asked the vendors to bring the food to them in the clinic.

Newspapers vendors were selling in one of the clinics on both clinic and non-clinic days. Mostly health workers bought the newspapers. Some clients and relatives who accompanied them also bought newspapers.

Finally, some traders contacted health workers in one of the clinic to discuss business interests. A woman used to visit the clinic at the end of almost every month. She explained that she was a trader and some of the health workers were her customers who sometimes bought items from her on credit. They asked her to come for the money in the clinic at the end of the month after their salaries had been paid. Some pharmacists who often supplied multivitamins to health workers to sell to clients also came to the clinic to see their business partners.

Some clients expressed concerns about the easy access other actors had to the clinic. Serwaa, a client contended that she could not trust all the vendors who came to the clinic. Some, she said, were 'okro mouth' and likely to talk about the clients to other people. Marie, a health assistant, confirmed the concerns of clients and mentioned the case of a vendor who used to sell in the clinic and was asked not to enter the facility any longer. This was because some clients who lived in the same suburb as the vendor suspected that she gossiped about them in the community. According to Marie, the clients gave instances that suggested that the vendor was responsible for the disclosure of their status to some relatives and friends. Clients feared that other people would get to know their status through the vendors.

Discussion

The discussion looks at four issues. It starts with the analysis of why the family homes of clients are no longer experienced as homes or have lost their character as homes, followed by a discussion of what makes the clinic a home for clients. It also examines the fictive kinship in the clinic as an alternative to the therapy management group. Finally, the discussion looks at the threat other actors pose to clients in the clinic as a public space.

The way that clients and other actors used the clinic as a home suggests that anywhere can be made a home if one chooses to identify oneself with the place. In order for a place to be considered as a home, it must have certain basic characteristics to make it suitable for self-identification (McColgan 2005). The place must guarantee the individual privacy and safety to go about some aspects of one's life unnoticed except by a particular group of people or insiders. It should also be a place where one can experience love and affection from other members of the home or family members. Freedom is another feature whereby the individual can do

certain things that cannot be carried out in public. In addition, it should serve as a refuge where one can find solace and peace in difficult times.

Due to the persistent stigma associated with HIV infection, most of the clients in this study are unable to go about certain activities as positive persons in their family homes. The family homes do not allow them to discuss issues related to the disease because the clients have not disclosed their status to their spouses or relatives. Their homes do not guarantee them privacy to talk about their status. Some of them do not experience love and affection in their family homes since they are deemed to be suffering from an 'immoral disease' and sometimes face divorce or rejection as a result. They do not have freedom of choice in their homes to converse freely or do whatever they want for fear that they would mistakenly reveal their status to others. Clients' family homes are also no longer places of refuge where they can find peace and forget some of the difficulties and challenges associated with HIV infection. They are always wary of the possibility of exposing their status to others and face stigmatisation. In essence, they do not find comfort in their personal homes that a place called home is supposed to give to its occupants. This makes it imperative for clients to look for another place. Unlike their family homes, such a place should be safe for them to go about their activities, conceal their status and live 'normal lives' as positive persons.

Clients found the clinic a place where they can associate with and use it as a home outside their personal homes. The good practice of health workers towards clients had made the clinic patient-friendly. Besides, the public space of the clinic makes it convenient for clients to adopt it as a home and use it for various activities as positive persons. Thus the place is always accessible to members of the general public and this could prevent one from being easily identified as a positive person and be stigmatised. A client for instance can be seen as a visitor in the clinic and not as a positive person who has come there to access treatment. More importantly, although the place is a public health facility, it has most of the characteristics of a home mentioned above which makes it ideal for positive persons to use as such.

In the clinic, health workers, peer educators and their fellow clients relate to one and other as fictive family members. Clients used these people and the clinic to settle disputes bordering on their status. They also had meetings and other gatherings in the clinic to discuss issues of interest to them. Clients fraternized with each other in the clinic and conversed freely on a wide range of issues. Positive persons also experienced love and affection from health workers, peer educators and their peers. It served as refuge for them to temporary have some peace from the problems they go through in their family homes for being HIV-positive. In fact, unlike their family homes, the indications are that most of the clients experience some comfort in the clinic because they feel accepted by health workers ('parents'),

peer educators ('uncles' and 'aunties'), and their peers ('siblings'). They feel 'at home', thanks to the fact that the clinic is a public facility.

Clients' use of the clinic as a home has made it possible for them to form their 'therapy management group' (Janzen 1987) in the facility. As seen in Chapter Four, relatives and in some cases friends and neighbours often play a significant role in the care and treatment of a sick person. These individuals come together and take decisions regarding care and treatment on behalf of the patient. They support the patient emotionally and may contribute financially towards the care and treatment of the patient. The group's responsibility goes beyond popular and folk medicine and extends to the hospital setting. Some members of the group accompany the sick person to the hospital for example and assist in various ways. Members of the group thus know the type of sickness or disease the patient is suffering from in order to take appropriate decisions on treatment, either in the hospital or at home.

The peculiar nature of HIV/AIDS brings a new dimension to the notion of therapy management group that normally has relatives as members. In the setting where positive status carries grave social risks, hiding it from relatives, friends and neighbours is crucial. Especially, as noted earlier, due to their positive status and the attendant social risks, the personal home of most clients had ceased to be comfortable as a home. It means that clients cannot make their relatives, friends or neighbours in their family homes members of their therapy management group. Yet they need some people they can confide in as positive persons and help them take decisions on their life-long infection and its treatment. Clients therefore, used health workers, peer educators and some of their colleagues in the clinic as members of their therapy management group. Instead of their relatives, clients consulted people in the clinic for advice and counselling. The conscious action of health workers to show good behaviours towards clients for instance made them to adopt health workers as 'parents'. Nurses became 'mothers' who helped them to take decisions on treatment and marital problems. Peer educators became 'uncles' and 'aunts' who also helped and advised. Clients, finally, consulted their fellow patients as fictive siblings for advice on a wide range of issues. As a result, these contacts in the clinic make up the therapy management group.

