



GÖTEBORGS UNIVERSITET

***Department of Social Work***

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*International Master of Science in Social Work*

## **FROM STIGMATIZATION TO INDEPENDENCE**

**EMPOWERING PEOPLE LIVING WITH HIV/AIDS IN UGANDA**

International Master of Science in Social Work

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## **ABSTRACT**

People living with HIV/AIDS suffer not only from their medical condition, but also from stigmatizing attitudes in society. Fear of stigma is a main barrier for testing and disclosure in Uganda. The effects of hiding ones status are that infected people are not reached by information and counseling that is essential not only for their psychological well being, but also to prevent further spread of HIV. Neither do they access treatment, crucial for their survival which causes both personal and societal strain such as orphaned children and increased poverty. Uganda Red Cross Society have succeeded in empowering people living with HIV/AIDS, leading to decreased self-stigma and increased independence. However, there are vast gender differences where men are less reached by the support than women. This is a qualitative case study. One geographical area is selected namely Kampala East, the slums of Naguru and Bukoto. The study explores the effects of Uganda Red Cross Society's work on empowering people living with HIV/AIDS, how it is perceived by their clients and its actual effects. The methods have been observations of activities arranged by the Red Cross, in-depth life world interviews with their clients and semi-structured, fact-oriented interviews with professionals working for Uganda Red Cross Society. The interviews have been analyzed via meaning condensation. Theories of stigma and empowerment have been utilized.

**Key words:** HIV/AIDS, stigma, discrimination and empowerment.

## AN OBSERVATION

The street looked familiar and the scene of luxury is an odd paradox to the dust underneath my feet. The sign said “Kabira Country Club” and I wondered what Franco, one of the Red Cross volunteers, thinks of the oddity of a country club being across the street from the Bukoto slums of Kampala. It was an odd paradox for me considering I was at Kabira two days ago playing tennis and then relaxing at the pool with a passion fruit juice in hand. I was going to attend a meeting with Red Cross clients and Franco was kind to meet me at the public taxi stop next to Kabira.

We entered a small gate, hardly visible if you didn’t know it, between some minor shops, hair saloons and cheap restaurants. This was another world, pretty distant from the wealthy areas surrounding the fancy country club on the other side. We walked on muddy roads that actually didn’t deserve to be called roads, more like rugged paths. As my foot almost dived into a dirty pool of water beneath my feet, I turned around to remind Franco to watch his every step. Not sure if I was reminding him or myself since there was also garbage spread all over the ground.

The houses were run down, even seemed tilted from lack of structure and others were literally falling apart. None of them had doors or windows, just some curtains as a thin layer of protection.

“Hey mzungu! How are you!?” some curious children shouted. They were excited at the foreign mzungu<sup>1</sup> walking around in their community. I had become quite a celebrity in a matter of moments as the children poured out onto the road, waving excitedly. I wondered if I was there to interview HIV/AIDS<sup>2</sup> clients or running for office. The children were all dirty, few of them had shoes or sandals and most of them had torn clothes.

In the midst of my celebrity fame, as we walked Franco explained that during the rainy season they can’t reach all the clients for home-based care or food provision because the roads become too wet. Many of the houses are often flooded up to knee-height level and there’s no possibility of people attending the Post Test Club meetings<sup>3</sup>.

We reached the meeting point (essentially a shack that is used as a church) and were met by a group of women with welcoming smiles and greetings. They were seated in clusters outside the church and as soon as I approached, they stood up and proudly introduced themselves in the typical quiet Uganda voice, ‘You are most welcome, I’m Sarah’. Everyone seemed attentive to all newcomers and to make sure that all felt welcome to the meeting.

More and more people kept coming. In the midst of all of the ‘hellos’ and ‘welcomes’ when I turned around to sit down, the place was full and about 35 women and one man (except for

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<sup>1</sup> Mzungu means white person in Swahili, a language widely used in most parts of Eastern Africa.

<sup>2</sup> HIV is an abbreviation for Human Immunodeficiency Virus, meaning virus that weakens the immune system, ultimately leading to AIDS, Acquired Immune Deficiency Syndrome (WHO 2008). The virus is transmitted in blood, semen, and other body fluids. It is mainly transmitted by unprotected sexual activity (Deacon 2006).

<sup>3</sup> Clubs for people who have tested for HIV, organized by Uganda Red Cross Society. They meet weekly for information, peer support and community sensitization about HIV/AIDS.

Franco and the project officer from Red Cross) sat staring at me. Could it be that so many women have HIV/AIDS and so few men? Or is it that so few men admit they have HIV/AIDS? No idea. The woman sitting next to me was kind to elaborate that 'men don't have time for meetings.'

It was the first meeting of the year and they had elections for important functions in the club for the coming year. They selected a chairman (or chairwoman) by voting democratically and other functions were chosen more spontaneously by suggestions from club members. They chose a secretary who was fluent in English and Luganda<sup>4</sup>, treasurer, spiritual leader, a crafts designate and finally one to lead the songs and drama program. As the nominations were called out, spontaneous applause, plenty of laughs and lots of joy just took over the room. Even the shy ones beamed.

'How many of you use boiled water for drinking – do you remember last rainy season? We cannot have another cholera outbreak this season' the project officer from the Red Cross began. It was now the time for Red Cross staff and volunteers to brief the group about hygiene and general health as well as to update each other on upcoming program events.

With formal procedures aside, the meeting really began. Club members spontaneously shared experiences about their sickness and medical recommendations, they asked for advice and supported each other. Members were attentive to each other. One woman looked weak, a fact that her fellow club members immediately acknowledged and asked how she felt and if she needed anything. The kind woman next to me told me that if one of the club members are too sick to work, they sometimes give her some two thousand shillings<sup>5</sup> to buy sugar, flour and passion fruits. Money for purposes like this are collected during the meetings when every member pay 200 shillings<sup>6</sup>. The whole meeting was embodied by love, care and support. There were lots of hugs, jokes, laughs and tears.

The meeting quickly shifted to making plans for when to create the crafts they would sell in market places (where goods of most kinds are sold in Uganda), and when to practice songs and drama to sensitize the rest of the community. The meeting ended with a prayer, led by the newly elected spiritual leader who was a little shy. Finally the newly elected chairman was encouraged to say a few words. She hoped for a good year with fruitful meetings, with good presence from all the members and that they would maintain and enhance their strength, health and good spirits. She also wished for the club to gain strength enough to be an independent club in the future, without being dependent of support from the Red Cross.

Applause rang out and people stood up quickly, beaming with many smiles and laughter. This was certainly a social group. It's a stark contrast to the deadly disease they are coping with alongside severe poverty, which most members are facing. It is said that life's triumphs are only measured in the eyes of those beholding it and here today I only witnessed great courage, joy and heroic living. I asked myself: was this empowerment in practice that I experienced today?

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<sup>4</sup> Luganda is one of the main languages in Uganda (next to English and Swahili). It is mainly spoken around Kampala and in Central and Southern Uganda.

<sup>5</sup> 2000 UgSh is equivalent to SEK 6

<sup>6</sup> 200 UgSh is equivalent to SEK 0,6

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# **CHAPTER ONE**

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## **INTRODUCTION**

The introduction chapter will firstly provide some general information about Uganda, the country where the study was conducted. Secondly, some facts about the country's HIV prevalence. Thirdly, Uganda Red Cross Society will be presented and their work on HIV/AIDS will be briefly described. Thereafter two sections will follow discussing choice and significance for the study and aims and research questions respectively. Finally, the reader will be briefed about the structure of the report.

### **An introduction to the Republic of Uganda**

Uganda's total population consists of almost 30 million people and the country is densely populated. The major part of the population lives in the countryside and along the fertile coast of Lake Victoria. Uganda's population consists of about 40 ethnic groups. The official language is English but that is only spoken by 10-20 % of the population, mainly the urban. Other major languages are Luganda and Swahili. Religion plays an important role and more than 75 percent of the Ugandans are Christian, mainly Catholics. 10 percent are Muslims and about 10 percent are adherent to traditional African religions (Landguiden 2007).

Uganda is one of the poorest countries in the world. Poverty has decreased during the last ten years, but there are still vast needs for developmental work and support with regards to the poverty control. Approximately 85 percent of the population is living under the poverty line<sup>7</sup> (Sida<sup>8</sup> 2008, UNICEF<sup>9</sup> 2008). Even though the country is strongly dependent on developmental aid, Uganda is often considered as one of Africa's most consistently good performers. The country is widely considered as "an African success" concerning advances in macroeconomic reforms, political stability and poverty eradication. This is to be seen in the context of years of civil war, economic decline and worsening poverty (Encyclopædia Britannica Online, Academic edition 2007, World Bank 2008).

President Yoweri Museveni rules Uganda since 1986, and his (nowadays) liberal party NRM (National Resistance Movement) is the governing party. There are general presidential elections every fifth year. Uganda's constitution went through radical changes in 2005 when the previous prohibition of political activity was abolished. Although party politics is allowed, the power in practice is with president Museveni and his party (Landguiden 2007). Since 1996, the government has run a strong decentralization policy involving substantial decentralization of powers, functions and responsibilities to elected Local Governments. Today, all Local Governments in Uganda have power to implement development plans based on locally determined priorities (UNCDF<sup>10</sup> 2008). Democracy is an important question as the country has been ruled by dictators since the independence of 1962. Uganda had its first multi party election in twenty years in 2006 when Museveni was reaffirmed as a president, but there has been much critique about the opposition being blocked from participating in the election campaign. The democratization process still moves very slowly (Sida 2008).

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<sup>7</sup> Living on less than 1 USD per day

<sup>8</sup> Swedish International Development Cooperation Agency

<sup>9</sup> United Nations Children's Fund

<sup>10</sup> United Nations Capital Development Fund



As mentioned above, Uganda's history has been characterized by numerous conflicts between ethnic groups. Today a conflict in the North is still continuing where the government has ongoing fights, mainly with a guerrilla movement called Lord's Resistance Army (LRA). LRA make their attacks from bases in the surrounding countries and has among other things been used by the Sudan government to spread unrest in Uganda and South Sudan. The guerrilla has committed severe human rights abuses i.e. abducted young boys to be soldiers and abused girls (Landguiden 2007). About 1,4 million inhabitants have fled from their homes and currently get protection in internal refugee camps, run by the army (UNICEF 2008).

## **HIV/AIDS prevalence in Uganda**

Since the HIV pandemic began, 25 million people have died and around 40 million are living with the virus throughout the world (IFRC<sup>11</sup> 2007). The African continent hosts more than 60 percent of people living with HIV/AIDS and Uganda is presented as both among the worst and the most promising countries in terms of HIV/AIDS (UNAIDS<sup>12</sup> 2008). In Sub-Saharan Africa, HIV has become a 'generalized' epidemic, meaning that more than one percent of the population is HIV-positive (UNICEF 2008). AIDS is the leading cause of death among individuals 15-49 years in Uganda (UNICEF 2001). In Uganda, 6,4 percent of the adult population and 0,7 percent of children are infected, which is approximately one million people. The number shows a decrease compared to the peak in 1992, when as much as 18 percent of the population was infected but trends point out a new increase since year 2000. Women are infected more than men in all ages why gender impacts of the disease are significant. In Kampala, 11,8 percent of the women are infected compared with 4,5 percent of the men. The decrease during the 1990s is mainly attributed to an increased age of sexual debut, reduction in sexual partnerships outside of marriage and increased use of condoms. Still at the current trend, a total of 1,3 million people will be infected by the year 2012 and 1,7 million in 2020 (Uganda AIDS Commission 2007). About 75 percent of the new infections are coming from sexual transmission and 25 percent derives from mother-to-child transmission. HIV/AIDS in Uganda has left around 2 million children orphaned. AIDS is also the 4<sup>th</sup> main cause of mortality among children under five. In addition, HIV has also far reaching social consequences such as children dropping out of school and caring for sick parents, early marriages, stigmatization, discrimination, disinheritance, child- and widow-headed households and street children. There are also new emerging issues regarding HIV/AIDS pandemic such as high levels of discordance among couples and the increase in HIV prevalence among the married couples (Ministry of Health Uganda and ORC Macro 2006).

## **Uganda Red Cross Society's work on HIV/AIDS**

Uganda Red Cross Society is one of many NGOs working on HIV/AIDS care and support in Uganda. They have projects in particularly affected and vulnerable areas such as the war-affected areas in Northern Uganda, some of the fishing communities around Lake Victoria and also in some slum areas of Kampala East and Kampala South respectively. The HIV/AIDS programs of the Red Cross provide a number of services for people in selected areas. Firstly, they provide voluntary counseling and testing. People who have tested (no matter if positive or negative) are welcome to join the so called Post Test Clubs that are described in the observation. The clubs provide education, peer support and psychosocial

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<sup>11</sup> International Federation of Red Cross and Red Crescent Societies

<sup>12</sup> The Joint United Nations Programme on HIV/AIDS

support from the volunteers, but people living with AIDS are able to get additional support in terms of home-based care. The home-based care consists mainly of psychosocial support but also of basic medical counseling and referrals to health centers. For bedridden clients, the Red Cross provides basic care i.e. support with hygiene. The program includes activities for prevention of mother-to-child transmission. They also provide income-generating activities for a few clients, where individuals are able to get a minor sum of money to start a business<sup>13</sup> in order to provide for their livelihood. Finally, the Red Cross provides peer support in schools meaning that they are educating selected students in schools to educate their peers about HIV/AIDS prevention. In terms of preventing further spread there are also activities in community sensitization e.g. radio shows and drama. These efforts will be discussed further in chapter four.

## **Choice and significance for the study**

In Uganda the HIV prevalence is relatively high and although it has decreased since the 90s, an increase is on its way since a few years back. Since the virus is widely spread (and the prevalence has been even higher), almost every Ugandan is related to somebody who died of AIDS. Some people deal with the fact, others refer to the phenomenon as the sick person being bewitched etc. Stigma is one of the obstacles for further prevention and to reduce stigma, people living with HIV/AIDS need to be empowered to disclose and to inform other people in society. Much work is going on to reduce stigma and discrimination in Uganda why the country is an interesting point of departure for this research. HIV/AIDS is perhaps the most stigmatized medical condition in the world and there have been relatively few studies concerning stigma experienced by people living with HIV/AIDS (Bell, Mtembu, O'Sullivan, and Moody 2007, Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo 2007). However, stigma and discrimination affecting this group has gained much attention in latter years, from researchers as well as governmental- respectively non-governmental organizations. For instance, stigma was high-lightened in the year 2000 from the Executive Director of UNAIDS as the most pressing item on the agenda for the world community. Furthermore, it was chosen as the theme for the 2002-2003 World AIDS Campaign (Parker and Aggleton 2003). Solutions are sought in order to minimize the impact and prejudicial effects of stigma in relation to HIV/AIDS. The stigma severely interferes with HIV prevention efforts. HIV-related stigma is a primary barrier to testing in Sub-Saharan African countries. To today, research on stigma and discrimination is relatively limited and there is a lack of theory as well as properly tested tools. Researchers call out for more research on the topic and some claim the need of sustainable theory of health-related stigma to reach further progress. Work on anti-stigma and also psychosocial support for infected people is an immense task for Social Work why more knowledge is essential.

## **Aims of the study and research questions**

The study looks into experiences of stigma and discrimination for people living with HIV/AIDS in Uganda. It also explores the work that is done by Uganda Red Cross Society to empower the infected people and how the support is perceived by the clients. One geographic area is selected namely Kampala East, and within this area the slums of Naguru and Bukoto. The study will examine if the support makes a difference for the individuals in terms of empowerment as well as for the stigmatizing attitudes in the community.

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<sup>13</sup> Small shops, grocery stores, restaurants, hair saloons etc. The money is supposed to be paid back within six months or as soon as possible before it is given to someone else in the project.

