Dissertation By

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MASTER OF ARTS IN SOCIOLOGY OF MAKERERE UNIVERSITY

PUBLIC DISCLOSURE OF THE HIV+ SERO STATUS: BENEFITS, CHALLENGES AND ASPIRATIONS OF PERSONS WHO HAVE GONE PUBLIC IN UGANDA

March 2010

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2006/HD14/6295U

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A DISSERTATION SUBMITTED TO THE SCHOOL OF POST GRADUATE STUDIES,
MAKERERE UNIVERSITY, AS PART OF THE REQUIREMENTS FOR THE AWARD OF A
MASTER OF ARTS IN SOCIOLOGY OF MAKERERE UNIVERSITY

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Abstract

Background: *Although disclosure of the HIV+ status can happen at four different levels –to a partner, family, friends and to the public, previous investigations in Uganda have concentrated on benefits and challenges from the first three levels (to a partner, family, friends) at which disclosure can happen.*

Methods: *To examine the benefits, challenges and aspirations of persons that have gone public, in-depth interviews with 30 individuals that have disclosed to the public were conducted.*

Results: *Benefits out of public disclosure to the community include, debunking myths and misconceptions about HIV/AIDS, notifying potential partners, educating both HIV negative and positive people about how to reduce the spread of HIV. Collective shame is the major challenge met by some groups from which individuals who disclose come. Benefits to individuals disclosing are; economic, treatment and intrinsic benefits, reduction of re-infection, and reduction of discrimination and stigmatisation. Major challenges to the individual include discrimination and stigmatisation from many sources, failure to be believed by the communities they disclose to and the necessity to change "careers". The aspirations that individuals who disclose to the public get after disclosing include, the desire to encourage more of positive persons to disclose, continuing the fight against discrimination and stigmatisation in whatever way is possible and working to strengthen organisations and institutions involved in the response to HIV/AIDS.*

Conclusions: *The challenges the individual who discloses and the community disclosed to meet, are currently less than the benefits they get from public disclosure. In view of this, programmatic efforts should focus on increasing public disclosure through drama group initiatives in an attempt to promote HIV prevention and treatment.*

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Abstract

The objectives of the study were; to examine the process to public disclosure. To examine the benefits (both to the individual and the communities from which they come) that arise out of the act of public disclosure. To establish the challenges (both to the individual and the communities from which they come) that arise out of the act of public disclosure. To establish the aspirations (largely of the individual disclosing) that arise as a result of the act of public disclosure.

In order to achieve the above objectives in-depth interviews with 30 individuals that have been able to disclose to the public were carried out to gather the data. In addition to individuals that have been able to disclose to the public, 6 counsellors who are involved in the outreach programme at TASO which is charged with the responsibility of sensitizing communities about the reality of HIV/AIDS were interviewed as key informants.

Public disclosure is part of the disclosure process and in most circumstances is the last phase of the disclosure process. In limited circumstances, public disclosure is able to happen without the lower levels (individual, the family) not being aware, but the ultimate result is that the important stakeholders finally get to realize that a certain individual is HIV positive, even when they disclose first to the public before disclosing to the family. Three categories of people were identified when the act of public disclosure was considered, the first category was that of people who even with the support of an organized group can never accept to go public, then the second category of people are those who with the support of an organized group can be able to go public, and the third category of people are those who have not waited and do not need the support of organized groups to go public.

The study established that public disclosure brings with it a number of benefits; and these benefits are enjoyed by the community to which the individual discloses and the individual who discloses their status. Community benefits include; notifying potential partners, encouraging people to come for VCT, educating those who are negative how to remain negative, educating those who are already positive. Individual benefits include, economic benefits (employment, allowances), spiritual benefits, treatment benefits,

intrinsic benefits (contributing something to society), helps to reduce re-infection and reduces discrimination & stigmatisation of the HIV+ individual.

The study established that those who disclosed to the public faced some challenges which include, failure to be believed by the communities they disclose to that they are actually positive, discrimination and stigmatisation from members of the community who would otherwise not have stigmatized them. Other challenges that those who disclose to the public include, family related challenges such as discrimination and stigmatisation of their children and work related challenges.