It can be argued that clients took the initiative and decided to make health workers and others in the clinic members of their therapy management group. They used them to take important decisions on their treatment and other related issues as positive persons. This enabled clients to exclude their relatives from decisions on treatment and avoid the social risks they can pose as their therapy managers. Health workers on the other hand used their authority to control events in the clinic and agreed to be members of clients' therapy management group because they are aware that the fear of stigma has made it difficult for most of them to discuss problems related to their status with relatives. Consequently, health workers often readily

advised clients on matters concerning their infection which enhanced their use of services. It implies that clients tended not to use their relatives as members of their therapy management group, as is usual, because of their fear for being stigmatised and worse, ostracised. Rather, they choose other persons as their therapy managers; the new found relatives in the clinic. It also shows how health workers and clients acted together and took a decision to enhance the provision and use of services.

There are also risks in the clinic for clients due to the easy access of other actors. These people could use their access to the clinic to spy on clients while they access care and treatment in the clinic. If they see clients they already know, they can broadcast news about their status in the community. As noted earlier, some clients and health workers expressed concerns about the presence of food vendors in the clinic. In general it could be argued that the public nature of the clinic in some respects could lead to the disclosure of clients' status to other people. That is, since the clinic is a public facility it is accessible to everybody. Over time, many people have identified the clinic as the place in the hospital where patients suffering from HIV are treated and anyone seen there is suspected of the disease. People who visit the clinic could see clients who access services and possibly reveal their status to relatives or friends. The clinic as a home for clients to go about some activities as positive persons and hide their status is not completely safe. In other words, the clinic is not a home like the family homes, and clients are always at risk of being identified as HIV-positive persons by other actors. Conscious of these risks, some clients have chosen to access care and treatment in clinics far away from their communities as a strategy to avoid identification by other actors or visitors who may not know them and identify them as positive persons.

Conclusion

Using a public health facility for various activities like a home as clients were doing in the clinic is unusual in Ghana, where hospitals tend to be rather uncomfortable if not dangerous and hostile locations. People normally are interested in only getting treatment in the hospitals and going back home. It is when a patient's sickness is serious and needs close monitoring by health workers that he/she willingly visits a health facility. There have been instances in which patients refused to use health care services or even go on admission because they claimed some hospitals were not clean and services were of low quality. Some Ghanaians have little attachment to their hospitals. In contrast, it was observed in the ART clinics that clients had a strong attachment to the facilities where they received care and treatment because they protected them partly against the stigma that society attaches to HIV/AIDS. In view of the life-long nature of the treatment they access in the clinics, clients are likely to continue visiting the clinics for the rest of their lives. As a result, they

consider the clinics as their second home and identify themselves with the facilities. This is the most remarkable finding of the study.

8

Conclusions

This book is the result of an ethnographical research in two health care institutions – St. Patrick's Hospital at Maase-Offinso and Komfo Anokye Teaching Hospital in Kumasi, both in the Ashanti Region of Ghana. The research was carried out at the voluntary counselling and testing centres and antiretroviral therapy clinics of these hospitals. Data on counselling and testing was also collected in the VCT centre of Suntreso Government Hospital in Kumasi.

In this concluding chapter, I concentrate on five main issues: I present some key findings of the study. Next, I reflect on some methodological issues of the study followed by an analysis of the relationships between doctors, nurses and clients in the facilities. I also look at the significance of hospital ethnography while focusing on the differences between clinic and society. Finally, I explore how health workers can deal with the dilemma of perceived stigma in the hospital setting to increase use of services.

The study describes the provision and use of VCT and ART services. Data collected through participant observation, informal conversations and in-depth interviews revealed that with a few exceptions health workers providing these services generally related to and treated clients well. They mostly displayed good practice towards clients during clinical encounters.

The study found that there was a gradual increase in the number of people who accessed services in the centres and clinics. Records in the facilities indicated that the up-take of these services increased over the last few years, due mainly to two developments: provider-initiated diagnostic testing and the opt-out policy. Health workers, particularly medical doctors at the outpatients departments of the hospitals referred patients they suspected to be positive to the centres for counselling and testing when they reported to the hospitals for general care and treatment. The action

of the doctors was necessitated by the reluctance of some Ghanaians to undergo voluntary HIV counselling and testing to know their status. The majority of the clients referred for diagnostic testing went for the service and most of them tested positive. The difficulty however with the diagnostic testing was that clients were often not explicitly told about testing. It was at the centres that clients got to know that they had been referred for HIV testing. The opt-out policy makes HIV testing mandatory for pregnant women attending antenatal care in government health facilities. Most clients and pregnant women who tested positive through diagnostic testing and the opt-out policy respectively, and were referred to the clinics for treatment, accessed the services. The study also observed that the increase in up-take of services has not matched the increase in staffing levels in the facilities. Nevertheless, the skills of peer educators who had been trained to complement the work of care providers in one of the clinics for this study were under-utilised.

The findings of the study also show that the persistent stigma and its unfavourable repercussions on positive persons had a profoundly negative impact on the use of counselling, testing and treatment services. This had led to concerns about the locations of centres and clinics in the hospitals, and the need for clients to use some services with other patients in certain units of the hospitals. Clients were worried that in some locations their status as positive persons could be exposed to other patients and people who visited the facilities. It implies that certain structural or institutional factors in the hospitals such as locations of centres and clinics constrained clients' use of services, while others enabled them to smoothly access services and hide their status.

It was also found that some health workers could not keep knowledge of clients' status private and breached confidentiality. Many clients feared that HIV testing is not confidential and could lead to unwanted disclosure to spouses and relatives. To such people, silence and denial seemed the most appropriate reactions to fear of stigma. Others also thought that not knowing their HIV status is far preferable to being tested. With regard to positive persons, the majority of them defied the stigma associated with the use of services and chose to access VCT and ART. They exercised their ability to act on issues affecting their lives and employed various strategies to manage the potential stigma to safely use services. They were therefore able to prevent others from identifying them as positive persons and kept their status hidden.