The main focus is on examining whether stigma and discrimination and/or its effects decrease by empowering people living with the virus. The study also explores if empowerment leads to decreased self-stigma respectively increased independence. The research questions are:

1. How are issues concerning stigma and discrimination perceived by people living with HIV/AIDS and their surrounding communities in Uganda?
2. What has been done by Uganda Red Cross Society to reduce stigma and discrimination against people living with HIV/AIDS in their targeted communities?
3. How do the clients of the Red Cross perceive the project and support they are given in terms of empowerment, self-stigma and independence?

## **Structure of the report**

This research report is divided into five chapters. After introducing the study and explaining some background facts about Uganda and HIV-related information in chapter one, chapter two presents the theoretical framework set out for this study, namely the theory of stigma and empowerment theory. Chapter two also introduces previous research on HIV and AIDS-related stigma and discrimination. In chapter three, the methodology is described, including a presentation of the qualitative research method, the case study, methods used for empirical data collection, validity, reliability, generalizability and finally some ethical concerns. Chapter four presents the results and an analysis of the research findings. Finally, chapter five presents some final conclusions and reflections.

## CHAPTER TWO

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### **THEORETICAL FRAMEWORK AND PREVIOUS RESEARCH**

This chapter will present the theories of this study, namely the theory of stigma and empowerment theory. Some general facts and characteristics of the theories will be presented. These are brought up in perspectives that are particularly interesting for the empirical data in this research. When discussing stigma, Goffman's (1963) traditional work is a corner stone. When presenting empowerment theory, the text is mainly based on the work of Adams (2003) and Payne (2005), but also some more recent work of Askheim (2007) and additional sources for definitions etc are used. When looking more specifically into HIV/AIDS related stigma, previous research in the field has been utilized.

#### **Previous research**

When searching databases for scientific articles about HIV-related stigma and discrimination, not much was found on Africa and nothing at all on Uganda. Most research on this issue seems to have been conducted in the Western world where stigma is a problem as well as in Sub-Saharan Africa, but the outcome such as discriminating activities are different because of different cultural and socio-economic contexts. However, a number of articles – some on stigma and discrimination in general and some that discuss HIV-related stigma specifically – were utilized in this research, and are referred to in this chapter and in chapter four.

#### **Stigma**

Stigma is a diverse concept. It is important to understand in relation to HIV/AIDS prevention and Social Work since HIV/AIDS-related stigma is a primary barrier for testing in Sub-Saharan African countries. For instance, among HIV-positive women in these countries, a primary reason for not disclosing their condition and failure to seek assistance are fears of stigma (Simbayi et al. 2007, Wolfe, Weiser, Bangsberg, Thior, Makhema, Dickinson, Mompoti and Marlink 2006, Bell et al. 2007).

Research on HIV-related stigma and discrimination is relatively limited and there is lack of theory as well as properly tested tools. So far, it has been difficult to develop a common theoretical perspective on stigma (Deacon 2006, Parker and Aggleton 2003, Simbayi et al. 2007). Deacon (2006) stresses the need for a sustainable, coherent theory of disease stigma as something that can improve HIV/AIDS-related stigma research and intervention planning.

#### ***Defining stigma***

The concept of stigma is widely used in different contexts, contributing to a lack of analytical clarity. Besides, definitions are often vague (Parker and Aggleton 2003:15). Stigma has a high degree of cultural diversity and complexity. Goffman (1963:12) defines stigma as “an attribute that is significantly discrediting, which, in the eyes of society, serves to reduce the person who possesses it.” People who possess a socially undesirable characteristic (like HIV/AIDS in this case) acquire what Goffman defines as a ‘spoiled identity’ which in turn leads to social deflation and discrimination. Stigma is conceptualized by society on the basis of what creates difference or deviance. It is applied through rules and sanctions, resulting in this kind of spoiled identity for the person involved. Goffman (1963) discusses matters regarding social change and the social construction of individual realities. He states three

aspects of stigma, namely blemishes of personal character, stained social identity and physical deformity or defects. These aspects can all be related to HIV/AIDS stigma of today. Parker and Aggleton (2003) suggest another interpretation of Goffman's work namely that stigma is not simply an attribute but that it represents a language of relationships. To label a person as deviant reaffirms the normalcy of the person who does the labeling.

In order to bring some clarification of the lack of analytical clarity of the concept of stigma, Deacon (2006) suggests a differentiation of various 'types' of stigma, namely *instrumental and symbolic stigma*. Instrumental stigma arises from basic self-interests like fear of infection of for example HIV/AIDS. Sometimes it originates from a fear that people with HIV/AIDS will consume too much resources. It might also include not wanting to shake hands with a HIV-infected person or refuse to care for or financially support a family member living with HIV/AIDS. Symbolic stigma arises from value-based ideology that compels moral judgments on others to affirm the own groups safe and moral identity. It is based on moral judgments causing a different kind of discrimination e.g. refusing to provide the same treatment for different patients. Thus intravenous drug users with HIV/AIDS might be judged as more blameworthy for contracting the disease than innocent victims. Another example is to not allow a person living with HIV/AIDS to serve on a school board because they are judged as immoral. Instrumental and symbolic stigma are both socially constructed and may lead to discrimination against people living with HIV/AIDS. Instrumental stigma however, does not include 'othering' and projection to distance people from risk (Deacon 2006).

Deacon, Stephney and Prosalendis (2005:19) go further, endeavoring to define disease stigma as something separate from the traditional concepts of stigma:

Disease stigma can be defined as an ideology that claims that people with a specific disease are different from 'normal' society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviors or groups in society. Disease stigma is thus negative social 'baggage' associated with a disease.

### **Social aspects of stigma**

There are social aspects of stigma that are especially present in HIV/AIDS related stigma. Deacon et al. (2005:23) describe disease stigmatization as a social process:

Disease stigmatization can be defined as a social process by which people use shared social representations to distance themselves and their ingroup from the risk of contracting a disease by: a) constructing it as preventable or controllable; b) identifying 'immoral' behaviors with 'carriers' of the disease in other groups; and d) thus blaming certain people for their own infection and justifying punitive action against them.

Regarding stigma as a social process enables us to understand it as something that is constantly re-enacted or re-created in different situations. Stigma can be understood as a problem of fear and blame. People in certain social groups often blame people in other groups for being affected by diseases and conditions like HIV/AIDS and also for risking further spread of the disease. This emotional reaction of danger helps people to feel that they are themselves less at risk of contracting serious diseases. Although its negative effects are many: associating disease, negatively-defined (immoral) behaviors and certain social groups all result in stigmatization of the disease and the people being infected. Some stigmatizing ideas are often able to grow in society because they fit into already existing prejudices and power

groupings. For example can more powerful groups in society be able to express stigmatizing beliefs more widely or discriminate more than less powerful groups on the basis of their stigmatizing beliefs. Stigmatization varies widely in different contexts and it can also occur in many different ways (Deacon et al. 2005).

In relation to HIV/AIDS, stigma has often been understood in highly emotional terms for example as anger and negative feelings towards people living with the virus, feelings that lead to beliefs that the infected individuals deserve their illness. It can also lead to avoidance and exclusion and might support coercive public policies threatening human rights. Some researchers have focused on the stigmatizing attitudes. They are concerned with the extent to which such attitudes correlate with misunderstanding and misinformation regarding the modes of HIV transmission as well as the risk of infection through everyday social contact. This research has also an interest in negative attitudes towards groups that are believed to be disproportionately affected by the epidemic i.e. homosexual men, sex workers or injecting drug users. This research has a clear focus on those who are perceived to stigmatize others (Parker and Aggleton 2003, Bell et al. 2007).

### **Self-stigma**

Deacon et al. (2005) differ between self-stigmatization or internalization of stigma, and perceived stigma. Self-stigmatization involves accepting some of the negative social judgments of one's identity. Perceived stigma is the stigma people expect from others for example if they should be known to be HIV-positive. In general, people know how society stigmatizes them.

Common reactions or strategies are either to conform or to resist this framework. To conform involves self-stigmatization or to accept society's negative judgment of ones stigmatizing condition (e.g. HIV/AIDS), a strategy that is very damaging because it reduces the individual's self-esteem that will in turn become an obstacle for testing, disclosure and treatment which will be further discussed in the results and analysis chapter.

The other approach, other than internalizing the stigma, is thus to resist this framework. Some people living with HIV/AIDS utilize an excessively positive identity in order to resist self-stigmatization. This strategy leaves little room for dealing with illness and distress. In this way people living with HIV/AIDS might emphasize their wellness and project the negative stigma elements onto other people e.g. those who do not know their status. It is common that people with HIV/AIDS adopt a strongly positive identity, a phenomenon influenced by the psychological need to avoid anxiety and also by social factors. There is a constant need for a broad promotion of positive HIV identity in strong individuals. This might lead to a decreased threat of HIV-positive people to society, by stressing that these people can take care of themselves (Deacon et al. 2005).

### **To hide or to disclose a stigmatized condition**

Since HIV is not visible it helps people to deny their status, even to themselves much of the time. Thus they avoid both stigmatization and self-stigmatization at a personal level. Although hiding stigmatizing characteristics is convenient in the short term, it leads to greater psychological distress in the long run (Goffman 1963, Deacon et al. 2005). Goffman (1963) makes a distinction between being *discreditable* and being *discredited*. To be discreditable means having an attribute that would be stigmatized if revealed, but the individual chooses

not to disclose it. To be discredited is to have a visible stigma or having disclosed a stigmatizing attribute. Both cases are relevant for people living with HIV/AIDS. Deacon et al. (2005) mean that hiding or revealing an up to that time hidden stigma causes greater psychological suffering than revealing a stigma that have been obvious all the time and cannot be hidden. Thus people who try to hide their, for example, positive HIV-status, experience more anxiety than those who disclose.

Since the issue of disclosure is complex and many people choose not to reveal their condition, Bell et al. (2007) emphasize the importance of confidentiality and continuity of care from health care providers. They also emphasize the importance of counseling (knowledge and information). Furthermore, they express the important role of support groups (which will be discussed in the following paragraph) and home-based care.

## **Empowerment**

The term empowerment came of age already in the 1920s, but was however at that time used rather sporadic. In scientific literature and in Social Work, it came of use in late 1970s and 1980s but did not achieve prominence until the 1990s when it became more frequently employed in Social Work texts. The major increase has been during the years 2001-2006 and it is now frequently utilized in Social Work texts as a central concept in Social Work, in theory as well as in practice (Adams 2003, Askheim 2007). Nevertheless, the concept is difficult to capture in an exact definition. It is multifaceted and encloses several different components. Empowerment refers to a variety of similar concepts such as self-help, mutual aid, participation user's rights and user participation. During latter years, it has also appeared in movements of liberation rights and social activism, often regarding critiques of inequalities and oppressions arising from differences in social class, age, disability, sexuality or religion. It is also connected to emancipation which, in the context of Social Work, refers to liberating a person from oppression. It can also be liberation from undesired physical, legal, moral or spiritual restraints and obligations. Literally, the term empowerment means 'becoming powerful' but in Social Work it has come to have a broader meaning (Adams 2003).

The theory of empowerment aims to enable people to overcome barriers in achieving their life objectives and gaining access to services. Power is perceived as something positive within empowerment ideas and not always, as in radical theory, oppressive (Payne 2005).

Adams (2003:28) emphasizes the lack of a unified set of concepts and approaches to empowerment:

The diversity of theories and models of empowerment reflects the lack of a single definition of the concept. It is a mish-mash of concepts and techniques, a stew of ancient and modern ideas, which something thrown in for everyone – politicians, managers, practitioners and people using services – and as a consequence it risks satisfying nobody.

Furthermore, Adams (2003) emphasizes that the idea of empowerment is inherently contradictory as it is set against the realities of people's life as they face conditions such as illness, disability, ageing, poverty, unemployment and discrimination. However, a few definitions and practices for this diverse concept shall be enlightened in the following text.

### ***Defining empowerment***

Humans in powerless positions can by means of empowerment gain strength to exit the condition of powerlessness. Empowerment is by some means to mobilize or to strengthen people to fight the powers that oppress and thereby, people gain influence and power of their own lives. As a result of that, empowerment is a target as well as a mean in order to reach the goal of mobilizing, strength and influence (Askheim 2007).

Empowerment has different meanings to different people. There is a diversity of theories and models of empowerment and there are many different definitions. A few working definitions will be given here. According to Adams (2003:8), empowerment is

(...) the means by which individuals, groups and/or communities become able to take control of their circumstances and achieve their own goals, thereby being able to work towards helping themselves and others to maximize the quality of their lives.

The Dictionary of Social Work states the definition of empowerment as being a

(...) theory concerned with how people may gain collective control over their lives, so as to achieve their interests as a group, and a method by which social workers seek to enhance the power of people who lack it. (Thomas and Pierson 1995:34)

### ***Traditions of empowerment***

Askheim (2007) suggests four different traditions or theoretical views of empowerment: 1) as an establishment of counter-power, 2) as a market oriented angle, 3) as a therapeutic situation and 4) as a liberal strategy of management. All the perspectives share the essence of a humanistic view, a positive view of humans as active subjects, who take action and who know their own best and what they want, given that the right conditions are created. However, the first of these four perspectives is the most relevant for this study and will be described a little deeper below. Empowerment as establishment of counter-power discusses the coherence between the life situation of individuals and the societal, structural conditions. Within these conditions individuals and groups become empowered to change the conditions that put them in a weak and powerless situation by starting processes and activities that can strengthen their self-control. Individuals gain enhanced confidence, better self-image, larger knowledge, skills and abilities. In the meantime, the point of departure from this perspective is that the individual's position in society is not given by nature but as a result of a historical process created by humans. This determines to which extent individuals have power or control over their life as well as the degree of powerlessness. But as the relationships are created by humans, they can also be changed. Therefore, a central standpoint within this perspective is to create an awareness of the connection between the individual's life situation and external, societal conditions. It is also important to show that many people share these problems and that they are not alone. Such increased awareness shall in turn lead to action.

### ***Self-empowerment***

Another domain of empowerment is self-empowerment. Self-empowerment necessitates people to take power over their own lives. For service users, this means to challenge their disempowerment, to take control over their lives. Then, they are able to influence other people and to bring about change. It goes hand in hand with politics and power, meaning that enabling people to feel better cannot be an independent substitute for liberating them from



oppression. However, self-empowerment will always involve a struggle. Sometimes the struggle will be for resources but it can also be struggle against one's own attitudes. Alternatively, the barriers may exist at the level of the attitudes of other people (Adams 2003).

### ***Empowerment in a Third World perspective***

There have been important contributions to the empowerment theory from parts of the Third World. The founder of the liberation theory for example, Freire (1986) has been an important inspiration for this empowerment tradition by his book *Pedagogy of the oppressed*. Freire discussed the concepts of consciousness-raising and empowerment. He was interested in the lack of knowledge and apathy that characterized poor farmers in North-Eastern Brazil. He thought it was a consequence of the present situation since they were victims of economical, political and social oppression and that they never got a chance to develop critical awareness or to react. His analysis was that the individual's state of mind – the psychological dimension of the empowerment process – was the priority to deal with. He raised the issue of consciousness-raising with poor people in order to overcome cultural, intellectual, emotional and even economic oppression. He wanted them to challenge their dependence and powerlessness, 'to get the oppressor out of their own heads'. He used the term 'conscientizacao'(eng. 'conscientization') that means "learning to perceive social, political and economic contradictions and to take action against the oppressive elements of reality" (Freire 1986:15). Freire had a vision of positive strategies that link individual empowerment with social change. Furthermore, Freire (1986) means that the oppressed are also their own oppressors as they have made the oppressors' awareness and perception of reality their own. They get caught by a reality that oppresses them. First when they realize this can they deliberate themselves from the oppressor, thus in order to fight for liberating, they must be aware of the actual process of oppression. Payne (2005) states that much research support the assumption that consciousness-raising in general leads to empowerment.

Although the consciousness-raising is perceived as something positive, it is not an unproblematic process. Empowering people concentrates on developing their capacities. It does not seek direct change in oppressive social structures and might therefore place responsibility for social change upon clients. The clients may be empowered but still they cannot overcome the social or practical obstacles (e.g. poverty and disease) that face them (Payne 2005).