The aspirations that individuals who disclose to the public get after disclosing include, the desire to encourage more of positive persons to disclose in order to contribute to the movement to defeat stigma and discrimination of HIV positive persons. Other aspirations include, continuing the fight against discrimination and stigmatisation in whatever way is possible, working to strengthen organisations and institutions involved in the response to HIV/AIDS and working to polish up the language of religious leaders on HIV/AIDS.

In conclusion, because sexual contact remains the major mode of HIV transmission, society presumes that whoever is HIV positive contracted it through sexual contact with numerous partners. This becomes the basis for stigmatisation and discrimination of those who are HIV positive. When public disclosure is being encouraged, those that disclose to the public should be encouraged to present the multiplier effect HIV transmission enjoys to their audiences so that, society should recognise that there so many other people out there who are HIV positive not because they had or have numerous sexual partners but only because they faithfully had unsafe sex with their partners.

Most of the discrimination and stigmatisation of HIV+ individuals is carried on by the people around the HIV+ individual rather than the wider public. Disclosing to the public would not be a big problem, but most of the HIV+ persons cannot disclose publicly because this would in the process expose them to their immediate friends, family members that they are not interested in getting to know that they are HIV positive. So, the appropriate strategy to fight discrimination and stigmatisation would require that entire families and or close relatives of the individual who is positive get involved in this person’s treatment so that they are given appropriate information about HIV/AIDS.

Acknowledgement

I wish to express my gratitude and appreciation to the following persons and institutions.

My supervisor, Prof. Charles Rwabukwali for the guidance and encouragement throughout the entire research process. The Deputy Director PSI-Research, TASO Uganda, Dr. Jonathan Wangisi for the support and guidance that enabled me to have my study cleared at TASO Uganda. The Manager TASO Mulago for welcoming me into the organization and introducing me to the relevant personnel who later helped me to complete this study. The Data Management Officer (DMO) at TASO Mulago, Mr.Cellistine for introducing me to the staff of TASO Mulago, and the clients of the TASO Mulago clinic.

The Council for the Development of Social Science Research in Africa (CODESRIA), for financially supporting this study. The Social and Behavioral Research on HIV and Capacity Building Project in Uganda (SABRES) team, for training me in qualitative data analysis, providing me comments on the draft dissertation, and generally introducing me to health systems research and particularly research within the field of HIV/AIDS. The Faculty of Social Sciences-Makerere University for financial assistance that I received which enabled me to complete the entire M.A course.

My friends and colleagues, Innocent Kamya, Anicia Nabukenya, Herman Butiime, Eric Sseguja, Susan Gamwino, Nicolate Nekesa, Joseph Kyebuzibwa, Peter Wabukala and the entire of the M.A Sociology 2006-2008 class, for the jokes we shared and encouragement that you gave me to complete the entire course. My respondents who for reasons of confidentiality I can’t list here, took sometime off their busy schedules to respond to my questions.

To all of you, I say, thank you so much. May the good Lord reward you abundantly!

Declaration

I hereby declare that this dissertation is a result of my own efforts, and where I use the works of other people, I have appropriately referenced those works. I also declare that this dissertation has not been submitted to any other university than Makerere University for any award.

Date: Feburary 25, 2009

Sign:

Christopher Tumwine (Student)

Dedication

This piece of work is dedicated to my sister Justine Tumusiime, who not only substantially supported my education from the lower levels but has continued to encourage me on.

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CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

The Millennium Declaration that was made in September 2000 by up to 189 world leaders at the dawn of a new millennium in New York, set 2015 as the target date for achieving 8 ambitious goals all aimed at enabling the world's poorest people to escape conditions of deprivation. Under this Millennium Declaration, the desire to combat HIV/AIDS in the struggle to bring development to the world's poorest nations was given due importance. Specifically under this declaration, the fight against HIV/AIDS is emphasized by Goal number 6 (United Nations, 2000b:5; , 2000a:5; , 2007:18). Under Goal 6, it is specifically targeted to have halted and begun to reverse the spread of HIV/AIDS by 2015.This study obtains its overall inspiration from the spirit that guided the world leaders to recognise the centrality of the fight against HIV/AIDS in an attempt to bring development to world's poorest nations especially in Sub-Saharan Africa.