Finally, the study found that the good practices of health workers towards clients made the clinics user-friendly. This led to a relationship between health workers and clients in which some care providers, particularly nurses, were highly commended by clients. Some clients adopted health workers as parents and siblings and consulted them on a wide range of issues for advice. They also adopted the clinic as their second home and used it to carry out certain activities such as meetings and

settling of disputes as positive persons. This resulted in what we may call fictive kinship relations in the clinic. Nurses were referred to as mothers, doctors as fathers, peer educators as aunties and uncles, clients as children and their fellow patients as siblings in the fictive family. Clients acted within the conducive environment in the clinic to form therapy management group with these fictive relatives in the clinic. They took important decisions relating to their status and treatment in consultation with the fictive relatives without the involvement of their close family members. In this regard, clients were able to conceal their status from their biological relatives who are supposed to be their therapy managers and avoided stigmatisation.

The findings of this study show the complexities involved in the care and treatment of HIV/AIDS. More than perhaps other sicknesses or diseases, the social context of HIV influences how its services are provided and used. Its care and treatment also involves different actors in biomedicine and non-health care professionals with varied interests and concerns.

Implications of the methodological approach

Social scientists are often not easily accepted to carry out research in hospitals because of the perception that their data collection approaches do not meet biomedical standards of scientific research. It was not surprising that health workers in the hospital were reluctant to accept me as an anthropologist. Initially, I was often confronted with the question "What is your professional background in health?" Whenever I explained to health workers that I was a social scientist who was interested in knowing more about how VCT and ART services are provided, I observed some reservations in the facial expression of care providers. The qualitative research approaches I used to collect data further strengthened their doubts about the study and its motives. Similar observations have been made in ethnographic studies in a hospital elsewhere. For instance, Mulemi (2010) reported that health care providers had reservations about his study in a Kenyan hospital cancer ward. He attributed this to the low awareness of the value of qualitative research in promoting patient care among health professionals. Albert *et al*. (2008) pointed out that biomedical scientists or health care professionals' doubts about qualitative research in the health care setting is due to the perception that its methods are devoid of any scientific foundation. This, according to the authors, is due to three opinions: its results cannot be reproduced, the researcher's subjectivity interferes at all stages of the research process, and there is no effective way to control for biases. Besides, the question whether quantitative research is as objective as its practitioners claim, or what objectivity or its so-called lack thereof means, has been a much discussed issue since Latour & Woolgar's (1979) classic study of laboratory work. Health professionals, however tend to overlook social and cultural

aspects of disease and care-seeking which do not always lend themselves to quantitative research.

The initial doubts of health workers gradually changed to cooperation with the researcher as they began to appreciate the contribution the study could make towards improvement of service provisioning and patient care. The use of qualitative research methods like informal conversations helped to bring health workers and clients together to share their views and opinions on how services are provided. The informal nature of such conversations enabled clients in particular to freely express their perceptions on the quality of services provided. Clients also used the conversations to express their pent-up emotions about certain practices of some health workers towards them. For instance, in a conversation which involved two clients, a health worker and myself, a client complained about the disclosure of her status to her grandmother by a nurse in the delivery ward. According to the client, the disclosure led to her rejection by the grandmother. The client had not been able to express her frustration in a clinical encounter for fear of being labelled as a bad or uncooperative client. The present study, however, has shown that clients felt comfortable discussing issues on service provision with health workers in informal conversations. This may encourage health workers to more often engage in conversations with clients outside clinical encounters and know more about their problems or challenges in care and treatment. Moreover, the personal views of clients in this study gave strong evidence about areas of client care and treatment that need improvement.

Doctors and nurses tend to be reluctant to allow non-medical observers to their work for the fear that as outsiders in the health care setting they may pass judgment on what they do in hospital (see Van der Geest & Sarkodie 1998:1374). Health professionals dislike being watched by outsiders such as ethnographers who do not always reveal their motive in the hospital research and will later put their observations on paper criticizing them. Medical professionals therefore tend to be suspicious about qualitative research.

This study has shown that ethnography in the hospital does not end up criticizing or antagonizing biomedicine *per se*. It has provided information about clients' individual level health care needs beyond figures that health workers often use as indicators to improve upon quality of services to satisfy clients. The study has established that health workers were mostly kind and supportive towards clients in their interactions, contrary to the often-held view in earlier studies that health workers tend not to treat them well. This finding recognises the efforts of health workers to provide quality care and treatment to the satisfaction of clients. It also serves as a boost to health workers to continue dealing with clients favourably and encourage more clients to use services.

Ethnography gives health workers the opportunity to learn about clients and find ways of cooperating with them and provide the services they need. The participation of both health workers and clients in conversations with the researcher helped to improve health worker-client communication. The study has shown that medicine is more than the application of scientific knowledge. Personal observation, reflection and judgment, which are akin to qualitative research, are also important for the translation of scientific results into the care and treatment of individual patients (Albert *et al*. 2008). It is for this reason that Long *et al*. (2008) point out that hospital-based ethnographic work offered a collaborative approach in which the ethnographer must take into account a broader range of experiences of hospital encounter. The present study shows that the ethnographer can be relevant to clients, health workers, families and other stakeholders in healthcare delivery rather than an advocate for only one interest group.

The dual role I played in the centres and clinics in some cases also facilitated the collection of relevant data despite its possible negative implications. As explained earlier, in Chapter Three, I was compelled in some situations in the facilities to deviate from the chosen role of academic researcher to be reasonably neutral of health workers and clients. The researcher role was meant to collect objective data as much as possible. However, I had to help health workers to carry out some of their duties whenever they were overwhelmed with heavy workload. For instance, I helped them by filling registration forms for new clients in the clinics. It was possible that this might have led some clients to think that I was a health worker and subsequently withheld some vital information from me. The opposite seems likely, however. On a couple of occasions, some clients approached me with questions about their treatment for explanation. Through my role as a quasi-health worker, I obtained useful data for the study. In the process of filling registration forms for new clients, I engaged in conversations with them about their experiences in the centres and clinics through which I obtained relevant information for the study. Besides, as a 'health worker', I got complaints from clients expressing their dissatisfaction with certain aspects of service provision. Such misgivings served as useful information for the study since they gave clues to clients concerns about how services are provided. In one instance, a client complained that I should talk to a colleague 'health worker' who was wasting too much time in conversation with a visitor while clients were waiting in a long queue to be attended to. I drew the health worker's attention to the client's concern and he readily stopped the conversation to attend to clients waiting in the queue. More importantly, the willingness to help health workers led to a good rapport between the researcher and care providers. Consequently, I received the needed support from most of them in the centres and clinics throughout the data collection period.