### ***Self-help***

According to Payne (2005) there is a strong link between the concepts of empowerment and self-help. To facilitate self-help is one way among others to empower people and to encourage people and communities to participate in decisions that affect them. As Dictionary of Social Work states:

Empowerment can refer to user participation in services and to the self-help movement generally, in which groups take action on their own behalf, either in cooperation with, or independently of, their statutory services (Thomas and Pierson 1995:134-135).

Also, the historical roots of empowerment lie partly in traditions of mid-Victorian self-help, a tradition that tend to reflect the dominant values of society at that time. Self-help was during the nineteenth century maintained by the prosperous middle classes to rave about their own

moral excellence. Currently, Social Work discourse is oriented towards personal and social change in pursuit of values such as anti-oppression. Thereby Social Workers of today are more likely to work in alliance with undervalued people in society (Adams 2003).

Adams (2003:84) refers to a list of self-help characteristics that have been identified by researchers such as

(...) members sharing a common experience; mutual help and support; the helping of peers by those normally on the receiving end of help themselves; differential association by which people who wish to change decide to join groups in which existing members reinforce the desired behaviour; collective willpower and belief in the group's values emphasizing the fact that change is within members' capacities; information about which experiences and changes are likely to be encountered by a member of a group; and finally the use of activities as a constructive occurrence which members share in pursuing planned goals.

Adams (2003) describes self-help groups as voluntary, small groups created for a specific purpose. Members support each other with mutual aid and assistance. Furthermore he discusses user-led groups that focus mainly on consciousness-raising and empowerment of its members. It involves activities of analysis and action. Payne (2005) states that this kind of group socialization contributes to reduced feelings of isolation, that it connects people to each other by relationships and that it creates greater feelings of self-worth.

### ***Self-help in a Third World perspective***

In the Third World, the core of health, social services but also economic and social fabric often consists of self-help. Much work is carried out as community based Social Work, not necessarily because that is the preferred model but because that is what is feasible out of restricted financial resources and lack of institutions. In most areas, the majority of people have traditionally had to provide their own tools, buildings, skills and other resources. Otherwise they run the risk of deprivation or even death (Adams 2003). In many developing countries, there are tensions between needs of people living with HIV and the economic and social realities, meaning that health care services for the entire population are grossly under-resourced (Bell et al. 2007).

In many countries in the Third World, self-help thus becomes a substitute for non-existent health- and social services rather than a complement. In most developed countries, self-help instead operates as an alternative to, or as a substitute for Social Work (Adams 2003). Also, poverty and material deprivation contributes according to Payne (2005) to oppression. A paralyzing condition that can be overcome by empowerment.

### ***The role of Social Workers in empowerment processes***

The role of Social Workers is to guide people to get control of their circumstances and problems, to be in charge of their own life situations. This is often done by facilitating a process of empowerment. Empowerment can be seen as a cornerstone in Social Work. Social Workers assist and guide people towards empowerment that leads to decreased oppression and increased independence. As Payne (2005:306) states:

Empowerment is a process through which workers support clients to identify the full range of possibilities which might meet client's needs. The work centres on helping clients to make decisions which affect their lives.

Empowering people is according to Adams (2003) a demanding work as it requires that before empowering other people, you need to be empowered yourself. It is important to consider one's own thoughts, feelings and situation in any work with other people. A person who feels empowered is more likely to have the motivation and capacity to empower other people and to be empowered by them. Before a group can work effectively to empower people, individuals in it need to feel empowered. Payne (2005:304) argues that Social Workers may be empowering by "achieving a positive relationship with clients, being determined to understand the client and their point of view, being self-aware and skilful in their practice, using language carefully and being sharing in work and use of records."

In the early stages of self-help groups, Social Workers often have a role as constructors, bringing structure and enabling the users to analyze the problem, to define what to aim for and to set norms. Members aim to take over the group, either partly or definitely. Sometimes the Social Workers can act in the background, or they leave altogether. In this context, it is also important to mention the problems that might arise according to the role of the Social Worker when empowering people. According to Payne (2005) there is a risk that Social Workers act as if all clients actually have the ability to reach a high degree of empowerment which is not true for everybody. It depends on the context and where the work takes its point of departure.

## **CHAPTER THREE**

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### **METHODOLOGY**

In this chapter, the research process will be presented. It will be described in terms of which research approach that has been used, the kinds of data collection and the process of analyzing the data. Initially, a description of qualitative research method will be presented including the fundamental themes for data collection. The next part includes a description of the case study as well as the motives to undertake a case study. Thereafter, a section describing the data collection will follow. There is also a section discussing validity, reliability, generalizability of the study as well as ethical concerns. Finally, there will be a section about processing the data, about transcription and how the interviews have been analyzed in terms of meaning categorization.

### **Qualitative Research**

This study is based on a qualitative research approach. When choosing whether to use qualitative, quantitative or both methods, the researcher has to consider the topic, time and available financial resources. In qualitative research, there are three types of data-collection, namely interviews, observations and documentary research (Gilbert 2001). Since this study aims to explore the situation for people living with HIV/AIDS regarding their experiences of stigma and discrimination and also whether they feel empowered or not, a qualitative research approach was chosen. The choice of scientific approach was based on a belief that the social world consists of multiple, subjective realities, that people construct their own versions of reality. By utilizing qualitative research methods such as observations and non-standardized interviews, the researcher can get “close to the data and studying social interaction in its natural surroundings” (Gilbert 2001:33). Thus, unstructured in-depth interviews have been conducted in order to answer the research questions and participant observations have been carried out for the purpose of deepening the understanding of the research topic, both to prepare for the interviews and to get perspectives on what was found in the interviews. The qualitative research method often deals with situations or individuals from a holistic perspective, meaning that the researcher studies individuals in their natural context. However, the researcher cannot dig deeply into all possible aspects of the case but should choose certain themes of focus (Gilbert 2001, Kvale 1996). This study is mainly focused on the following themes: HIV/AIDS, stigma, discrimination and empowerment. Via these perspectives, the subjective experiences of the informants are presented by means of their own words and expressions. When conducting qualitative interviews, the method requires empathy as well as maturity and sensitivity from the interviewer (Kvale 1996, Gilbert 2001). This has been taken into account in this study where the intention has been to maintain as much objectivity as possible.

### **Case study**

This is a case study exploring the perception and personal experiences of stigma and discrimination among people living with HIV/AIDS in Uganda. The study also focuses on the effects of empowering people living with HIV/AIDS through a project run by Uganda Red Cross Society. The target has been to focus on the informants’ descriptions of their situations, but the information has then been interpreted according to the theoretical framework of the study. Trygged (2005) discusses field research whereby the researcher throughout interviews and documentary research gains results for theoretical discussions. Yin, referred to in Larsson

et al. (2005), discusses three different case studies, namely explorative, descriptive and explaining case studies. This is an explorative case study with thorough descriptions of the case, aiming at creating an empirically based understanding of the case as a phenomenon. Case studies have different focuses on different levels e.g. individual, organizational or societal. They often focus on practical matters in order to enlighten the problem or to make decisions. This study illuminates the problem of HIV/AIDS related stigma in Uganda. It is mainly based on interviews with people living with HIV/AIDS and staff within a project run by Uganda Red Cross Society. The interviews form the base for the theoretical discussions, but data from policy documents from GOs and NGOs<sup>14</sup> has also been used. Furthermore, three observations have been conducted in order to bring alternative perspectives of the data collected from documents and interviews.

Typically, a case study seeks a lot of information from a few cases with the purpose of creating a deeper understanding of the studied case. Case studies can be conducted at all levels, from individual to state level. Yin refers to the case study as an empirical research question that examines contemporary phenomenon in their actual context, especially where the difference between phenomenon and context are unclear. Case studies are often historical, but can also be future scenarios or, as in this study, descriptions of a current situation. A case can according to Trygged in Larsson et al. (2005) be studied either by one or several methods. A number of cases can also be studied with either one or several methods. In this case study, one case has been studied with several methods in order to increase the validity. Common patterns and significant findings from the empirical data have been puzzled together and then related to and analyzed in relation to existing theories and previous research.

## **Data collection**

In the following section, the two empirical methods of data-collection used in this study will be described. The purpose has been to gather information about stigma, discrimination and the effects of empowering people living with HIV/AIDS in Uganda. The methodology of the observations will be presented as well as interviews that have been conducted.

## **Observations**

Observations as research method origins from the social anthropology and also from the Chicago School of Social Research in the 1920s and 1930s. Since social life is constantly changing, observations have an advantage when studying social phenomena. The research is conducted in the natural settings of the people being studied. Knowledge when undertaking observations “comes from experience and the undertaking of detailed and meticulous inquiries through which we generate our understandings.” (May 2001:148). The purpose is to develop a scientific understanding of the group of people being observed. Observations encourage the researcher to get involved more deeply in the day-to-day activities of the people they study and whom they are trying to understand. Ideas may be developed instead of tested (May 2001).

Three observations were conducted in the early phase of the study, before the interviews were carried out. The purpose was to get an overview of the meetings and to observe whether the intentions from the Red Cross were in line with what actually took place in the meetings. A purpose was also to look for empowering activities, if and then how they took place in reality.

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<sup>14</sup> Governmental respectively non-governmental organizations

The findings from the observations were helpful when designing the interview guides (appendix 3). The observed objects were meetings in two different Post Test Clubs. The clubs are situated in three different slum areas of Kampala and they are initiated and lead by Uganda Red Cross Society. The targeted slums are poor communities with high prevalence of HIV/AIDS. The club members are people who have tested for HIV irrespective of positive or negative result. Some of them are clients in a home-based care project run by the Red Cross and some of them are volunteers, either HIV positive or negative. A few members have joined the clubs because of interest in singing or drama and also to improve their knowledge about sexual health, hygiene and nutrition. Many members join the club with hopes to get material support. The club activities are formalized, weekly meetings including information, counseling and peer support. The clubs also work on community sensitization in the form of song and drama performances. Some club members receive additional support such as home-based care, income generating activities, food supply and scholastic materials.

The researcher attended the meetings and was presented as a student doing research and observing the activity. The presentation was particularly important since the clubs are frequently visited by western donors, often involving expectations of extended resources and contributing to a feeling that they need to do well, to show how they benefit from the Red Cross support.

Fieldnotes were taken on what actually happened during the meeting but also reflections from the researcher. Directly after the observed meetings, they were re-written and further worked through in order note down as much as possible from memory. As Gilbert (2001) states: “The production of the fieldnotes is the observer’s *raison d’être*: if you do not record what happens you might as well not be in the setting.” Taking notes were chosen rather than tape-recording the meetings because writing, according to Gilbert (2001), has the advantage of leading to a more productive and reflective approach. Since writing is slower, it facilitates to grasp the “first reflections on connections between processes, sequences and elements of interaction.” (Gilbert 2001:153) Since the observations were overt, notes could be taken during the observation. There was also a possibility to ask clarifying questions during the time.

## **Interviews**

For this study, two types of qualitative interviews have been conducted. Part of the interviews have been unstructured in order to grasp the life world<sup>15</sup> of the informants. Another part has been semi-structured interviews with the purpose of gathering actual facts from professionals. The unstructured life world interviews have been conducted with eight people, seven women and one man, living with HIV/AIDS in Kampala. All of them were members of the Red Cross Post Test Clubs. Some of them were also volunteers in their home-based-care project. The fact-oriented, semi-structured interviews were conducted with two staff members working for Uganda Red Cross Society, one in a rural area and one in the city.

Two staff members were asked to participate and both agreed. Among the clients, eleven were asked but only eight agreed to be interviewed. The ones who did not agree were all men. The intention was to have an equal part of men and women which turned out not to be possible. One male informant agreed to take part but did not show up at the time and the point agreed for the interview to take place. The interviews were conducted during the period from March 14th to May 15<sup>th</sup> 2008. The reason why they are spread over such a relatively long period of

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<sup>15</sup> The informants’ lived world and their relation to it (Kvale 1996)

time is that plenty attempts were made to find male informants. Different gatekeepers were used to track and to persuade men to take part in the study, although with relatively little success. The interviews with staff members took between 45 minutes and an hour while the interviews with clients varied far more in time, depending on the client's different situations and ability or willingness to talk. One interview took only half an hour and some of them lasted around one and a half hours.

All the interviews have been recorded and verbatim transcribed in order to increase the validity by not losing any data from the interviews and to be able to focus on the conversation during the interview situation. The records also offered the possibility to review the interview material, listening to words, pitch, pauses etc, all useful for the analysis (Kvale 1996, Gilbert 2001). All the informants agreed with the interview being recorded and they were all offered to acquire the transcripts.

### ***Unstructured life world interviews***

The unstructured life world interview as data collection method is, according to Kvale (1996), best suitable for studies focusing on peoples' view of how they live their lives, narratives about their experiences and how they perceive themselves. It can also bring about clarity and develop the perspective of life. The interview is based on an interview guide that includes a number of pre-determined themes and suggestions to relevant questions. Within these questions, the researcher can adjust and change the questions during the interview or between different informants. The questions can be adjusted in terms of how they are posed, the internal order or how to follow up the answers from the informants. Moreover, Kvale (1996) states that the interview is an interpersonal dialogue about a theme out of equal interest. Although it is not a reciprocal conversation between two mutual parts, it is the researcher who is responsible for the interview. The intention of doing in-depth, unstructured interviews in this study was to let the informants freely describe what was important and relevant for them, using their own words. An interview guide was used and thus the questions were not phrased and fixed in advance which allowed both the interviewer and the informants the flexibility to examine details or to discuss certain issues as they come up. The interview guide with its themes was tested in a pilot interview. The themes were mainly focusing on getting to know ones HIV-status, certain experiences of disclose and experiences of stigma and discrimination. The interviews also focused on the meaning of being part of the Red Cross project, how the support is perceived and whether it has lead to empowerment and reduction of stigma or not. When formulating the interview questions, the research questions were constantly in mind in order to, as Kvale (1996) emphasizes, judge whether they were relevant to the research subject and thus could create a good ensemble between the interviewer and the informants. The ambition was to pose the questions in an order that encouraged the informants to talk and to create a positive, mutual dynamic.

The interviews were all conducted in English. Since neither the interviewer, nor the informants were native English speakers and since most of the informants were not highly educated, an unfussy language was used in order to meet the informant's on their level, to make them feel comfortable and to fully understand what was asked for. Another purpose of the simple language was again to let the informants create their own story with their own words. The questions were therefore descriptive and simple.

Kvale (1996) points out nine different types of questions that can be included in an interview: introducing questions, follow-up questions, probing questions, specifying questions, direct

questions, indirect questions, structuring questions, silence and finally interpreting questions. All of these were more or less used during the interviews: Introducing questions were used to acquire facts about the informants' background such as description of the household, marital status, number of children, age etc. Follow-up- and probing questions were used to dig deeper or to bring a more detailed description from the informants. Then, specifying questions were used in order to get more precise descriptions of general statements. Direct questions were utilized during the latter parts of the interviews in order to cover important themes that did not come up spontaneously. Indirect questions were posed when the informants did not seem to be sure about their own standpoint or to bring about earlier experiences. Silence occurred several times during the interviews to give the informants time to associate and reflect upon what was said and what else could be added. Since the topic was rather sensitive and since many of the informants did not analyze or articulate the matter before, it was particularly important to give them time and space to think and reflect throughout the interview. That also provided time for the interviewer to think about how to continue the interview, where to dig deeper etc. Sometimes towards the end of the interview, particular issues were followed-up again, things that were said earlier and that could be further deepened after some time. Structuring questions were frequently used as many questions were open and often led to lots of reflections and new thoughts for the informants. Often the informants also brought up issues that were not relevant for this study, questions relevant to them such as financial issues. Finally some interpreting questions were used in order to clarify statements that could be understood in different ways. The interviews were always completed with the question if there was anything they wanted to add or something else that should have been asked according to the informants. This allowed further space for spontaneous reflections, sometimes upon what has been said during the interview and sometimes new things were brought up and enlightened.