The devastation the epidemic has caused and continues to cause on the world cannot be questioned. UNAIDS (2008:15) shows that since the beginning of the epidemic, 25 million people have died of HIV-related causes. In many of the severely affected countries, the impact of the epidemic on societies has been catastrophic, with previous development gains being eroded, life expectancy declining, health services overwhelmed and families and communities devastated (United Nations, 2007:11; WHO, 2006:10). In 2007 alone, between 30 million-36 million people were living with HIV, between 2.2 million-3.2 million people became infected with the virus, and between 1.8 million people died of HIV related causes world wide (UNAIDS, 2008).

Sub-Saharan Africa remains the region most heavily affected by HIV, accounting for 67% of all people living with HIV and for 75% of AIDS deaths in 2007 in the world. An estimated 1.9 million people were newly infected with HIV in sub-Saharan Africa in 2007, bringing to 22 million the number of people living with HIV in the region (UNAIDS, 2008). Across the Sub Saharan region, women bear a disproportionate part of the AIDS burden: not only are they more likely than men to be infected with HIV, but in most countries they are also more likely to be the ones caring for people infected with

HIV (UNAIDS/WHO, 2006). The secrecy that surrounds sexual issues partly explains the above high prevalence rates in Sub-Saharan Africa.

UNAIDS (2001) shows of how HIV/AIDS has caused a major development crisis in sub-Saharan Africa, and is making deep inroads into economic and social development in most of Sub Saharan Africa. In subsistence agriculture, labour shortages and declining incomes because of AIDS deaths are changing the way people farm and compounding food insecurity. Among poor households, people may be unable to seek treatment for sexually transmitted infections which, left untreated, increase the risk of contracting HIV, the virus that causes AIDS. Poverty continues to push young people and women into unprotected commercial sex to provide for their families. At the same time, one of the consequences of HIV/AIDS is greater poverty as individuals, families and communities lose productive labour as well as face escalating health and funeral costs (UNAIDS, 2001).

In Uganda, HIV/AIDS was first described in 1982 at two fish landing sites on Lake Victoria of Lukunya and Kansensero (Neema, Musisi, & Kibombo, 2004:1; Rwabukwali, 2007:2; Uganda AIDS Commission (UAC), 2006:1). Since then the HIV/AIDS epidemic has gone through three identifiable phases. The first phase of a rapid increase in the infection rates stretched from 1989 to 1992, the second phase of a rapid decline in the infection rates from 1992-2002, and the third phase of stable infection rates stretches from 2002 to today (Kirungi, Musinguzi, Madraa, Mulumba, Callejja, Ghys et al., 2006:1; Rwabukwali, 2007:2; Uganda AIDS Commission (UAC), 2006:1; UNAIDS/WHO, 2006:17). With this current stabilisation phase, there is still great potential for the infection rates to rise once more, and therefore efforts to curb the spread of the epidemic (that include reducing stigma and discrimination significantly) need to be strengthened. Stigmatisation and discrimination of HIV+ people partly explains the above high prevalence infection rates in Sub-Saharan Africa.

Discrimination, in a non-legal sense, is the discernment of qualities and recognition of the differences between things. Human beings have the power of discrimination, which is essential for us to be able to make decisions and judgements about things.

Discrimination toward or against a person or group is the treatment or consideration based on class or category rather than individual merit. It is usually associated with prejudice. It can be behavior promoting a certain group or it can be negative behavior directed against a certain group. The latter is the more common meaning.

While stigma according to Link and Phelan (2001:367) exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them”. In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Link and Phelan go on to show that the term stigma is applied when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.

Identifying which human differences are salient, and therefore worthy of labeling, is a social process. There are two primary factors to examine when considering the extent to which this process is a social one. The first issue is the fact that significant oversimplification is needed to create groups. The broad groups of black and white, gay and heterosexual, sane and mentally ill are all examples of this. Secondly, the differences that are socially judged to be relevant differ vastly according to time and place. An example of this is the emphasis that was put on the size of forehead and faces of individuals in the late nineteenth century – which was believed to be an indication of a person’s degree of criminal nature (Link & Phelan, 2001).