It must be emphasised that the role I played as health worker does not suggest that I abandoned the original role of an academic researcher in the facilities. In fact, I often reminded clients and others that I was 'only' a researcher. It is also worth noting that I did not carry out the core activities of health workers. I was involved in activities which any non-professional health worker could carry out. Unlike the academic researcher role, the limited health worker role was clearly not assumed in order to collect data, as some researchers have done. Those researchers played the liminal role (Van der Geest & Finkler 2004) by putting on the doctor's coat in the hospital like a staff and collected data (see Gerrits 2010, Zaman 2005). Through the limited dual role, I was able to oscillate between clients and health workers without serious problems to gather data in the centres and clinics while maintaining good rapport with both groups.

Hospital ethnography: Clinic versus society

In Ghana, several needs-assessment and evaluation studies have been carried out through quantitative research methods in a health care setting. Hospital ethnographies with a qualitative research approach like the present study are a recent phenomenon. I am aware of three of such studies in Ghana: Andersen (2004), Van der Geest & Sarkodie (1998) and Böhmig (2010). Andersen's study demonstrates how hospital organization and structure replicates the class structures and relations, as well as the bureaucratic organization of the larger society and shows how social inequality in Northern Ghana reproduces the differential treatment of patients. The study by Van der Geest & Sarkodie was a research experiment involving the admission of the second author as a pseudo-patient in a rural Ghanaian hospital. The experiment was meant to assess the feasibility of carrying out unobtrusive participant observation in a hospital setting. Lastly, Böhmig's study on nurses describes their working routine on a medical ward in the largest hospital in Ghana and revealed perceptions and expectations both from the involved nurses and the surrounding society. Although health care professionals and policy-makers have long recognized the importance of the social dimensions of health and health care, this recognition has not equally been matched by a strong commitment to the social sciences in health research, particularly, in the hospital. As Baziak and Denton point out some decades ago, the hospital was viewed as an 'isolated subculture' and Coser also termed the hospital as a 'tight little island' (Zaman 2005:15). Moreover, there was the commonly held notion that hospitals are nearly identical clones of a global biomedical model (Van der Geest & Finkler 2004). These perceptions about the hospital might have contributed to the lack of hospital ethnography in Ghana and other parts of the world.

Zaman, who carried out a hospital ethnography in Bangladesh, also contends that the few qualitative studies that were done in the hospital decades ago ignored the link between hospital events and forces operating in society at large. Those studies mostly concentrated on the biomedical issues within the hospital and did not show interest in the link between hospital life and the life in the broader society. This study, like those by Zaman (2005) and Mulemi (2010), shows how the social and cultural beliefs of people about disease or sickness and its treatment, as well as matters of class, gender, religion, etc enter and affect activities in the hospital setting. It is in this context that Van der Geest & Finkler (2004) in their introduction on hospital ethnography noted that hospitals both reflect and reinforce dominant social and cultural processes of a given society. I devote this section to a discussion of the social and cultural effects on the treatment of HIV in the hospital. The most remarkable difference between their (Zaman, Mulemi) and my research is that hospital experiences around HIV/AIDS contrasted starkly with what was happening in society. I therefore titled this section Clinic versus Society.

The study has shown the actions, views and concerns of various actors in the centres and the clinics. These are consequences of and reactions to societal attitudes towards HIV/AIDS and its treatment in the hospital. The study found that the good practices of health workers towards clients in the clinic had led to a special relationship between the two. Such practices made the clinic a safe haven for clients to feel at home in contrast to their family homes where they were mistreated by their relatives. This led to a fictive kinship in the clinic. Health workers were referred to as parents in this fictive family while peer educators became aunties and uncles. Their peers were also the siblings of the family in the clinic.

Clients used the clinic as their second home to carry out certain activities which they could not perform in their family homes due to the fear that their status could be exposed to spouses and relatives. They used the clinic to settle marital disputes and other problems related to their status. It is also a place they meet to discuss serious matters concerning their welfare. Unlike in the community, they used the clinic for various social activities as positive persons. There were church services on clinic days during which both Christians and Muslims enthusiastically sang gospel songs in praise of God with health workers as the leaders. They thanked God for taking good care of them and not dying despite their HIV-positive status. The involvement of Muslims in such Christian services in the clinic is a rare occurrence since in the community, it is uncommon for Muslims to join Christians in their services and vice versa. The clinic thus brings unity among positive persons who are Christians and Muslims and they see themselves as one people with a common destiny – treating their HIV infection. Besides, the clinic is a place for them to fraternise with their peers who share similar health problems and experiences with them.

The favourable attitudes and behaviours of health workers towards clients in clinical encounters made them to form their therapy management group (cf. Janzen 1978) in the clinic outside their extended families. As observed earlier in this study, a patient's close relatives are usually members of his/her therapy management group and they take decisions on treatment on behalf of the sick person. They also provide emotional and in some cases financial support (cf. Bossart 2003). Members of the therapy management group must know the type of sickness the patient is suffering from in order to make decisions on treatment. However, clients choose not to use their relatives as their therapy managers for fear that they would be stigmatised, and in some cases ostracised, if they disclosed their status to them. Since clients needed people to advice them on decisions related to their status and treatment, they decided to form their therapy management group in the clinic with health workers who had treated them well as fellow patients. In short, stigmatising attitudes and behaviours of relatives towards clients had prompted them not to use close relatives as their therapy managers. Clients consciously consulted health workers as members of their therapy management group and took important decisions on treatment without the involvement of their relatives. Health workers also used their problem-solving capabilities to advice clients on treatment and other issues without the knowledge of their family members. Thus the good practices of health workers and the conducive atmosphere in the clinic are a haven from the negative reception and lack of respect clients experience in society. While clients are despised, rejected and discriminated against in the community for contracting a deadly and shameful disease, they felt accepted and treated well by health workers in the clinic.