According to Kvale (1996), the interview technique is a craft whereby the result and the quality of the interview is dependent on the interviewers knowledge, sensitivity and empathy. He specifies the interviewer's qualifications in the following criteria: knowledge, ability to be structured, to be clear, friendly, sensitive, open-minded, controlling, critical, to have good memory and to be a good interpreter. The quality of the interviews in this study have benefited from the researcher's vast experience of conducting interviews from working ten years as director in the Social Services, doing needs assessment interviews with clients and employment interviews. The interviews in this study were undertaken using all knowledge from previous experiences of interviews such as technical issues regarding the structure of the questions as well as psychosocial issues such as how to create a relaxed and safe environment where the informant feels free to open up as much as possible. The researcher aimed to be sensitive to the informant's personal experiences and their cultural and socio economical context, being different from the researcher's. A friendly environment was created by a humble approach where the researcher was eager to show respect by learning some basics in Luganda, used in the introducing phase. The researcher also strived to maintain sensitivity and open-mindedness for cultural and socio economical differences. This was particularly important since the researcher was a, by comparison, rather wealthy, white person, visiting poor, marginalized black people<sup>16</sup>.

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<sup>16</sup> Being white (mzungu) in Uganda is most often strongly connected to being perceived as someone extremely rich and superior in status.



### ***Fact-oriented interviews***

To gather information on what Uganda Red Cross Society actually do to empower their clients and how they generally perceive stigma and discrimination in Uganda, two semi-structured interviews were conducted with staff members of Uganda Red Cross Society. One interview was conducted with an HIV officer working in central Kampala and one interview was conducted with a Branch Field Coordinator in Masindi, a small town in Western Uganda. The informants were both professional Social Workers and thus familiar with the concepts of stigma, discrimination and empowerment why it was possible to be rather direct in the questioning and to quickly get to the point. Semi-structured or semi-standardized interviews is according to Gilbert (2001:24) “[...] when the interviewer asks major questions the same way each time, but is free to alter the sequence and to probe for more information.” Since the intention was to gather actual information and facts, a standardized interview guide was utilized. However, the informants provided different, sometimes unexpected perspectives on the issues and they sometimes answered questions that were about to come later on during the interview which resulted in some variations in the questioning.

### **Sampling**

In this study, a purposive sampling method called snowball sampling (Gilbert 2001, Kvale 1996) has been used. A small number of people, intended to be representative for the category of people, have been chosen. The sampling was made by an open question to people who attended a Post Test Club meeting, to take part in the study. Four people agreed to participate. From those four (all women), snowball sampling was carried out via one of the informants who was well connected in the community. She was asked to recommend possible informants with diverse stories and experiences. Men were specifically asked for since none of the first informants were men. The first sample showed that people who suffered from stigma and who had not fully disclosed were difficult to reach. Therefore people in this category were specifically searched for. Twelve people living with HIV/AIDS were asked to participate, eight agreed. Regarding staff members, they were simply selected out of their position as Social Workers with responsibility for HIV/AIDS projects and they both agreed to participate.

Three of the four people who were asked but chose not to participate were men. Out of the eight informants living with HIV/AIDS, only one is male. It has been very difficult to find men who agree to participate in the study. Several different gatekeepers<sup>17</sup> among the first informants, volunteers and staff in different communities have been used to encourage the participation of men; still only one interview with a man finally took place. Reasons for this will be discussed in the Results and analysis chapter. The informants thus consisted of eight people living with HIV/AIDS who are members of two different Post Test Clubs of the Red Cross, situated in the poorest slum areas of Kampala. Seven of them are women and one is a man. They are aged 28-54. The informants had different levels of education. Some of them were educated up to primary school, some had finished secondary school, and one of them had a university degree. The interviewed staff members were both Social Workers with university degrees.

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<sup>17</sup> In this case a person who can refer to people in the category of informants, who knows the community and who can explain where and how to reach people.

## **Analysis**

The interview material in this study has been analyzed from a phenomenological perspective, in the sense that information is understood from the informant's own perspectives, how they describe the world and how they experience it (Kvale 1996). Below follows a description of how the collected data has been handled and how it was analyzed.

### ***Transcriptions***

Kvale (1996) states that transcription in itself is an interpretative process. Since the informant's experiences of different phenomena are reported according to the phenomenological tradition, the ambition has been not to make interpretations in the collection and transcriptions of the interviews. The interviews were, as mentioned above, verbatim transcribed. The quotations are also given in their original shape in order to be more real and lively. The Ugandan English has a strong 'local flavor' not only in terms of the accent but also the way in which grammar is used, and sometimes it is blended with local languages. Those words and expressions from the transcripts are explained in footnotes as they occur. In Ugandan English, it is also common to use expressions that might not make sense for people who have not spent some time in Uganda. Also these are reported in their original outcomes and explained in footnotes.

### ***Analysis of the interviews***

The ambition has been to, as accurate as possible, explore the informants' experiences of HIV/AIDS related stigma and discrimination and also of taking part in the Red Cross project. In order to do this, Kvale's (1996) method of meaning condensation has been employed. The foundation of this method is the possibility of organizing data that still remains formulated in terms of everyday language. The purpose is to express the meaning of what the informant actually expressed in a more concentrated manner. Lengthy meanings expressed by the informants are compressed into shorter formulations. Within these sections of text, the essence of what has been said is re-phrased with a few words. In that sense, larger interview texts are reduced to shorter, with only the essence of what has been said.

The meaning condensation consists according to Kvale (1996) of five steps whereby the first step is to initially read through the interviews to get a sense of the whole. The second step is to set up 'natural meaning units' as they are expressed by the informants. In this study, eight different themes were chosen, themes that were searched for in the transcriptions. Searching for the themes required additional reading of the interviews, a total number of eight, as each theme required one perusal each. The themes were 1) stigma and discrimination, 2) feelings and hesitation before testing, 3) reactions from getting the result, feelings and reactions at the time of disclosure, 5) support from the Red Cross, 6) peer support, 7) empowerment and 8) gender perspectives. The statements were compiled under each theme in two-columned tables. (An example of such a table is enclosed in appendix 1.) The left column in "the meaning-condensation-table" includes the natural meaning unit, meaning the informant's own words, classified under respective theme. The third step consists of formulating short and simple sentences, summarizing the essence in what were said, so called central themes. In this step it is important that the researcher is as neutral as possible, avoiding own interpretations and prejudices. The central themes are written in the right column. Each interview resulted in eight tables, one of each theme. The fourth step of the meaning condensation is to interrogate the meaning units from the specific purpose of the study, in this case the research questions. The fifth step is where all meaning units are compiled to a descriptive statement. This was

done by copying the meaning units from each meaning-condensation-table to separate documents. In this way, the meaning units from all interviews were assembled in one document per theme. This assembly resulted in eight documents with meaning units from all informants. The meanings units from each interview were thus tied together to a descriptive statement.

A sixth step is added in this analysis consisting of looking at the descriptive statements from a theoretical point of view (from the chosen theories). At every perusal, specific statements were searched for that could be related to any of the chosen theories. Each statement that was connected to respective theory had a special color-marking. This final step in the analysis created further clarity of the interview findings and linked it to the theories of empowerment and stigma. The different statements connected to theoretical perspectives were compiled in yet another table. In this table, the statements from every theme were analyzed with regard to the theories. Some statements could be related to both theories and were thus put under both theory headlines.

A phenomenological perspective includes according to Kvale (1996:38) “a focus on the life world, an openness to the experiences of the subjects, a primacy of precise descriptions, attempts to bracket foreknowledge, and a search for invariant essential meanings in the descriptions.” The phenomenologically based meaning condensation is faithful to the phenomena, the primacy of the life world. The descriptive approach opens the possibility to a description of the situation from the informant’s viewpoint, whereby the researcher can look for meaning in the description. Thus there is accordance between content and method. In this study, the empirical phenomenological method has given the possibility to break down often comprehensive and complex interview transcriptions to natural meaning units in order to explore their main themes.

## **Ethical concerns**

There are some general ethical principles for social research of which a few will be described here. Kvale (1996) and Gilbert (2001) mention the following ethical principles:

One principle is *informed consent*, meaning that the informants are informed about the overall purpose and design of the study, possible risks and advantages connected to participate and that participation is voluntary. In the study, informed consent was received from all the informants (appendix 2). The informants were informed about the purpose of the study, the main features and issues concerning confidentiality and could from that information choose whether to participate or not.

Another ethical principle according to Kvale (1996) and Gilbert (2001) is *confidentiality* meaning that no private data that might identify the informant will be reported unless the subjects agree to it. All data that might risk anonymity of the informant, i.e. facts that are characteristic for a specific informant, should be revised. To preserve the identity of the informants in the study, their names are omitted in the report. Fictive names that are common in Uganda are used instead. Several of them are gender neutral in order to protect the identity of the single male informant. Since the chosen communities are relatively small and most people know each other well, the de-identifying of informants might be insufficient. They might be recognized among their own group by certain statements. Thus this risk is taken into account so that the quotations mentioned in the study are not of a sensitive character or disclosing something in particular about a certain informant. The transcriptions from the

interviews are kept in a confidential place and will be erased after the conclusion of the study. This research is for academic purposes only and the findings are therefore not meant for other purposes.

The third ethical principle according to Kvale (1996) and Gilbert (2001) is *beneficence*, the purpose of which is to minimize the risk of harm to the informant. The advantages and significance of the knowledge given by the informant, must compensate for the risk of harm for the informant, and justify a decision to conduct the study. The researcher must pay attention to the consequences, the possible harm that the people being studied are exposed to as well as the expected advantages that participation in the study can bring. Kvale (1996) points out the researcher's responsibility when considering possible consequences for participants as well as the larger group of whom they represent. The interviewer should be aware that in an interview situation, people might reveal things that they did not intend to reveal, things they might regret later on. This demands the researcher's sensitivity concerning how far to go in his or her questioning (Kvale 1996, Gilbert 2001).

In order to respect the integrity of the informants and to create a comfortable and secure interview situation, the people who agreed to participate in the interview were given the freedom of choice of where to meet. Hospitality is highly valued in the Ugandan culture why all the informants except for one chose their own homes for the interviews. One of the clients who had not disclosed to his family chose to meet at a public place (a grass lawn) in the community. Interviews with staff members were conducted in their offices.

## **Validity, reliability and generalizability**

When it comes to qualitative research, validity, reliability and generalizability have often been rejected by positivistic researchers. They claim that the leading questions of an interview study make the results less reliable and that the results cannot be generalized because of the limited sample-frame. It is reasonable to question the validity of qualitative interview studies as they are built on subjective interpretations (Kvale 1996). In the following section, the concepts mentioned above will be discussed in order to assure the scientific reliability of this study. The validity of the study will shortly be presented, thereafter the reliability and finally, its generalizability.

### **Validity**

Validity refers to whether the research has actually measured what it is supposed to measure (Gilbert 2001). To assure the validity in this study, Kvale's (1996) table of seven stages of an interview investigation has been followed. The steps are thematizing, designing, interviewing, transcribing, analyzing, verifying and reporting. It is important that the researcher is aware of these seven steps throughout the study in order to maintain its reliability and validity. The validity of the interview is about the reliability of what the informants say and also the quality of the interview. The planning of the interview guide is important as well as the sampling and the interview itself. As the informants were permitted to speak freely, it is difficult to judge whether their experiences are 'true' or not. What could be done was to verbatim transcribe their sayings as detailed and correct as possible. An exact description of their perception can never be obtained, but by carefulness in creating the interview guide and doing the interviews, the interviews probably came as close to the truth as possible. In the analytical work, quotations found to be relevant for the chosen theoretical perspectives and for the chosen themes are used. Subjective judgments have thus been made why one can assume that if

somebody else chooses to undertake a similar study with the same questions, methods and with the same persons, the results will most likely differ. With awareness of this fact, the study still proves an acceptable validity.

### ***Reliability***

The reliability of a study refers to how consistent the results are from one measurement to the next. It measures whether an instrument or a method gives the same result at different occasions during similar conditions. The reliability within qualitative research is shown by getting the same result with repeated measures and also the reliability of the measuring tools (Gilbert 2001, Kvale 1996). In order to assure the reliability of this study, the measure instruments have been reflected upon, whether it was the right way as the interviews were openly interactive. The informants were encouraged to speak freely about their experiences and perceptions and leading questions were avoided. Furthermore the physical environment (their own homes) most likely encouraged the respondents to be relaxed and able to express their views in a comfortable way. To clearly describe the methodology as done in this study, also increases the reliability.

### ***Generalizability***

Generalizability is the degree to which findings can be generalized from the study sample to the entire population. According to qualitative research views, it is not possible to create universally generalizable rules for human behavior (as claimed in the positivistic research tradition), but every situation is unique concerning structure and logics (Kvale 1996). In this study, a specific case is studied under specific conditions in order to draw general conclusions from it. Generalizability concerns to see patterns and to understand how things relate to each other. In this way, it is possible to consider the experiences and results as an exemplifying knowledge. Thus it is possible instead of using the concept generalize, to talk about translating knowledge to new contexts. This study might not be large and geographically spread enough to be generalized into a greater context. Though, it can be seen as an example, possible to compare with other related studies.

## CHAPTER FOUR

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### RESULTS AND ANALYSIS

This chapter presents the results of the study as well as an analysis of the findings. The results and analysis are based upon the themes from the interview analyses namely 1) stigma and discrimination, 2) feelings and hesitation before testing, 3) reactions from getting the result, feelings and reactions at the time of disclosure, 5) support from the Red Cross, 6) peer support, 7) empowerment and 8) gender perspectives. The analysis also aims to answer the research questions that are:

1. How are issues concerning stigma and discrimination perceived by people living with HIV/AIDS and their surrounding communities in Uganda?
2. What has been done by Uganda Red Cross Society to reduce stigma and discrimination against people living with HIV/AIDS in their targeted communities?
3. How do the clients of the Red Cross perceive the project and support they are given in terms of empowerment, self-stigma and independence?

The chapter is divided into six sections where the nine themes of the analysis are covered. The first and second section presents the prevailing situation regarding stigma and discrimination in Uganda as well as feelings and reactions when people reveal that they are being infected with HIV/AIDS – those two sections answer the first research question. The third and fourth sections discuss self-stigma and how to manage stigma. Even these two sections concern research question one. The fifth section presents how the Red Cross supports people living with HIV/AIDS in terms of empowerment and how it is understood by their clients. This section answers the second and third research questions. Finally, there is an overall section where gender issues are discussed, a section that has connections with all the themes and sections in this chapter.

### Experiencing stigma and discrimination in Uganda

In Uganda, large efforts have been made to minimize stigma and discrimination and its effects for people living with HIV/AIDS. Much has been done, but there are still things to do. More or less every family has been affected by HIV/AIDS in one way or another. Besides the emotional effects, HIV/AIDS also leads to practical and economical consequences for the remaining relatives e.g. becoming a single parent and/or the loss of a family provider. If the one left behind has the privilege of having a job, there might be nobody to take care of the children. HIV/AIDS also causes many child headed households in Uganda. An example of the wide spread effects is given from a Red Cross staff member interviewed in this study:

Everybody in Uganda is infected or affected. For me, I pay school fees for three orphans of my brother since the mother died in AIDS too.” (Red Cross staff 2)

Since the prevalence of people living with HIV/AIDS in Uganda, as in other Sub-Saharan African countries, is relatively high (in Uganda it is 6,4 percent for adults and 0,7 percent for children) - adding the recent history of rates being 18 percent in the early nineties – it is a nation where knowledge of HIV/AIDS is widespread (Uganda AIDS Commission 2007). According to the Uganda HIV/AIDS Sero-Behavioral Survey conducted in 2006, 99 percent of Ugandans aged 15-49 years have heard of AIDS. Actual knowledge differs, however, and there are quite a number of misconceptions and myths about the virus, e.g. how it is spread, how to avoid contracting the actual effects of the virus. Some of the misconceptions lead to further spread of the virus, others lead to stigma and discrimination for those infected. One

such misconception, leading to discrimination, is that one can contract HIV by sharing food with someone who is infected with HIV/AIDS<sup>18</sup>. Many people would not buy food from a person with HIV. As little as 29 percent of the population aged 15-59 would buy sugar or fresh vegetables from a HIV-positive market vendor. Only 64.8 percent think that HIV-positive female teachers should be allowed to teach. Another misconception is that people with HIV/AIDS are bewitched and thus need traditional treatment (which will be exemplified further below) (Ministry of Health Uganda and ORC Macro 2006). The results from the study at hand confirm that prejudice like these often lead to social exclusion and discrimination of the infected individuals.

People point and discriminate people who look sick. They fear getting infected from drinking from the same glass, even after washing it. There is also fear of even being around an infected person for risk of being infected. (W 3)

In the early politicization of HIV/AIDS there was, according to Adams (2003), a general hardening of attitudes towards people living with the condition. There was a tendency among governments and officials to blame the individuals themselves for being infected. HIV/AIDS was perceived as a pure consequence of lifestyle (mainly referring to homosexuality or promiscuity) rather than a matter for public health. Many self-help groups were formed in order to oppose such moralistic attitudes. According to Simbay et al. (2007) HIV still today has connotations with risk behaviors such as sexual promiscuity, homosexuality, prostitution and drug use. The results of the research at hand show that these attitudes still remain in many parts of society thus causing stigma and discrimination. People living with HIV/AIDS are often held responsible for their condition because it is most often contracted from behaviors that are considered avoidable.

Some of them, they look at you as somebody – maybe you might have been so reckless with your life. Maybe you are moving up and down with men, that's why you got the sickness. That is what easily come into people's mind. They say that this one<sup>19</sup> must have been what what<sup>20</sup>. (W 8)

No, I didn't tell anybody, I kept it to myself. I didn't want to tell anybody.

Researcher: What was the reason for that?

The reason was... you know HIV was so associated to immorality you know. And for anybody to know you have HIV it means either you are a slut, you are a prostitute, you mismanage yourself or something like that. It was an abomination sort of, for somebody to live with HIV. Yes, the stigma was so high and I didn't know a way to break it out to people. (W 4)

As discussed in the theoretical chapter, stigmatizing attitudes probably correlate with the misunderstandings and misinformation regarding HIV/AIDS as exemplified above.

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<sup>18</sup> Sharing food in terms of that all family members eat from the same plate is customary in Uganda.

<sup>19</sup> Ugandan English do not differ between him or her. Instead 'this one' or 'that one' is used. Some of the indigenous languages in Uganda (e.g. Luganda) do not differ between the two.

<sup>20</sup> The 'what what' is also commonly used in Ugandan English, often used to fill out sentences or to not complete sentences where the message is more or less obvious. In this sentence it refers to 'move up and down' i.e. to have multiple sex partners.

This research shows that stigma in relation to people living with HIV/AIDS thus exists in Uganda even if it has decreased over the last couple of years. Stigma certainly affects people living with HIV/AIDS and many people consider it a large problem. The effect of stigmatizing and discrimination from family members is a particular burden for many reasons. In the Ugandan society, the extended family is an important institution. Most people are dependent on their families why bad relations do not only cause emotional difficulties but also practical problems such as lack of economical support or care when being sick. This study shows that most people infected with HIV/AIDS disclose at least to one or a few close friends, but many choose not to reveal their condition to their family. Even within couples it is common that people do not tell their partner about their condition after getting an HIV-positive test result. The reason is fear of being stigmatized as described above but also fear of getting accused for being the one who brought the virus into their family. Except for fear of stigma, experiences show that many families are not willing to care for an AIDS sick relative. According to Ministry of Health Uganda and ORC Macro 2006, only about 86 percent of people aged 15-59 would be willing to care for relative who is suffering from AIDS in their home. This should be seen in the context of Uganda being a society where the extended family traditionally has far-reaching responsibility for its family members. In this study, among those who have told their families about their condition, several have experienced stigmatizing attitudes and discrimination. Many of them are no longer in contact with their families, instead living on their own, relying on friends and neighbors for economical and practical help.

So when I fell sick I went home one Christmas, I think in the year 2000. When I went home, my step mother saw my condition and she just rejected me. Whenever I used to go home, these people really used to respect me. I was the eldest in the home and all the support used to come from me. Now when I lost my job I had no support to give. Even the money I used for transfer to go home was given from my sister. So I had nothing to give at home. Those people turned against me. They no longer saw any value of my life. They knew anytime I was dying. (W 4)

What the informant describes in the quotation above is an expression of what Deacon (2006) calls instrumental stigma, discussed in the theoretical chapter. The relative's actions arise from basic self-interests. Their conclusion was that she would no longer be able to financially support her family and they most likely feared being close to her because of her HIV-infection. As time went by, they considered her a burden for her family since they would need to pay for her medical treatment and finally get extra expenses for her burial. This is a common phenomenon in Uganda, expressed by several informants. The same informant continues:

Now, the best my relatives could do, they collected money. They started with it when I was very sick, they collected money and they said they wanted to take me back to the village.

Researcher: To take care of you there?

Yes, to do away with me so that if I die I should not give them expenses of carrying a dead body. I said what about my children, would they come along too? They had no answer to that. I refused. And little did they know that I would recover.

There was also an uncle of mine who visited me here. That one told me instead of me staying here I should better go back because it seems I have been bewitched. So for him he believed I was bewitched, that I should go back home and they'll give traditional treatment. So I refused and when I refused, that man insulted me the whole night. The



whole night! Here in my house! He went away in the morning and have never come back to this day. (W 4)

The interviews also reveal that relying on friends is sometimes vulnerable and most informants, even those who perceive themselves as stigma-free today, have previous bad experiences from being stigmatized by friends. Many have changed their circle of friends so that it is based on the ones that are reliable and trustworthy, friends who understand and do not fear or stigmatize. Many of them are people within the same stigma category e.g. people living with HIV/AIDS.

So me, stigma took me right up to our home. Now, when I was bedridden here, the friends I used to have around here, nobody stepped here. If someone came once and found me in that condition would never come back... There was also the burden, because when they would come, they would find me sometimes in the house dry like this. They would start by buying me water of 50 shillings<sup>21</sup>. So that was the burden. They never wanted to carry that burden. [...] (W 7)

Even the people who perceive themselves as stigma-free today all have previous experiences of stigma and know that it is a major problem for many people. The informants who have disclosed are thus convinced that the problem of stigma – also in the urban setting of Kampala - still exists. Still they are grateful that it is nowadays easier to reveal ones condition and to get support from others.

People were so scared to come out before. People were so scared. How will people hear that you have got that, that you have AIDS. How will your family feel? But now these people are so open. [...] You see your friend has come out, you come out also and they support you. The more you are open the more you get the support. (W 1)

The examples of stigma and fear of stigma as described above could all be explained by Goffman's (1963) theory about stigmatized people being discredited and diminished in the eyes of society, leading to spoiled identities for the individuals affected. Almost all informants in this study described personal experiences of what Goffman would call social deflation and discrimination. The so-called spoiled identity is a severe condition, not easy to rise from. It might lead to a stage of confusion or even rejection of one's own identity and value as human being. The stigmatizing attitudes in society are reflected in the individual's self-esteem, however they often appear even worse within the individual than in the eyes of society. Most of the informants in this study witness about bad judgmental and stigmatizing attitudes towards themselves in the early stages of knowing that they were infected with HIV.

A faltering self-confidence caused by stigmatization is a heavy burden to carry and it is very demanding to turn negative feelings into more realistic and positive points of view. In addition, the informants in this study are already stigmatized and diminished in the eyes of society because of severe poverty and everything that it brings. Poverty-related stigma is strongly linked to actual deficiencies such as lack of education, unemployment, bad housings and bad hygiene. It is also connected to prejudices such as poor people being lazy, immoral and engaged in criminal activities. In combination with the disempowering conditions that comes with poverty, it is exceptionally difficult to re-construct one's spoiled identity, to rise up, to get rid of the self-stigma and to respect and to even be proud of oneself.

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<sup>21</sup> 50 UgSh is equivalent to 0.16 SEK

## Feelings and reactions at the time of disclosure

Some people do not disclose their condition because of fear of stigma. One of the informants has been living with HIV for eight years but he has chosen not to reveal it to his family. His fear is based on previous experiences of stigma in his family where his brother got badly discriminated when dying from AIDS. He was excluded from his family and was finally left to die alone and abandoned. His family did not even bring him food.

I can feel badly because if I tell somebody like my sister 'I am like this and like this' [having HIV] she can start to discriminate me. Even I don't think she would allow me to sit there [pointing towards the sister's veranda close by]. I am sure about that.

Researcher: Why do you think so?

Because mostly people they think that when you sit with an infected person you can get the disease. Which is not true. (M 1)

The informant quoted above sometimes brings his sister to the Post Test Club meetings, to listen to the songs, the drama and the information, hoping that she will one day understand so that she will not discriminate when the time comes for him to reveal his condition. This fear of telling people that you have got HIV/AIDS is strong for many people in Uganda, and was the main reason for people declining to be interviewed in this study. Many people also fear participating in contexts like the Post Test Clubs because of the risk of being identified as a person carrying the disease.

The staff members from Uganda Red Cross Society claim that stigma only exist to a minor extent in the urban settings nowadays. They believe that it is partly a result of the efforts from different NGOs including community sensitization such as information campaigns and counseling. Uganda Red Cross Society provides information to the communities via radio (since many people are illiterate or cannot afford to buy news papers), through specially arranged meetings with community leaders and via songs and drama performed by the Post Test Clubs. The fact that stigma is less widespread in the urban areas than in the rural is explained by the fact that people are less likely to live with their extended family in the cities than people in the rural areas and families have a higher tendency to discriminate.

Stigma is not there so much anymore in the urban settings. It is mainly the families who stigmatize and in the city you often live without any relatives, just among friends. They tend to be less judgmental. Before, in the end of the 80s people with AIDS were often left to die alone. Somebody might throw them some food but not more. And still today it is like that in some rural areas. (Red Cross staff 1)

Stigma as a main barrier to disclosure, is mainly based on symbolic stigma and fear of getting discriminated. According to Deacon (2006), the fear is sometimes realistic i.e. based on previous experiences of stigma and discrimination, but most often it is a social construction, a matter of fear of unknown reactions that prevent people from testing and disclosure. Thus people also failure to seek assistance. The fear is connected to symbolic stigma (value-based ideology that compels moral judgments causing discrimination) e.g. the moral judgments from people who are not HIV positive. They fear getting separated and excluded from activities and social life in their family or among friends as a consequence of moral judgments of their HIV status. The informant quoted in the beginning of this chapter says further about fear of stigma:

In my family, not even anybody knows about it.

Researcher: They don't?

They don't. Because then they discriminate, they stigmatize. So I wanted to tell them about my status but let me first leave them, I'll tell them later.

Researcher: What do you think they would do if they got to know?

You know, in our culture, people are discriminating... (M 1)

To avoid disclosing one's condition because of stigma causes not only emotional distress but also brings practical consequences and can be negative for a person's health. Simbayi et al. (2007) have listed a number of behavioral and emotional implications likely to occur as consequences of HIV/AIDS related stigma. The consequences they underline include people not seeking treatment and care services, engaging in unprotected sex practices and fostering a sense of isolation, emotional distress and self-hatred. Avoidance of disclosure can also lead to development of depressive symptoms. Many informants in this study have experienced all those consequences and felt a great relief at time of disclosure. As time went by, they learned how to handle peoples' reactions. Before disclosure they struggled a lot, some even risked their lives for fear of disclosure.

You go to hospital, you want to hide, you don't want somebody to get you in the hospital... I almost died because I never wanted to go to the Zambya [hospital in Kampala] for care. Because they give free drugs but it is a place particularly for people living with HIV and AIDS. So everybody would know. At least let me go to this paying side, they may think I have some just ordinary cough and you know, that type of things. But time came... (W 5)

Actually what broke the stigma was poverty. When I became totally poor, I had no way out. I had to speak out for help. And I had to come out. [...] I'm totally open. I'm stigma free now. Completely. It is a relief. (W 5)

Even though the informants who have disclosed described a relief after coming out, the disclosure itself was very stressful for all of them. Besides the personal feelings, they also had to deal with reactions from people who received the information. Some reactions might be of stigmatizing character as described above, but it might also be emotional reactions and fear of losing a dear one, fear of what is going to happen with the people left behind etc.

When I brought the news to him [a younger brother] he wept. Then I told him, I said no Godfrey,<sup>22</sup> don't cry. I'm not going to die now. He said how, how? I said 'no please, don't cry'. This is not the end of me. Now what we can only do is that maybe we can try and get me some medicine which can push me ahead. So that maybe I can live longer and I look after my children and maybe I can also help you people who are behind me and that's all. (W 1)

One large problem in Uganda is the fact that people, due to fear of reactions from others after disclosure, engage in unprotected sex even when they are infected with HIV. Several informants of both sexes tell the same story, particularly about men who do not want to disclose because they fear losing their possibility of having multiple sex partners. This is a considerable cause for further spread of HIV (and also explains the increasing numbers of infections among married couples).

Most people around here are sick, but because the symptoms are not out, they keep on infecting others. If they all came out like I did, that would be the only vaccine. [...] (W 4)

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<sup>22</sup> Fictive name

[...] but they don't come out or come to the club meetings. And why are they afraid – because they are still killing people. They want their freedom to have sex with multiple women. And we have no power to expose them, we are not allowed to do that...we are not. So they don't care about that they are spreading it. (W 3)

This issue will be further expanded upon below, in connection to a discussion on gender inequalities related to HIV/AIDS in Uganda.

## **Self-stigma**

The informants in this study all have different experiences and stories regarding self-stigma (i.e. accepting some of the negative social judgments of one's identity). Some of them have suffered hard from self-stigma in the early stages of being HIV positive. The informants internalized the negative social judgments prevailing in the community in line with the argument of Deacon et al. (2005). The prejudices were in many cases stronger in their home villages in the countryside. By internalizing these prejudices they were self-stigmatized to such an extent that they were severely reduced with low self-esteem and little ability to see their own value as a consequence.

And now when I knew, I said I'm even getting scared of the children. How should I be with my children? How should I not give this to the children – eating from the same plate, drinking water eh!? So I said no. I started like discriminating myself. I made my clothes be washed in a different basin; they should not mix my clothes with theirs... I was so protective, but discriminating myself. Not even the people from outside... It was terrible. (W 2)

Another informant explains the emotional effects of self-stigmatization, having feelings of lost value and self-respect:

Self-stigma, that is the toughest. Because if you are confident of yourself, even if people talk, people's opinions will never move you. But if you yourself, you ignored your self-confidence, you have put down your integrity. Your values are all finished. I'm not better than a dead person. Then if you don't have value for yourself, who should have it for you? (W 4)

Self-stigma can also lead people to take concrete actions according to the internalized stigma e.g. what they think people would do if they knew. One of the informants resigned from work because of self-stigma.

[...] it was self-stigma. I was not stigmatized from place of work. Nobody knew I was sick. But it was self-stigma. You know. I didn't want... I knew time would come when I would have full blown AIDS and those were my friends and they would laugh at me. So I wanted to run away from them before. I resigned. (W 4)

The study shows that reduced self-esteem affects the person in many ways. According to Deacon et al. (2005), damaged self-esteem affects the way a person responds to the sickness and it also reduces the motivation to challenge stigmatization or discrimination. This has further negative consequences both for the person living with HIV/AIDS and for public health in general, as it becomes an obstacle for testing and disclosure. Further, the likeliness that people seek treatment decreases (Deacon et al. 2005).

It is essential to keep an ongoing discussion about stigma and not to lean back and relax in what is done so far. Obviously stigma still exists and must be continuously addressed and challenged since it brings about wrong treatment, lack of disclosure and thereby further spread of HIV.