The ethnographic data presented in this study shows that unlike society, the clinic protects clients against stigma and its negative effects. This obviously makes the clinic the starting point for the fight against HIV/AIDS-related stigma. Clients were welcomed and respected in the clinic by health workers. They felt comfortable to discuss any issues with health workers that they might not discuss with their spouses or relatives. The clinic gave them refuge from the negative attitudes and behaviours they feared of family members and friends. Likewise, health workers in the clinic showed compassion towards them and sometimes supported them financially. Similarly, Hodgson (2006) also observed in a study in the United Kingdom that a unit which provided HIV care and treatment was perceived by respondents as especially adept at protecting people living with HIV/AIDS from stigma, as a place where carers are open and not upset by unusual or novel situations (2006:267). The clinic has become a sanctuary for clients where they could find privacy and safety that were lacking in their family homes. Members of society can learn from the positive role the clinic is playing in the lives of people living with HIV/AIDS and also show compassion and love towards them. These can help to reduce the sigma associated with the infection.

In short, the good reception care providers gave to clients and the ease with which they interacted with them during provision of services portrays the clinic as the possible answer to the persistent stigma associated with the infection in society. Health workers make a conscious effort to draw clients closer to them and help them to solve their problems whenever necessary. This is contrary to what pertains in the society in general where people tend to treat positive persons with disdain and regard them as people who do not have anything good to offer relatives and are destined to die prematurely. In cases where clients could not converse with relatives in their family homes, they visited the clinic to meet their colleagues and conversed with them to reduce stress. With regard to peer educators, the clinic is their work place where they work to earn some income for a living. This is against the backdrop of the reluctance of some people to work with positive persons or employ them. It shows that AIDS is not as contagious as some members of society believe, a view which might have influenced them to stigmatise positive persons (cf. Crentsil 2007, Mbonu *et al.* 2009).

Finally, the fact that clients continue to access services in the clinic shows the trust they have in the facility and the staff who work there. While clients in most cases complained that members of society did not treat them well, they spoke positively about care providers for showing good practices towards them. According to some clients, they pray often that God should take good care of the health workers so they would be always available to provide them with treatment. In fact, the clinic has restored clients' hope of living longer with the infection and they believe that a permanent cure for the disease will be found in the clinic one day. Conversely, society's negative treatment of positive persons had often made them feel like outcasts, which worsened their condition and quickened their death. The clinic thus empowers clients to take control over events which affect their HIV-positive status and its treatment, whereas society through stigmatisation takes away clients' ability to make decisions on their infection.

The study has shown that interactions between health workers and clients in the clinic and their outcomes are not only a mirror of society's beliefs and perceptions about HIV/AIDS. The persistent stigma associated with it in society is in stark contrast to the stigma-free reception that clients experience in the clinic. What goes on in the ART clinic in terms of the good treatment is contrary to society's negative attitudes and behaviours towards HIV-positive persons.

This does not mean that there were no matters that were less favourable to clients in the clinic. Health workers were found to have mistreated clients during interactions in the clinic, as was observed in Chapter Five. This notwithstanding, the clinic was relatively safe for clients because it protects them against stigma in contrast to what pertains in society.

Relations between doctors, nurses and clients

The study observed that medical doctors and nurses had different relations with clients. This had an impact on the way and manner they interacted with clients and related to them during encounters in the centres and clinics. It also influenced the perceptions of clients of different categories of health workers and how they interacted with them outside clinical encounters. During participation in counselling and testing sessions, consultations and other activities in the facilities, it was observed that medical doctors had brief interactions with clients. Discussions in the encounters were limited to clients' medical concerns or problems related to treatment. Nurses, on the other hand, had more interactions with clients and showed concerns for their welfare beyond care and treatment. They were also interested in the social well-being of clients and were attuned to their individual needs. Nurses had a cordial relationship with clients, especially in the clinic. Clients as a result adopted nurses as 'parents' or 'siblings' in the clinic and took decisions on treatment and other related matters with them. It also encouraged clients to continue accessing services. In this regard, the good practices of nurses towards clients facilitated their use of services at the facilities.

Similarly, Campbell-Heider & Pollock (1987: 422) describe the striking contrast between the physician's contacts with hospitalised patients, which are characterised by brief, highly structured, almost ceremonial interactions, and those of the nurse, who may spend hours in direct, spontaneous contact with patients, from casual conversations to the most intimate bodily functions. The authors, who studied barriers to physician-nurse collegiality in the United States of America, attribute the nurse's closeness to patients and physician's remoteness to features of ideologies of social relations within hospitals, in which status is proportional to separation from patients. That is, the physicians' top position in hierarchical relationship in the hospital explains the limited social interactions they have with clients who are at the bottom of this relationship. Robertson (1996) for his part contends that the parallel difference between doctors and nurses in their approaches to patient care is due to their different professional goals. The study which was carried out in a British psychiatry ward notes that nurses' prime professional goals are daily care and helping patients as normally and independently as possible, goals which are pursued through ongoing relationships. The most important goals of doctors, on the other hand, are systematic problem solving that is technical in nature, improving organic function and research. Unlike nurses, doctors have brief contacts with clients, negatively affecting communication between them and clients. This, Robinson (2001) notes, deprives the physician of adequate time to identify and fully discuss patients' additional concerns. The same can be said in Ghana about doctors and nurses.

Clients in this study were of the view that medical doctors distanced themselves from them because "they are not friendly" (*Wɔnnte wɔn anim*). Clients often found it difficult to ask doctors questions for clarification on issues they did not understand during consultations. On many occasions clients refused to go back to doctors and asked questions related to treatment after they left the consulting room. Clients sometimes worried that the concerns they expressed in such brief clinical encounters might appear irrelevant to the technical interventions of doctor and other care providers. They feared they would be labelled as non-compliant, uncooperative, troublesome or irritating. Clients therefore hesitated to discuss their personal problems with medical doctors during the brief consultations they had with them. It also led to the perception among clients that medical doctors lacked sensitivity. Throughout this study, clients did not talk much about doctors in their narratives as they did about nurses.