And now we keep on talking about stigma as if it has become something that has no value. [...] Stigma is still there, it is still with us. It is only the few who have managed to fight stigma of their lives who are the ones who walk stigma-free. But stigma is still with us. (W 4)

A few informants claimed that they had no experiences of stigma, either self-stigma or being stigmatized from other people. They claimed that stigma still might exist in the countryside, but not in their community. This might be what Deacon et al (2005) refer to as resisting the framework of stigma, that they make use of an excessively positive identity in order to resist the self-stigma. Just as discussed in the theory chapter, some informants in this study stressed their own wellness, projecting negative stigma on other people (Deacon et al. 2005).

## **Individual management of stigma**

In spite of what has been discussed above, some informants actually seemed to be free from stigma, without denial. Those persons had supportive friends and families who made the process easier from the day they got to know they were HIV-positive. In some cases the reason they got infected played a role (i.e. people who did not contract it from sexual transmission tended to experience less stigma). Although in most cases, they have experienced periods of hardship where they suffered badly from stigma and discrimination before reaching where they are today. For most of them it has been a process to get stigma-free. Whether the process was long or short, it was always described as a decision they took at a certain point. This decision was often the result of successful counseling from professionals as well as peer support and listening to other people's stories. A striking number of informants mentioned a strong faith in themselves and in God as factors for overcoming stigma.

I was not all that afraid because most people having this problem. The more you come out, the more free you feel. And the more you talk to your friends, you hear this side, the other side, everyone talks and you become strong. It is good to become strong. (W 1)

To me because I knew the bible so well, what the bible tell us, I didn't have any fear. And I felt no one was discriminating me up to today. Cause I'm ever reading the bible, reminds me of what the bible talks about. People, when they discriminate you, when they send out rumors, that and that is sick... Because I was strong in my faith, I remained strong. I felt no one was discriminating me. (W 1)

Another informant on the same theme:

Yes, somehow people also started to coming out and for me also. I am blessed in the heart I think I should say. When I decide to do something, I do it whole-heartedly. When I decided to say I am getting out of stigma, what is stigma doing for me? I got out of that one. (W 4)

## **Managing stigma by support from the Red Cross**

Uganda Red Cross Society is aware of the hindrances for some people to access their services. Obstacles in terms of stigma restrain many people from accepting home-based care or to join the Post Test Clubs to take part of counseling and essential information. To overcome this, the Red Cross offers some food provision, scholastic materials for orphans and other vulnerable children and even some income generating activities (described in chapter one). The main purpose of the program is psychosocial support and the practical support is a deliberate means to reach people who would not have come for the psychosocial support itself. For some people the need of food and material support becomes the entry point to join the project and then further on to other benefits such as counseling and peer support. Eventually most people in the project become empowered enough to cope with their life as HIV positive and are also ready to disclose. Many informants mention food provision and scholastic materials as their main reason to attend the project. Beside the counseling and support given within the Post Test Clubs, the Red Cross works all over the communities with songs- and drama performances about HIV/AIDS. As mentioned earlier, many people are illiterate in poor areas and people cannot afford to buy news-papers, therefore that is a feasible way to reach many people. For the same reason, radio is frequently used for spread of information. The information spread is mainly about ways of transmission and how to protect oneself. Further knowledge is believed to decrease stigmatizing attitudes in society. Another important channel for spread of information are the volunteers within the Red Cross. Their daily tasks are to serve people in need of home-based care and assist the Post Test Club members with psychosocial support. But they are also strategically picked to spread information and enable people who are not yet attached to the Red Cross projects to seek help and to disclose. Everybody in the community knows who the Red Cross volunteers are and where they live. In this way they have the possibility to anonymously and informally come and ask for support or just information. As described by a club member who is also a volunteer:

And some of them don't want their children to know. So when he comes and he tells me you register my child [as a vulnerable child, entitled for support] but don't come to the house, I'll do that. Because I am trying to win him. Slowly by slowly some of them have come out. (W 4)

## **Empowerment in the Post Test Clubs**

Being member of a Red Cross Post Test Club means a great deal to many people. The Red Cross facilitates self-help in order to empower the members to be encouraged enough to get along with their lives, to find sustainable solutions for their livelihood and to support each other in the community. As mentioned before, the Red Cross focuses mainly on the psychosocial support but also on practical issues such as teaching people how to run businesses and giving out minor loans to get started. The objective is to make the members independent and self-sustaining. As Payne (2005:303) states: "Skills can empower. Gaining and using skills can be an important way of experiencing liberation." By gaining new skills i.e. running a restaurant or selling charcoal, one can become someone important and needed in the community, someone who is useful and not just considered a burden or a threat. This study shows that activities that results in new skills and tasks is clearly empowering, thus making people more independent. There is also a strong focus on the Post Test Clubs and the peer support within them. The target is that the clubs will function even without future support from the Red Cross. This is important since the activities are based on economic support from foreign donors, a support that has no future guarantees.

Mainly it is psychosocial support and mainly via the Post Test Clubs. If they get a lot of psychosocial support they can come to see that it is not that bad to have HIV, life is not over. You can live for another 20 years, more than that and you can still live and earn your livelihood. That is our main goal, not to make them dependent. We start giving them some food, scholastic materials and IGAs<sup>23</sup>, but they are not supposed to be dependent. The main goal is to enable them to be self-sustainable and earn their own living. Also that they will remain supporting each other even when this project has ended. The peer support means a lot. [...] Our food supply and other things is mainly an entry point for them to come here. (Red Cross staff 2)

The Red Cross staff members have a clear role as constructors, typically for Social Workers (as discussed in the theoretical chapter). They build up the structure of the meetings, highlight the problems and define what to aim for in the clubs. This support is essential for members to be empowered. When they are strong and independent enough, they are able to support and empower others, finally it is a mutual support. But before reaching to this stage of empowerment, most people are not able to see the advantages of the psychosocial support itself. That is why, as mentioned before, food supply and scholastic materials is offered as an entry point for people to become members. Some informants confirm that the only reason they originally joined the club was to get food and scholastic materials.

He [a Red Cross staff member] was teaching us and when we had every meeting we started here. People would start coming one by one, one by one. And good enough he was motivating us by giving us the food. Eh! When people saw the food they just said, `aha, we are now going to the Red Cross`. So I became one of the members here. (W 3)

Eventually, by attending the meetings, the club members also realize how they can benefit from the information, the counseling and the peer support as well. For many of them, being in the club context has led to a state where they have come out with their HIV status, which is, as discussed in the theoretical chapter, essential in order to deal with the situation and to find ways to get on with their lives. For some of them it was a long way with a great deal of counseling, both from the Red Cross staff, volunteers and medical staff at hospitals and health centers. As mentioned before, empowering people is a demanding work requiring a lot of reflection and self-analysis. As Adams (2003) points out, a professional Social Worker must have a great self-awareness, he or she must be self-empowered in order to successfully support other people.

One informant went for training to be a Red Cross volunteer and describe the experiences like this:

The whole group, there was about 500 people. People started giving testimonies... I said hmm, am I serious to not disclose? If these people can all come out, who am I to not be like them? Then I like started coming out, I talked. (W 2)

As mentioned in the theoretical chapter it is clear that empowerment can make people overcome barriers in achieving their life objectives and gain access to services (Payne 2005). The clients of the Red Cross overcome their barriers of stigma, thus getting access to support in different ways. The support also makes them overcome large barriers in terms of bad self-confidence and self-value. It seems like being a volunteer is one of the optimal forms of empowerment. Firstly, they get access to different training programs and workshops as part of

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<sup>23</sup> Income-generating activities

their education. The information and deepened knowledge about HIV, stigma and discrimination is strengthening itself. Secondly, this study shows that being able to help others is an important aspect of empowerment, generating a valuable fulfillment in life. Empowerment is according to Askheim (2007) connected to strength, feeling of power, the right to speak, self-control, self-trust, social support, pride, competence, cooperation and participation. Empowerment thus, emphasizes the importance of positively regarding humans as actors with a high level of knowledge concerning their own situation, as long as the right conditions are created. That is the common base for all positions of empowerment. This study shows that the Red Cross clients who are also volunteers have the strongest experiences of the positive feelings (listed above) connected to empowerment. However it is true for most people in the Post Test Clubs.

Counseling is something that is generally emphasized as essential (in combination with peer support) both in order to go for testing and also to disclose if the result is HIV positive. Counseling is given by staff at medical centers and hospitals but also by Red Cross staff members and volunteers. The informants in this study all believe in constant counseling and that some people need it for a long time before they are empowered enough to deal with the situation.

Counseling is very important because the more they counsel you the more you come to live in the reality, knowing that you are a sick person. The counseling makes us strong. When you put your heart and follow the way they have counseled you to make you strong. (W 1)

As discussed in the theoretical chapter, this guidance and counseling is a vital task for Social Workers. Their role is to facilitate a process of empowerment, to guide the clients into ways of getting control over their situation and being in charge of their own lives. As Payne (2005) states, the Social Workers help clients identifying their possibilities and focus on helping them make decisions that are essential for them. This study shows that this kind of empowerment actually takes place in the Post Test Clubs. Staff members (who are professional Social Workers) are aware of their role in the empowerment process, aiming to educate volunteers and strengthen them to empower others.

Groups can achieve a great deal in terms of empowerment. According to Adams (2003:77), they can provide “support for the individual, reduce the risk of isolation, offer a context in which personal skills can be developed and practiced and a means by which an individual, whose consciousness has been raised, can work towards fulfilling heightened personal expectations.” Empowered groups may give their members a positive experience, but they will probably not be able to tackle wider problems arising from phenomena such as poverty, joblessness, poor housing, inadequate health or social care services (Adams 2003). These remain severe problems for the informants in this study. The peer support is the most clearly expressed benefit from being a member of the Post Test Clubs.

The peer support is very important, it means a very great deal to us. Because when you are there, you forget other problems that you have here at home. We laugh, we chat with dear friends, you hear the story of the other person, this one's side also and it encourages you. You become stronger. When you are in a group, you can think that you are badly off but when you hear your friend's stories, you will know you are not that badly off. There are other people outside there who are more badly off than you. In that faith you support each other and you pray for one another. Whenever there is anything, we are able



together. Find one person has a problem, we are able together. We support each other like that. (W 1)

But it is a good place, cause when you meet and then you find people who are cracking jokes, you laugh, you do what? You forget all about the past. Actually, you know when you stay at home, at times that thing comes to ring in your mind every time that you are sick, you are sick. You cannot avoid it. But if you go and stay among friends, you forget it so fast. [...] look at me, I am not alone. There are many people who are also sick. And some people they come and even tell you `Me I've been sick for 20 years`, `I've been sick for 15 years` like that. And they are still living. Then you also have that hope of staying. Maybe I will also live for some time. (W 1)

The peer support in the Post Test Clubs also contributes to emotional and practical security and sometimes it actually works as a minor safety net. When someone gets sick and is not able to work, the club members use the collected money to buy some food in the acute situation. This study shows that this is for many of them a stark contrast to the stigmatization and isolation they most often have experienced from friends, family and neighbors. The peer support in combination with counseling, information and training seems to be an important key to empowerment.

[...] to me, it is good because I have got so many friends now. Even when I'm sick, people are concerned, they come and help me. [...] What is important is somebody who can tell you don't do this, do that. If you do like this, it would become like this and you would become like this. So you decide and see what is better for you. Do you want to leave your children when they are young? Or do you want to see them grow? I think it has helped me. I have made friends, I know how to talk to people, I can express myself. And when I am talking about something, I am sure of what I'm saying. Because of this training. [...] That's how I have benefited. And training, they are very vital and they help. They keep people moving. People keep on meeting and getting new ideas. (W 2)

There are many people who do not get any practical support from the Red Cross since only a minor part of the community, mainly families with the most vulnerable children, are prioritized for food support, scholastic materials and income generating activities. Many members are never reached by those benefits even though the needs are vast. The aim for the support is, as mentioned before, to strengthen people to find sustainable solutions for their livelihood. One of the informants in this study benefited from an income generating activity where she had a loan to start a minor business. The business today generates enough income to pay the rent, food and school fees for the children and orphans that she is responsible for.

So the loan was given to me and I liked it so much. My child Peace<sup>24</sup> was taken as one of the vulnerable children so she received scholastic material like books, pens and all those things. And it has really helped me so much. So, so much. (W 3)

All the informants expressed hope for more food supply and scholastic materials as well as income generating activities for more people. Those who have already got the loan, wish that their fellow members will also get it since they can clearly see how they have benefited from it. The ones who got food supply and scholastic materials are not satisfied with the amount they have got, it is not enough to cover their needs. They are also critical to the fact that the Red Cross does not provide school fees for the most vulnerable children. Some informants are also critical to the ways of distribution i.e. who got the benefits and who did not. Some

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<sup>24</sup> Fictive name

informants witnessed about corruption among staff members and volunteers who was said to take some of the food that were supposed to be distributed among club members. These statements are expressions of mistrust towards the Red Cross among the clients, a matter that should be taken seriously, and be discussed. The Red Cross staff members confirm the lack of resources and need for more money from the donors, however they do not mention corruption at any level in the organization.

There is a strong link between the concepts of empowerment, self-help and stigma (discussed in the theoretical chapter). Many researchers such as Shih (2004) have moved focus from the stigma itself towards attitudes and coping-skills (empowerment) of the stigmatized people. She refers to people who are successfully empowered to overcome the harmful consequences of stigmatization. Empowered, stigmatized people can be successful spokespersons for the group they are representing and also role models for success and strength (Adams 2003, Shih 2004). This is also confirmed by some informants in this study:

But some of them get encouraged when they see people like us come out and talk about ourselves. In fact one time, a friend of mine was telling me, when I was passing the market... And some women in the market they would say: `If AIDS is like this one of Faith<sup>25</sup>, then I should also go and test! Because Faith was dying here, we expected her even to cross over. And if she's looking like this, then we'd better also go and test and follow the steps she has followed'. (W 4)

Self-help groups such as the Post Test Clubs of Uganda Red Cross Society are created in favor of individuals experiencing stigma. Goffman (1963) discussed the phenomenon of social movements such as clubs or groups for mutual support, self-help and emotional security, groups that are habitual for people with common disabilities or shared difficult experiences in life. Members sharing the same stigma, people of certain stigma categories, tend to get together in social gatherings where the recruitment is entirely based on the shared stigma. When two people with the same stigma come together, they tend to respond to each other and to act in a particular way according to the fact that they belong to the same stigma category. It is more likely that friendship occur among them because of sharing the same stigmatized characteristic.

I have a lot of friends. I go with them to Red Cross, I talk to them, we chat every evening, we are together and so we have overcome it [the stigma]. (W 1)

In order to summarize what has been said so far in this chapter, we let one of the informants give voice to what empowerment means in this context.

Yes, you overcome it completely! Now, we can be empowered in many ways. We can be empowered with knowledge, we can be empowered with material things, we can be empowered with relationships. And all those parts I can get with the Red Cross. (W 4)

As mentioned earlier, all the informants are not entirely positive to the support from the Red Cross. From the researcher's point of view, much can be said regarding their organization, leadership and lack of cooperation with other organizations having similar activities. However that is not the focus of this study, therefore not explored entirely and is left out of this study. What is obvious though is that the Red Cross carries out a successful work on empowering their clients, thus reducing stigma and discrimination.