The generally good relationship between nurses and clients in the present study was also characterised by challenges that led to the perception that in some cases they did not treat clients professionally. Their closeness to clients for instance led to frustrations with some of the clients who were non-compliant, uncooperative or troublesome. They reacted harshly or angrily towards such clients by using abusive language on them or condemned them. Others were punished with denial of services. These observations fit into Robertson's (1996) assertion about nurses in Britain that engaging in close relationships with patients, however, was not always a matter simply of compassion and affection. It sometimes also involved tension and negative or mixed feelings about difficult patients (1996:295). In this study, since nurses had daily contacts with clients, they were identified as the group of health workers who often showed compassion towards clients and supported them in various ways whenever they were in difficulties. On the other hand, nurses were mentioned as the category of care providers who showed the most negative practices towards clients during interactions in the facilities. In some cases, the unfavourable treatment they gave to some clients discouraged them from accessing care and treatment. This way, their negative behaviours were a constraining factor on the use of services by clients.

Clients however looked for other avenues to talk about their non-medical concerns. Some of them found it appropriate to discuss such concerns with the researcher who they considered as an outsider. I was seen as a neutral and safe audience for many clients to discuss their non-medical concerns or personal issues with. I was an outsider in the field because I am neither a health care provider nor an employee of the hospital, which made clients to assume that I would empathise with them. This suggests that clients were careful in choosing the audience to make their complaints in the hospital setting. In a few cases, some personal complaints of clients were discussed with health workers for attention before I left the field. A

client, for instance, complained that a nurse had refused to transfer him to another clinic so he could reduce the high transportation cost to and from the facility for treatment. The nurse was reluctant to do so on the assumption that the client might not continue with the treatment at a different facility. I discussed this with the nurse and she agreed to transfer the client to the other clinic where he continued to access treatment.

This study shows that the way health workers related to clients in some cases did not adequately address their non-medical and personal concerns during clinical encounters. Clients may suffer from the same disease but their experiences of it may differ and they have to be assessed in their own right. Hospital ethnography studies give health authorities and care providers a unique opportunity to understand the clients' point of view. As the ultimate beneficiaries of health care services, clients' appraisal of quality of services deserves consideration, too. According to Stein (1985), data collected in the hospital through ethnography can help health practitioners become better observers in medical encounters. These can be used to formulate appropriate interventions to improve upon client-centred care and the quality of services provided.

Another relationship is that between health workers and peer educators who are also clients, which was not always good. The peer educators are selected clients who have successfully undergone the treatment and have been trained as peer educators to work in the clinic as volunteers. Their training and work in the clinic was necessitated by the increase in the number of clients accessing services in the face of limited health staff. The main role of the peer educators in the clinic is to complement the work of health workers, particularly in the area of adherence counselling. However, these peer educators were not given due recognition by the hospital authorities and some health workers. The peer educators were not rewarded financially or in kind for their contribution to the provision of services. They were also sidelined from giving or attending adherence counselling sessions and confined to certain peripheral duties in the clinic which they were not trained to do. This led to tensions between health workers and the peer educators in the clinic.

According to health workers, peer educators were excluded from formal counselling sessions because some of them were not following the procedures laid down for conducting adherence counselling. They allowed some clients to go through the three weeks of adherence counselling without adequate knowledge on treatment and the commitment to adhere to antiretroviral drugs. Peer educators on the other hand explained that the decision of the health workers was motivated by the fear that they were becoming too popular with clients who often consulted them first with their problems for advice instead of health workers. It was, however, observed that the tension between the two was mainly due to lack of clearly defined roles for the peer educators (see Shiner 1999). The training and work of the peer educators in the

clinic was at the instance of a non-governmental organization. Their skills as experience experts in adherence counselling were under-utilized in the clinic. Nevertheless, they continued to work in the clinic in spite of the lack of recognition and employed various strategies to change their misfortune of HIV infection into a relatively lucrative venture.

A close analysis of the relationships between health workers and clients in the facilities point to one important thing: nurses were dominant and powerful. The role of nurses in the centres and clinics was crucial for the provision and use of services. Doctors might be taking all the important decisions on care and treatment, but their limited interactions with clients in the facilities created a distance. It also reduced their control over clients who only saw them briefly during consultations. The nurses had daily contacts with clients. They implement the decisions of doctors on care and treatment, sometimes with some level of discretionary powers. In one of the clinics, nurses decided when a patient who had tested positive would be registered as a new client and start the processes leading to treatment. Besides, they often decided whether a client had understood adherence to treatment after three weeks of adherence counselling to be initiated onto antiretroviral drugs. On clinic days, they sometimes determined which client could see the doctor first, depending on who they considered to be in need of immediate or preferential treatment. They are also the intermediaries between doctors and clients. Clients feel reluctant to approach the doctors with questions about their treatment and other personal issues, so they pass such questions through the nurses to the doctors for clarification. Unlike the doctors, the nurses in the clinics know clients by name and not merely as clients of the facility. Nurses are therefore the most powerful category of health workers in the clinics, although hierarchically doctors are on top and wield power in decision-making process in the hospital. The strong position of nurses in the clinics derives mainly from their close relationship with clients and the intermediary role they play between doctors and clients.

Dilemma: how to deal with stigma?

The fear of stigma is the most important factor that discourages people from using voluntary counselling and testing and antiretroviral therapy services. The discussions showed that many clients and other people felt their status as positive persons could be exposed through the use of services in the facilities. They also had concerns that some health workers could inform other people about their status. These would then lead to stigmatisation by relatives and friends. The fear of disclosure leading to stigma could thus constrain the success of the scale-up exercise in Ghana. The scale-up is aimed at increasing the availability of VCT and ART services throughout the country for easy access as part of the national campaign to

reduce the spread of HIV/ AIDS. The exercise is largely donor funded and the expectation is that its success would sustain donor support and funding. This makes it imperative for policy makers and health workers to address the negative influence stigma has on the use of services and put in place appropriate intervention programmes to reduce or prevent it. Overcoming stigma would likely encourage many people to go for counselling and testing and treatment.

Health workers find themselves in a dilemma as to how they would effectively tackle the challenges stigma poses to the use of services. The stigma associated with HIV/AIDS and its negative repercussions on the individual have proved persistent in Ghana. Historically, stigma has been a difficult social problem in health care delivery everywhere. The pervasiveness of stigma in society accounts for the difficulty in finding solutions to it. The fight against stigma associated with diseases like leprosy and mental illness in the past had not been very successful in eliminating the problem. People suffering from these diseases are still being stigmatised by relatives and friends. In Ghana, for instance, Mwinituo & Mill observe that certain illnesses and behaviours have traditionally been regarded as disgraceful and are therefore stigmatised. Mental illness, tuberculosis, leprosy and sexually transmitted diseases are among those illnesses (2006:370). It follows that relatives have in many cases refused to accept such patients back into their families and they are often left in the health facilities after they have been successfully cured or treated of the disease. The belief is that even if the relative is cured or treated of the illness, the disgrace associated with it is still there for the person and the family as a whole. As a result, cured patients may remain outcasts in their own family.

Overcoming the stigma of HIV/AIDS could be a similarly daunting task. In view of this, the research team organized a one-day stakeholders' workshop in Kumasi to brainstorm on how to tackle the issue of stigma and its negative influence on the use of services. It brought together partners in the research including health workers, policy makers, clients, peer educators, scholars and non-governmental organizations. Deliberations at the workshop led to some suggestions as how stigma could be overcome, especially in the health care setting, to ensure increase use of services. Some of these have been included in the questions and answers below as guides for consideration by health workers, policy makers and other stakeholders in the campaign to combat the spread of the disease through provision and use of services.

How can we provide counselling, testing and treatment to clients with good care and treatment while strictly ensuring their privacy? Contrary to the present system of organizing special training for selected health workers, all health workers must be given additional training on HIV/AIDS and the provision of HIV counselling, testing and treatment services. During this study, it was observed that health workers in other units of the hospital who shunned clients did so due to their limited knowledge about the infection and its treatment. Special training on the disease and

the treatment can equip them with skills on how to relate and communicate with clients particularly, positive persons during interactions. For instance, a study by USAID in Indian hospitals reported that an HIV/AIDS training which was organised for health workers helped to sensitise them to the needs and rights of positive persons. The training also led to a change in their negative attitudes towards patients, and cleared up misconceptions and fears in order to ensure the provision of humane and equitable care and treatment. The training covered areas such as HIV/AIDS transmission and procedures for infection control and concepts of confidentiality, patient rights, voluntary counselling and testing, as well as social care and support (Horizons 2006:30). Similar training could be organized for health workers in Ghana to sensitise them on clients' concerns about care and treatment. This would include, for example, ethical issues such as privacy and confidentiality.

Is accepting stigma and privacy for the time being and, focusing on care likely to lead to a reduction of stigma in the future? Most of the health workers who participated in the workshop were of the view that they would have to provide care and treatment while fighting stigma at the same time. According to them, provision and use of services and stigma go together and these must be tackled simultaneously. On the other hand, health workers could consider the option of focusing on the provision of quality care and treatment services and accept stigma as a fact that cannot be overcome in the short-term. According to a senior nurse in one of the facilities for this study, a similar approach was adopted to fight stigma associated with tuberculosis in the nineteen seventies. Following the failure of various intervention programmes to fight the stigma related to tuberculosis, health care authorities and professionals decided to focus their attention on providing care and treatment. Thus, issues about stigma were given limited attention and over time the stigma gradually went down by itself. It must be mentioned that besides this strategy by health workers the later discovery of a cure for TB also contributed to the reduction of the stigma associated with it. In the present case of HIV/AIDS, health workers can adopt this approach, and the advent of antiretroviral therapy can also contribute to the reduction of HIV-related stigma as it happened with TB. Health workers can focus mainly on the provision of quality care and treatment and leave matters on stigma to take their natural course and go down by itself. Health workers and peer educators thought that the prominence being given to stigma in the HIV/AIDS prevention campaigns in the media and through outreach programmes might have contributed to its persistence. During outreach programmes in the communities, health workers educate members of the general public on the need to show compassion towards positive persons and support them to live longer with the disease. The print and electronic media also send out messages to encourage society to accord people living with the infection the compassion and support they need. Some health workers and peer educators think these campaigns, aimed at reducing

stigma, had made it a topical issue and thereby fuelled the persistent stigma associated with the infection. Care providers should rather concentrate more on the provision of quality care to the satisfaction of clients.

What should be done to reassure clients that their status as positive persons will only be known to people with their consent? Health workers must do what they promise during counselling. They always assure clients that strict confidentiality will be maintained about their status and any other information obtained from them. Their status will be disclosed to others only with their consent. If health workers truly keep this promise, clients and other people will be encouraged to use counselling, testing and treatment services. However, some health workers breach confidentiality and purposely or accidentally disclose clients' status to others without their consent as was seen earlier in this study. They pointed out that there are cases in which disclosure without the consent of clients is better. It helps to prevent the infection of other people who may not be aware of the status of a client. Such behaviour by health workers can discourage clients and other people from using services.

What messages should we send out to people who want to undergo HIV counselling and testing, yet fear that others such as spouses and relatives could find out about their results? During outreach programmes in the community and in radio talk shows, health workers must clearly explain to their audience and listeners respectively that the infection is no more deadly as it used to be in the early stages of the epidemic. Through antiretroviral therapy, the infection is now a chronic one and it is treatable. Although I did not conduct a survey in the community to know the general public's perception of HIV/AIDS and its treatment, interactions and informal conversations with some community members showed that many people are not aware that there is treatment for HIV/AIDS. They still believe that the moment one gets the disease, one's 'death warrant' has been signed and one is destined to die in a short time. There is urgent need for intensive education about antiretroviral therapy treatment in the communities to correct the perception that HIV/AIDS is deadly (*yareɛ koankɔ, owuo yareɛ*) and has no treatment. Health workers must educate the public on the professional practices of their work and assure people that they would be given attention when they present in the hospital to access services as seen in this study.

Besides, policy makers and health workers need to take a second look at some of the messages which are sent into the public domain as information, communication and education materials on the condition and its treatment. These materials include brochures, leaflets, posters and billboards. Some of these have frightening messages on the disease. For instance, some of the posters and billboards read as follows: "AIDS is a Killer, AIDS is a deadly disease so avoid it, AIDS can kill you and AIDS kills." Others have pictures depicting HIV positive persons as thin and skinny

people while some show images likening the disease to death. Most of the billboards that have been erected along the Kumasi-Techiman-Tamale trunk road for instance made no reference to the availability of antiretroviral therapy as a treatment for HIV. These messages portray the disease differently and sometimes contradict messages from health workers which indicate that it is now a chronic one due to ART treatment. Though some of the billboards and posters belong to community based organizations and non-governmental organizations, policy makers and health workers should correct the wrong or biased messages they send out to the public and provide correct information about the disease.