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<sup>25</sup> Fictive name

## Gender perspectives

Throughout all the empirical data; observations and interviews, the lack of men and therefore male voices has been evident. However, there has been a lot of talk about men in terms of reflections and questions regarding the prevailing gender inequalities in Uganda and the effects of the lack of male participation in the Post Test Clubs. They all (male and female informants) express worries and/or a sort of sadness that most men are absent. They strongly believe that knowledge and a strong faith in God (and thereby increased faithfulness in sexual relationships) are the primary means of prevention for further spread of HIV. The study shows a strong sense of resignation among women regarding the male dominance in what they call 'the African culture'. 'The African culture' is described as a culture where most men are absent in contexts where women are typically represented such as the Post Test Clubs. The men are said to take less responsibility for their families in terms of providing school for the children, fighting for sustainable livelihood solutions etc. Most men do not want to discuss sensitive problems and difficulties such as HIV/AIDS together with women. Discussing in that sense is considered a female thing. 'The African culture' further exhibits large inequalities in the power balance between men and women. There is a male sexual dominance where women have no right to negotiate for sex i.e. whether to agree to sexual activity or to condom use in order to protect her physical health. Rapes within and without families are common and partly socially accepted among men. Finally, the most striking statement about 'the African culture' is that most men have multiple sexual partners and cannot be satisfied with only one, even though he is formally in a monogamous marriage. And if he travels at work or works far from home, it is taken for granted that he needs extramarital sex. As expressed by an ICRC<sup>26</sup> staff member in a pilot interview: "*You know men cannot remain without sex for that long [talking about somebody who was on duty away from home for three weeks and thus asked his employer for condoms]*". One of the informants explains 'the African culture' as follows:

Researcher: What do you think are the reasons that men are not there? [in the Post Test Clubs]

It is the African culture mostly bringing that. When ten women are sitting, men would say it is the women's talk now and why would I sit and talk there? I cannot be part of it. Not only that, they would say when women say 'Man, start to use a condom', many men don't believe in that. 'I was paying bride price for you and now you are telling me to use a condom!' Maybe even when you found the discordant couples<sup>27</sup>, he will not understand. So there are things which they think they do not work. (W 2)

Since stigma is such a barrier for testing in Sub-Saharan Africa (Simbayi et al. 2007, Wolfe et al. 2006, Bell et al. 2007), many people do not get access to services provided by NGOs and other institutions. Without being reached by the information, the counseling and peer support, people are less likely to test, but also to disclose and to seek treatment, a fact that almost all informants in the study confirm. It seems to be particularly true for many men in Uganda.

You know men are scared to come out openly.

Researcher: Why?

That's when you see other men when a woman comes out, a married woman, when she comes out and finds out she is HIV positive, tells the man 'let's go for testing', the man refuses. Maybe she starts her drugs and the man obviously knows now he is sick. He

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<sup>26</sup> International Federation of Red Cross and Red Crescent Societies

<sup>27</sup> Discordant couples are couples where one of the spouses is HIV positive but the other is negative.

would force her, he would want to share the what? The drugs of the lady. That one is very common among men. Men are scared to come out. They are ashamed of themselves. They don't want to be known that they are sick. (W 1)

For us women we don't fear because it is better if we know our status and to come out and we know that maybe it will help us. To live longer. When you know what you are, you know how to protect yourself. But with men, they keep hiding. [...] But men just fear because they don't want to associate themselves with such groups because people would say 'Ah! That man is sick, that man is sick!' That people would talk about them. That's what they fear. (W 8)

The lack of knowledge leads to disastrous effects for example as illustrated in the quotations above. According to all the informants, both staff members and people living with HIV/AIDS, it is common that men who fear to disclose do not seek treatment. Instead, they take the medicine of their wives, meaning that none of them will get correct treatment required for their survival. Eventually this leads to pre-mature death which, except for the emotional aspects, causes severe poverty and hardship for the widows and often orphans left behind. Besides, the widow and children are often left infected with HIV.

Yet, another consequence is that these men keep spreading the virus again and again. Commonly, they ignore the rather obvious fact that they are HIV positive and also refuse condom use. Thereby they infect other people in the community as well as keep on re-infecting<sup>28</sup> their wives over and over again.

[...] and they [refer to men] spread a lot. They are the ones spreading. They know they are sick, they don't go for counseling. They don't know what to do, they don't know how to prevent it so they just keep on. Spreading AIDS. (W 1)

No, we have some men also [in the Post Test Club] but you know men, they don't generally want to come out. That's the main problem. Most men fear. At the moment you find that women don't fear coming out. But with men, when a man finds that maybe he is sick, they fear to come out so that maybe if I come out, women will see me and they will think this one is sick. Maybe they will loose relationships with women. Maybe they want to go around with other women, the what what – spreading also. But that is spreading to other people. That's what most people fear. And that's the most difficult thing we have at the moment. (W 8)

It is obvious that the issue of men's disclosure needs to be stressed so that they can get access to counseling and essential information. That seems to be the main challenge for NGOs like the Red Cross at the moment. Nobody, nor men nor women, in this study had an answer to the question of how to reach out to men. A few things have been tried out (i.e. male Post Test Clubs), but nothing has been successful so far. Today, most people just appear to be resigned to the fact that men are difficult to reach in this matter, referring to 'the African culture'.

They fear. Men are here in the village but I don't know... I don't know what they can do so that men can come out. (M 1)

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<sup>28</sup> Re-infection (also called super-infection) is when a HIV positive person gets exposed to a new form of the HIV-virus which might be resistant to certain anti-retroviral drugs. HIV infected persons having unprotected sex are also exposed to other sexually transmitted diseases such as syphilis and gonorrhoea.

To sum up; as long as nothing else is being done to the unequal power balance between the sexes and what is referred to as 'the African culture' in this study (but that occurs in different forms all over the world), people will keep spreading HIV within and outside families and stigma will continue to be a main barrier.

## **CHAPTER FIVE**

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### **DISCUSSION**

The aim of the study has been to explore the experiences of stigma and discrimination for people living with HIV/AIDS in Uganda and to examine the work that is done by Uganda Red Cross Society to empower infected people. The study also investigates how the support is perceived by the clients and if it leads to empowerment in terms of decreased self-stigma and increased independence respectively. The study takes its point of departure in Naguru and Bukoto, two slums of Eastern Kampala. The research questions and the empirical data are discussed and analyzed by means of stigma and empowerment theories.

The study is a qualitative case study. The methods of data collection have been in-depth interviews with people living with HIV/AIDS, semi-structured interviews with staff members of Uganda Red Cross Society and three observations of club-meetings arranged by the Red Cross for HIV-tested clients. The observations formed a base for the interview questions. The interviews have been analyzed via meaning condensation.

### **Perceived stigma and discrimination among people living with HIV/AIDS in Uganda**

Research question one concerns how issues regarding stigma and discrimination are perceived among people living with HIV/AIDS and their surrounding communities in Uganda. The study shows that stigmatizing attitudes and discriminating activities have decreased but that they are still prevalent, constituting major obstacles for people living with HIV/AIDS in Uganda. Firstly stigma and discrimination contributes to fear of disclosure which has both psychological and practical effects. General psychological consequences are emotional distress, sense of isolation, self hatred and sometimes depressive symptoms. Additional consequences shown in this study are that people engage in unprotected sex, which is likely to lead to spreading the HIV virus. Since many people are poor in Uganda, there are also economical consequences mainly for widowed women and orphans. Secondly, living with stigma, either instrumental stigma, symbolic stigma or self-stigma, generates a large psychological burden. Previous research on women in Sub-Saharan African countries shows that women often avoid disclosing and thereby fail to seek assistance and treatment for fear of stigma. The study at hand points out that the fear is even more evident among men since they rarely take part in group activities or talk about sensitive issues the way women do. Men are not reached by information or counseling. Thus, they lack necessary information needed for a positive living and continue to engage in unprotected sex. According to the results of this study there seems to be two reasons why men are not easily reached by information and counseling. Firstly, they seem to fear stigma more than women and secondly, they seem to be anxious to continue with their life style in the sense of having multiple sexual partners.

### **Empowerment as means to reduce stigma and discrimination**

Research question two asks what has been done by Uganda Red Cross Society to reduce stigma and discrimination against people living with HIV/AIDS in their targeted communities. Uganda Red Cross Society has a number of activities aimed to fight stigma and discrimination. The Red Cross provides voluntary counseling and testing. People who have tested for HIV (no matter whether they are positive or negative) are welcome to join so called Post Test Clubs, created for the purpose of spreading information, providing psychosocial

support, counseling and peer support. The Red Cross also provides home-based care for people who have developed AIDS and who needs psychosocial support and care in their homes. Further, they provide income-generating activities, mainly aimed to empower clients to become self-sustainable, but it also generates decreased stigma as people living with HIV/AIDS start businesses such as shops or restaurants. In this way, they become important and valued in the community via the services that they provide. Finally, the Red Cross provides peer support and community sensitization in terms of radio shows, songs and drama that are aimed to increase the awareness of HIV/AIDS including reduced stigmatizing attitudes and discrimination. The research showed that it is evident that empowerment in terms of information, counseling and peer support helps people to overcome stigma.

## **From stigmatization to independence**

Research question three concerns how the clients of Uganda Red Cross Society understand the project and the support they are given in terms of empowerment, self-stigma and independence. The research shows that the entry point for most clients is the food provision, provision of scholastic materials for orphans and vulnerable children and the knowledge that some people receive income-generating activities. But as time goes by, they also realize the benefits in terms of empowerment and reduced self-stigma. In this way they also become less receptive to stigmatizing attitudes in society. The clients emphasize the peer support and counseling as main factors for empowerment.

Since there are obviously successful methods to reach and empower women living with HIV/AIDS, to educate them in positive living e.g. how to access treatment, to live healthy and to prevent further spread of the disease, it is crucial to further research to find out how men could be reached and how to engage men in the fight of HIV. That would probably lead to a number of tools to prevent further spread of HIV. Also, a more educated and informed population in general, would most likely be less inclined to stigmatize people living with HIV/AIDS.

## ***The African masculinity culture***

On a long-term basis, it is essential to work on gender structures in the Ugandan society to overcome stigma. What is said to be 'the African culture' is, as mentioned earlier, prevalent all over the world, it just takes different expressions in different societies. However, it will here be discussed from a Ugandan perspective. It has impacts on both men and women why it is crucial to discuss the issue from different angles. One of them is of course to empower women who are subjected to male oppression. But it is also important to discuss masculinity since 'the African Culture' also becomes a burden for men. It is necessary to work with men as well as women regarding attitudes and to keep an ongoing discussion about different conditions and prevalent inequalities between the sexes. I believe that masculinity is a social construction, expressed differently in different cultures. In the Ugandan context, men are expected to act according to 'the African culture'. The 'African culture' is also a social construction, leading to images and stereotypes of the male sexuality. Men are, according to some unspoken norms in Uganda, supposed to "womanize", e.g. having multiple (female) sex partners and to have a high level of sexual activity in general. They are also supposed to be superior to women in terms of decision-making and power. These norms, combined with the fact that many people do not practice safer sex, lead to disastrous consequences regarding the spread of HIV/AIDS. It is important to include men in discussions concerning gender inequalities and masculinity why it is again a crucial task to find ways of how to reach men. It

is important to see that these gender constructions can be changed. However it is possible that it requires playing on the prevalent masculine identity, sometimes in unconventional settings in order to do that, but with whatever means, the issue must be addressed. In this context it is important to mention that what is referred to as 'the African culture' is of course not true for all of Africa and certainly not for all men. It is a concept describing a masculine, social culture, generally used by people in parts of Sub-Saharan Africa and elsewhere.

## **Stigma in the Swedish context**

Stigma and discrimination towards people living with HIV/AIDS is not a phenomenon unique for Uganda or other countries in Sub-Saharan Africa. Stigmatizing attitudes occur all over the world. However expressions and consequences differ depending on social and economical contexts. In Sweden, stigma and mainly fear of stigma is a major problem among people living with HIV/AIDS. According to staff members at PG Väst<sup>29</sup>, common prejudice in the Swedish society is that HIV/AIDS only affect injecting drug addicts and homosexual men. Further the staff members at PG Väst state that there are still misconceptions regarding how HIV is contracted, which contributes to an exaggerated fear or carefulness when being around an infected person. Many people have experienced bad treatment from staff members within medical services, especially when seeking assistance for other medical complaints. For example it is common that people get questions about issues rather irrelevant for their complaint i.e. how they were infected. It is also common that staff members within the medical services are scared and even refuse to work with HIV positive patients. Many people with HIV in Sweden avoid revealing their condition for fear of stigma. Most people disclose only to a few close friends and siblings. It is common not to reveal to ones parents. Only a few people are entirely open with their HIV-status in the wider circle of acquaintances and in relation to people at work. They fear reactions that are commonly expressed by silence and that people do not know how to handle the situation. Thus, stigmatizing attitudes prevalent in the Swedish society cause similar emotional effects as in Uganda. However, a major difference is that people in welfare states like Sweden are less dependent, economically and socially, on their families and most people are able to carry on with their lives even without accepting and understanding families.

## **Limitations of the study**

This study has a number of limitations. The language might have limited the research since the researcher do not speak Bantu languages like Luganda, Luo or Swahili, the respective mother tongues of the informants. Instead, our second language was used namely English. A way to avoid the language obstacles would have been to use an interpreter who knew the Bantu languages but this person would have needed training in HIV-issues and also in interview technique. Engaging an interpreter would also have caused expenses that there was no budget for. Finally, as an experienced interviewer, I saw the advantage of being alone with the informants in order to be able to access the truthfulness. These are the reason why the interviews were conducted in English. My perception is that all the informants were fluent enough.

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<sup>29</sup> PG Väst is a support group focusing on self-help for people affected by HIV/AIDS in the Western parts of Sweden. The information is given from personal communication with staff members at PG Väst namely Camilla Stridh, Joakim Berlin and Marie Johansson.



Another limitation is that there are few male informants in the study, leading to a lack of male perspectives. If there were no limit in time, even more effort would have been put into finding male informants i.e. via further presence in the communities since most communication in Uganda is based on physical presence and face-to-face networking.

I am aware of the kind of difficulties that might occur when trying to understand a culture so different from the one I was brought up in. During my research I have come upon issues that I do not understand or that I might have misinterpreted due to cultural differences. The fact that I spent a relatively long time in Uganda (six months) was an advantage though, as it gave me the ability to learn as much as possible about the country and its culture. Regarding the fact that I was white and Westerner among black Africans was also an issue for my research. I was obviously seen as a foreign (even exotic) element when moving around in the communities, doing interviews and attending club meetings. Even though I was carefully introduced as a student doing research, there was always a risk that I was seen as somebody representing the rich Western world and the Western donors that normally visit the clubs. The clubs are frequently visited by donors why it was difficult to differentiate me as a researcher from other guests. The information about being student and the purpose of my visit was repeated several times in order to assure the informants and club members that the only reason I was there was for the purpose of this research.

## **Future hopes**

As this study shows, there are feasible ways to diminish stigmatizing attitudes and its effects for people living with HIV/AIDS. Uganda Red Cross Society has taken major steps to empower people living with the infection and to sensitize people in general regarding this issue. However there is more to do and it is important to find long-term solutions regarding stigma and also to prevent further spread. It is crucial for the gender inequalities and causes of 'the African culture' e.g. African masculinity to be addressed. Although it requires long-term efforts, there is hope for a society free from stigma. Finally, one of the informants will give voice to this hope:

Researcher: Is there something you want to add?

I just wish you good luck with this study... And I hope we can meet again, to talk about that thing again.

Researcher: To talk about stigma?

Yes, maybe we can meet sometime again when stigma is not there. (M 1)

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**Meaning condensation, theme stigma and discrimination**

M 1

I can feel badly because if I tell somebody like my sister 'I am like this and like this' [having HIV] she can start to discriminate me. Even I don't think she would allow me to sit there [pointing towards the sister's veranda close by]. I am sure about that.

Researcher: Why do you think so?

Because mostly people they think that when you sit with an infected person you can get the disease. Which is not true.

I have never got discriminated of that. Because as I have told you I never told my family. But I think I can get discriminated or stigmatized by my family. But of friends, I don't think so.

You know, I told you about my brother (who died in AIDS), the father of that child I have. They discriminated him very bad.

Even they don't wanted to treat him, to care for him when he was sick. They just said let him go to the village and die there. Even if somebody would have helped that brother of mine, they would have been sick. Because of that he didn't get any treatment or nothing. Even they didn't give him something to eat, he stayed in the house alone, with that child.

W 1

To me because I knew the bible so well, what the bible tell us, I didn't have any fear. And I felt no one was discriminating me up to today. Cause I'm ever reading the bible, reminds me of what the bible talks about. People, when they discriminate you, when they send out rumors, that and that is sick... Because I was strong in my faith, I remained strong. I felt no one was discriminating me.

People were so scared to come out before. People were so scared. How will people hear that you have got that, that you have AIDS. How will your family feel? But now these

Avoiding disclosure for fear of being stigmatized by the family. People fear being near infected people.

Fear of being discriminated if revealing his condition to the family.

Experiences of a family member being discriminated by his family.

The family rejected his brother when knowing he had AIDS. He was left to die.

To stay empowered and resist stigma from other people via faith in God.

Stigma was higher before, nowadays it is better and people are more open.

people are so open. You see your friend has come out, you come out also and they support you. The more you are open the more you get the support.

People were just scared. But now everyone is open. People are so open. You see your friend has come out, you come out also and they support you. The more you are open the more you get the support.

Same as above

W 8

In fact at first when I went back to the village, most people would look at me because I had all those swellings on the body and then they just knew, this girl is sick. People pointed and said “this girl is sick”. Even some uncles of mine, they could say “Look at you! You have even lost weight, you have even become black! (I used to be light skinned) What is the problem?” And unfortunately all those fellows have died. And me, I’m still living. All of them, they have all died, even my dad passed away in 2005. They have all died. The only one who is still alive is my mom.

Stigma shown openly by commenting. No compassion. Express that people who used to stigmatize have died before her.

Yes, of course! That’s what they think. But me I knew what I was so I didn’t bother so much. And it is very funny, most of those fellows even who used to talk about me that “Ah this one is sick!”, they – most of them have died.

Coping stigma by knowing who you are and what you have done.

Some of them, they look at you as somebody – maybe you might have been so reckless with your life. Maybe you are moving up and down with men, that’s why you got the sickness. That is what easily come into people’s mind. They say that this one must have been what what. And especially like a person like us, like when you are working in a hotel. You know in a hotel that’s where you meet so many different people. You work with different types of people, these who come from outside and what? So they say “Ah, this one maybe was moving up and down with people, that’s why she contracted the sickness or what.”

Describing that people have prejudices, stigmatize and blame people being infected with HIV.

But me I just kept it in my heart, I said I don't mind, let them talk whatever they talk so long I know my stand, how I was. So that one didn't affect me. It didn't affect me.

No, it is the stigma. They just fear, they know that if they come out and people know that they are sick, then you will lose friends. You will lose friends and maybe it will put him out of place. But like us women we don't usually have that fear mainly with us.

For us women we don't fear because it is better if we know our status and to come out and we know that maybe it will help us. To live longer. When you know what you are, you know how to protect yourself. But with men, they keep hiding. We used to have about five men in our group but there is only one man who usually come and that gentleman is there with the wife but that day when you came the wife was not around. So he didn't also come. But men just fear because they don't want to associate themselves with such groups because people would say 'Ah that man is sick, that man is sick.' That people would talk about them. That's what they fear.

W 2

And now when I knew, I said I'm even getting scared of the children. How should I be with my children? How should I not give this to the children – eating from the same plate, drinking water, eh?! So I said no. I started like discriminating my self. I made my clothes be washed in a different basin; they should not mix my clothes with theirs... I was so protective, but discriminating myself, denying myself. Not even the people from outside. (Sigh..) It was terrible.

Researcher: So you hadn't disclosed by then?  
No, I hadn't, I had not disclosed to anybody.  
Researcher: Not even the family?  
Not even the family. But people knew, those people who saw my husband die, for them they already suspected like I was also infected.

Coping with stigma, self-empowerment by keeping in mind who you are and what you have done.

Men fear losing friends if they disclose.  
Women most often do not.

Women take advantage of the support in the group. Men avoid it for fear of stigma.

Fear of infecting the children. Started to discriminate herself, separating everything in the household. Perceive it as a terrible experience.

Did not disclose for fear of what people were going to think or say. People already suspected.

### W 3

So stigma in our community, they use to point. If they see you very tiny, they say that one is thin, she is now gone. And people used to say when you have AIDS you don't even have to take a glass of water. If you take that glass of water you may just destroy it because you have HIV/AIDS. Mm. Yes, they said you are now useless and if you come near to them you will give them AIDS. That is what they would say.

People point and discriminate people who look sick. They fear getting infected from drinking from the same glass, even after washing it. There is also fear of even being around an infected person for risk of being infected.

And when we go in [as Red Cross volunteers] some will say Eh, you come and help me! And some will say No! You are just coming, I am not sick. Just go away. Others would just tell you to go away from their place.

Researcher: Do you think there are some people who fear to come to the club?  
Yes, there are very many. But they come out when they have seen that they are starting to falling sick. But when they are not yet very sick, they try to hide themselves.

Researcher: Are there some people who would like to attend the project but who can't come?  
Yes, they need to come but you know the age, which they have said, at times they don't qualify within the age (not older than 50). But most of our young ones, they are the most people who are really affected and they still fear to come out, they still have that stigma.

### W 4

No, I didn't tell anybody, I kept it to my self. I didn't want to tell anybody.

Researcher: What was the reason for that?

People point and discriminate people who look sick. Fear getting infected from drinking from the same glass, even after washing it. Also fear of being around an infected person for risk of being infected.

Stated example when she came out. People came to her for advice and help. Other people stigmatized, took a distance.

Getting different reactions when knocking doors as Red Cross volunteers. Some welcoming, some rejective.

Many people fear coming to the club before starting to falls sick. Try to hide their conditions as long as possible.

Young people don't joint the Red Cross project because of stigma, fearing to come out.

Didn't disclose because of fear of stigma.

The reason was... you know HIV was so associated to immorality, you know? And for anybody to know you have HIV it means either you are a slut, you are a prostitute, you mismanage your self or something like that. It was an a abomination sort of, for somebody to live with HIV. Yes, the stigma was so high and I didn't know a way to break it out to people.

Yes, somehow people also started to coming out and for me also I am blessed in the heart I think I should say. When I decide to do something, I do it whole heartedly. When I decided to say I am getting out of stigma, what is stigma doing for me?

Mmm, it's not easy, I usually stand with them because I was there, I don't despise them. I know it is not an easy thing to do. It takes a decision. It takes a decision and it's not something you wake up one morning and say I'm getting out to tell people and to expose myself, no. That is why you find even in Red Cross, we have people who are sick around but they cannot come to Red Cross because of that stigma. They know Red Cross is supporting people living with HIV so they say A ah, I'm not going there, they will see me as somebody with AIDS. That is the problem.

But anybody who still has stigma, I respect the person. I always give them a hand. I keep – it is just constant counseling that can get them out. Constant counseling. You give them the positive part of it, the negative part of it and they decide.

It is me who is dying! You know, it is not those people! For them, they are talking, maybe they are not sick, or they are just stupid talking and they are also sick, they don't know. And most of them who point the finger at me, at least I have buried some and others, we take medicine together.

Researcher: Is it still like that, that people talk and point finger?

Decided to disclose when other people did. Questioned what stigma did to her.

Understand people who have still stigma/doesn't disclose. Takes a decision to disclose. People avoid Red Cross activities because of stigma.

Respect and understand people who have still stigma. Believe that constant counseling and information is the only way to break the stigma.

Don't care about people who stigmatize. Knowing that many people share the same destiny.

People talk and point finger and avoid people for being sick. Isolating. Need more



They do! To this very day, people still do. In fact we still need a sensitization in this measure. Not everybody is aware totally about HIV. People, when I was very sick here, even my neighbours used not to come at my door here. Maybe they thought it was a disease that was contagious or, I don't know. They used not to come. And that bad thing is still in people.

Most people around here are sick, but because the symptoms are not out, they keep on infecting others. If they all came out like I did, that would be the only vaccine. That would be the only vaccine – behaviour change!

Researcher: So you think stigma is the key to prevent further infections?

Yes! And anti-stigma behaviour. That is the only thing! If people changed their mentality, way of thinking, that would just be the end.

Yeah, I remember when my son was very sick and his class mates started to stigmatize him, calling him skeleton. Then even the teacher. The whole school eventually started to call him that. I had to pull him back from school. He came from school crying, he told me, it was not easy. I wept the whole night.

So that boy had to stay home for a whole year until he started the medication and recovered and I took him to another school. I shared with the head master. And the head master told me never to share this with anyone else, not even to the class teachers. So she took me to the school nurse and we called the boy and I introduced the boy to her, they are now very good friends. But nobody else in the school knows. Only those are the ones who knows. Otherwise he would be badly treated. Stigma is still strong, it is still there.

And now we keep on talking about stigma, stigma as if it has become something that has no value. There should be another strategy of attacking stigma again, there should be a new strategy of attacking the spread of HIV and AIDS again. The old strategies seem to have

sensitization. People are still not aware enough.

People keep infecting others since they don't disclose (because of stigma) and since the symptoms are hidden. Believe the only vaccine would be if all infected people came out.

Peers and the teacher in school used to stigmatize her son, calling him skeleton. Had to take him out of school. Emotionally hard for both of them.

Started in a new school with the advice not to tell anybody else but the principal and the school nurse. Otherwise he would be badly treated because of stigma.

Rave for a new strategy against stigma as a matter of preventing further spread of HIV. The old strategies are not efficient anymore.

gone down. Like the ABC strategy. Stigma is still there, it is still with us. It is only the few who have managed to fight stigma of their lives are the ones who walk stigma-free. But stigma is still with us.

So when I fell sick I went home one Christmas, I think in the year 2000. When I went home my step mother saw my condition and she just rejected me. Whenever I used to go home, these people really used to respect me, I was the eldest in the home and all the support used to come from me. Now when I lost my job I had no support to give. Even the money I used for transfer to go home was given from my sister. So I had nothing to give at home. Those people turned against me. They no longer saw any value of my life. They knew anytime I was dying.

And now coupled on my own experience. Because I have been there where those people are now. So the way I hated to be stigmatized, the way people mistreated me is the way... I can look at somebody and I just assess that this person has a problem.

It is funny that there are some people who come to the club and they tell you don't come and visit me. I don't want my neighbours to know because when we go out in home visiting we are in our t-shirts, we have our first aid kit, so they know – Red Cross project is handling people living with AIDS so when we enter somebody's door.

Whereas for me when somebody comes and we talk about the programs I shout here, I don't care about anything. But there are people, they want that if you are entering they just want you to talk in a very low voice so that the neighbours cannot hear. So those are the people, when a person tells you – you don't put yourself in a house. But slowly by slowly you'll find that person starting to come out. You know it's a process. Stigma can be broken! Stigma can be broken if there are many people who are like us who have come out.

Was discriminated from the family because of HIV. The family turned against her, lost value of her life.

Use her own experience of stigma to understand and support people who have not disclosed or who are stigmatized.

People fear attending the meetings or getting home-based care because of stigma.

Work slowly by slowly by counseling and information in order to get access to help people fearing of stigma. Believe stigma can be broken if more people come out like she has.

I was there, I used also to fear. Even to see somebody, any nursing person branching to my house. I said no. So I think everybody has stood there talking about me. But that is not the case. So I know their feelings. I know their feelings.

Researcher: Why did you lose your job, was it also because of stigma?

Yes, it was self-stigma. I was not stigmatized from place of work. Nobody knew I was sick. But it was self stigma. You know. I didn't want... I knew time would come when I would have full blown AIDS and those were my friends and they would laugh at me so I wanted to run away from them before. I resigned.

Self stigma, that is the toughest. Because if you are confident of yourself, even if people talk, people's opinions will never move you. But if you yourself, you ignored your self confidence, you have put down your integrity. Your values are all finished. I'm not better than a dead person. Then if you don't have value for yourself who should have it for you?

But now, why do these people not want to come out? Because they still have hidden agendas. And also, another reason is that some of them – I have a family where the wife came out like me, they used to live in the UK. Then when they came back the woman came out open and that caused the husband a job.

Researcher: Why did he lose your job? Stigma at the place of work. They started pushing him away until he was eventually restrained without anything. But it was because he was HIV positive. So some people do it so that they protect their positions at places of work.

W 5

You go to hospital, you want to hide, you don't want somebody to get you in the hospital... I almost died because I never wanted to go to the Zambia for care.

Suffered from stigma before, didn't want anyone to see that she got medical treatment, fear of people talking. Not anymore.

Lost her job because of self-stigma. Fear of people laughing at her when it was obvious she had AIDS. Ran away and resigned before that happened.

Self-stigma is the toughest. Makes one lose the self-value.

People who not disclose sometimes have hidden agendas e.g. want to continue having multiple sex partners. Another reason can be fear of losing a job because of stigma at work. Those things happen.

Almost died because of stigma. Didn't want to seek free medical care because then it would be obvious.

Because they give free drugs but it is a place particularly for people living with HIV and AIDS. So everybody would know. At least let me go to this paying side, they may think I have some just ordinary cough and you know... that type of things. But time came...

Actually also what broke the stigma was poverty. When I became totally poor, I had no way out. I had to speak out for help. And I had to come out. One time they even published my story in The Monitor (news paper). I'm totally open. I'm stigma free now. Completely. It is a relief. I can stand anywhere, I can stand on TV and speak about myself. I have no problem.

W 7

So me, stigma took me right up to our home. Now, when I was bedridden here, the friends I used to have around here, my relatives around here, nobody stepped here. If someone came once and found me in that condition would never come back.

There was also the burden, because when they would come they would find me sometimes the house dry like this, they would start by buying me water of 50 shillings... So that was the burden. They never wanted to carry that burden. Secondly of course there was that fear that when you relate with a HIV infected person you could possibly catch it in a way or so.

Poverty broke the stigma. Had no way but seeking help. After disclose she became totally open.

Exposed to stigma in her own home. People who found out that she was sick never came back.

People also avoided visiting her because she needed things that were costly – she became a burden. Again some people feared getting infected from being close to her.

### INFORMED CONSENT

UNIVERSITY OF GOTHENBURG  
Department of Social Work

International Master of Science in Social Work  
Spring 2008

#### **From stigmatization to independence: empowering people living with HIV/AIDS in Uganda**

This research project is one of the requirements of International Master of Science in Social Work at University of Gothenburg. The purpose of this particular study is to research on HIV/AIDS related stigma and discrimination in Uganda and to explore the outcome of Uganda Red Cross Society's work on anti-stigma.

The information collected will be used for education purposes and will be handled in a very confidential way so that unauthorized persons cannot access it.

The research study is on a voluntarily basis and you have the right to decide whether to participate or not, even after the interview is conducted.

The interview will be recorded as this makes it easier for me (the researcher) to document what is said during the interview. In the analysis, data will be changed so that no interviewee will be recognized. After completion of the project, the data will be destroyed. It will only be used in this research project.

You have the right to refuse answering any questions, or terminate the interview without giving an explanation.

You are welcome to contact me in case you have any questions.

Mobile: 0777 135012

malinalb@yahoo.se

Thank you  
Malin Albrektsson, student

## Interview guide clients of Uganda Red Cross Society

Introduction, presentation

### Situation, disclosure and stigmatization

Significant events/occasions regarding stigma and discrimination

How get to know about the positive HIV status

Feelings when getting the results

Reactions from family, friends, community

If reactions affected the way of telling/disclose

Personal experiences of being stigmatized

### Support from the Red Cross

Their own history about attending the project – when, how

Why selected to the project

What does it mean to be part of the project, experiences, role, tasks

How has life been affected by being part of the project

What is good with the project

What is less good or what can be developed

Who are not reached by the project – who should be reached – who are coming to the positive living clubs and who are not - why

Should everybody get the chance to take part – why just some people?

Grasp during the interview: age, religion, ethnicity, time lived in the community, back-ground, family etc.

## **Interview guide staff members**

Introduction – presentation

Name, age, position, number of years working

What are the reasons that you work with these matters?

Why is the work important?

How is stigma towards people living with HIV/AIDS shown in the Ugandan context?

How is it shown in terms of discrimination – concrete examples?

How do you work with community sensitization?

How do you work with empowering the clients?

Support in sharing experiences and disclosure?

Is there a difference in the community since before this project started – what?

What do you see as the main achievement for the clients?