How should we handle the delicate issue of convincing positive persons that they should at least inform their partners about their status? Health workers must spend time to educate people on the medical and psychological benefits of willingly disclosing one's positive status to a spouse or relevant others like a trusted relative or friend. Most people do not know the importance of disclosing their status to others and prefer to keep it private. As well as pre-and post-test counselling, health workers undertake couple counselling or encourage shared confidentiality, as we saw in Chapter Four. However, they do not provide adequate information on this type of counselling to clients and the public during pre- and post-test counselling sessions and in outreach programmes respectively. Couple counselling or shared confidentiality can be seen as the likely solution to the inability of most clients to disclose their status to spouses or relevant others. As explained in Chapter Four, some clients who benefited from couple counselling pointed out that if not through this type of counselling, they could not have disclosed their status to their spouses. This was due to the fear that their partners would divorce them. Others also recounted how health workers helped them in the form of an arranged meeting in the clinic to disclose their status to spouses without negative repercussions. Health workers must clearly explain to clients and the public the benefits of this type of counselling and encourage clients, particularly spouses, to opt for it. Through this type of counselling, health workers can disclose clients' status to others with their consent in an organized way. This would prevent the negative consequences that sometimes characterise disclosures to spouses or relatives by health workers without the consent of clients. Besides, health workers can use couple counselling or shared confidentiality to encourage spouses or relevant others who have not undergone the test to do so. They can then be encouraged to accept treatment together, if both tested positive. In short, nurses can make use of their authority to help clients manage the problems associated with disclosers.

How can counselling and testing centres and treatment clinics be located in the hospitals without compromising the privacy of clients? There seem to be two options. The hospital authorities could decide to locate the centres and clinics in parts of the hospital that are isolated or tucked away from main thoroughfares. This

can help clients to use strategies such as sneaking into the facilities and accessing services unnoticed by other patients and visitors to the hospital. On the other hand, the centres and clinics can be sited in other units of the hospitals. Clients can then join other patients as if they are also accessing general health services and sneak into the centres or clinics for care and treatment. However, both suggestions still have negative implications for the privacy of clients. Other patients and visitors can easily identify isolated centres or clinics and anyone seen there could be suspected of the infection. Centres or clinics sited in other units can lead to the disclosure of clients' status to other patients while in the same queue with them to access services. Most clients preferred the first option because they thought it is convenient for them to use services in privacy and avoid identification as positive persons. Locating centres and clinics in isolated or obscure places in the hospital can be a serious consideration for new facilities that are currently being built under the on-going scale up exercise to provide counselling, testing and treatment services.

How can peer educators be integrated into service provision to complement the work of health workers in the clinics and also contribute to the reduction of perceived stigma in the hospital setting? The formal inclusion of peer educators in service provision would enhance the credibility of the centres and clinics. This would encourage the peer educators and clients to see themselves as stakeholders in the smooth running of the facilities. Besides, it would let clients feel that the peer educators are representing their interests in the facility. The life-long nature of the antiretroviral treatment makes clients stakeholders in the clinic and they must be recognised as such by health authorities and care providers.[1] Such recognition can help health workers, peer educators and clients relate to each other and contribute to the success of the scaling up exercise. Moreover, the complementary role of peer educators would help reduce the heavy workload of the limited number of health workers providing services, especially in the clinic.

HIV/AIDS has come to stay in Ghanaian society and in the health care system. Although the campaign to reduce its spread through behavioural change and provision and use of health care services has achieved some positive results, there is more to be done. This study shows that the provision of high quality HIV counselling, testing and treatment services can lead to an increase in up-take of treatment. Treating clients well during interactions in the centres and clinics is crucial for the increasing use of these services by both clients and other people. It can be the first step to reducing the perceived stigma associated with the use of services in the hospital setting that has discouraged many people from accessing VCT and ART. In this regard, many people will feel encouraged to undergo counselling and testing, and if they test positive, would access treatment services. Besides, clients already on treatment will continue to use services and stay on treatment in order to live healthy

[1] Efforts are on going all over the world by scientists to find a cure for HIV/AIDS.

lives with the disease. This can lead to the success of the future scale-up of VCT and ART and contribute to the reduction of the spread of HIV/AIDS in Ghana.

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Appendix A: Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARVs	Antiretroviral Drugs
CD4	White Blood Cells
CHAG	Christian Health Association of Ghana
CT	Counselling and Testing
DFID	Department for International Development
DOH	Department of Health
ELISA	Enzyme-Linked Immunosorbent Assay
ESTHER	Ensemble pour une Solidarité thérapeutique hospitalière en Réseau (Network for Therapeutic Solidarity in Hospital)
FHI	Family Health International
GAC	Ghana AIDS Commission
GAP	Global Access Project
GHS	Ghana Health Service
GSS	Ghana Statistical Service
HB	Haemoglobin
HIV	Human Immunodeficiency Virus
IAE	Institute of Adult Education
MSF	Médecines Sans Frontières
MOH	Ministry of Health
NACP	National AIDS/STI Control Programme
NGO	Non-Governmental Organization
NHIS	National Health Insurance Scheme
OI	Opportunistic Infections
OMT	Oral Mucosal Transudate
OPD	Out Patients Department
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother-To-Child Transmission
PNC	Postnatal Care
SRN	State Registered Nurse
START	Support Treatment for Antiretroviral Therapy
TB	Tuberculosis

TRIPS	Trade-Related Aspects of Intellectual Property Rights
UG	University of Ghana
UN	United Nations
UNAIDS	United Nations Agency for HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
WTO	World Trade Organization

Appendix B: List of health workers (pseudonyms)

Name	Rank
Suzane	Principal Nursing Officer
Vera	Principal Nursing Officer
Caroline	Matron
Rebecca	Nursing Officer
Roseline	Enrolled Nurse Superintendent
Marie	Health Assistant
Martinson	Disease Control Officer
Thelma	SRN
Prince	Counsellor
Bernard	Counsellor
Denis	Laboratory Technician
Benedicta	Senior Community Health Nurse
Mike	SRN/Counsellor

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