The second component of this model centers on the linking of labeled differences with stereotypes. The linking of negative attributes to differentiated groups of individuals facilitates a sense of separation between “us” and “them”. This sense that the individuals of the labeled group are fundamentally different causes stereotyping to take place with little hesitation. The "us" and "them" component of the stigmatization process implies that the labeled group is slightly less human in nature and at the extreme not human at all (Link & Phelan, 2001).

The fourth component of stigmatization in this model includes the “status loss and discrimination” that is experienced. Many definitions of stigma do not include this aspect, however it is the belief of these authors that this loss occurs inherently as individuals are “labeled, set apart, and linked to undesirable characteristics.” The members of the labeled groups are subsequently disadvantaged in the most common group of life chances, including income, education, mental well being, housing status, health and so forth (Link & Phelan, 2001).

The authors also emphasize the necessity of power (social, economic, and political power) to stigmatize. One example of a situation in which the power role can be clear is when we consider patients and medical personnel; while each category may have stereotypes about the other, patients may not successfully stigmatize medical personnel because they have little power in the patient-medical personnel relationship but medical personnel can stigmatize patients (Link & Phelan, 2001).

Fear of discrimination and discrimination prevents people from seeking treatment for AIDS or from acknowledging their HIV status publicly. People with, or suspected of having, HIV may be turned away from health care services, denied housing and employment, shunned by their friends and colleagues, turned down for insurance coverage or refused entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder. The stigma attached to HIV/AIDS may extend into the next generation, placing an emotional burden on children who may also be trying to cope with the death of their parents from AIDS (UNAIDS, 2001).

Stigmatisation and discrimination of HIV+ individuals is a violation of their fundamental human rights and fans the further spread of HIV/AIDS. It undermines willingness on the part of the HIV+ individuals to seek out testing, counselling and treatment services. HIV testing for instance, is important in halting the further spread of HIV, but stigma always works against it leading to negative consequences for the campaign against the spread of the epidemic (Abadı´a-Barrero, 2005:1219; Program of International Health and Human Rights, Francois-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, & International Council of AIDS Service Organisations (ICASO), 2004:1; UNAIDS, 2005:1).

Generally stigma implies the branding or labelling of a person or a group of persons as being unworthy of inclusion in human community, resulting in discrimination and ostracization. The branding or labelling is usually related to some perceived physical, psychological or moral condition believed to render the individual unworthy of full inclusion in the community. Stigmatisation is usually applied to those we regard as impure, unclean or dangerous, those who are different from ourselves or live in different ways, or those who are simply strangers. Stigma often involves a conscious or unconscious exercise of power over the vulnerable and marginalized (Uganda AIDS Commission (UAC), 2006:6; UNAIDS, 2005:11). Despite widespread recognition that stigmatisation and discrimination of HIV infected individuals contributes to the further spread of HIV/AIDS, the two are still with us here in Uganda. Despite the existence of this widespread stigmatisation and discrimination of HIV+ individuals, an increasing number of individuals have been able to defy this community imposed branding and have gone public about their HIV+ status. This study was therefore aimed at examining the benefits, challenges and aspirations of these HIV+ persons after disclosing their status to the public.

1.2 Statement of the Problem

Disclosure of the HIV+ status is one of the hardest stages an HIV/AIDS patient has to go through if they are to obtain treatment from any HIV treatment clinic in Uganda. The treatment clinics require that a person who has tested positive should disclose to another-who is to turn out to be a treatment buddy. Disclosure of the HIV+ status can be done at different levels, the first one being to a partner, the second to the entire family, the third to friends, the fourth to acquaintances and lastly to the entire public (Ryan, 2007).

Although treatment clinics require persons who have tested HIV+ to disclose their status to at least another person; some of the infected individuals keep it to themselves, majority of the infected individuals disclose to their partners, their families, and few of the infected individuals manage to disclose to the public.

Unlike when disclosure of the HIV+ status is made at the first two levels (partner, family), disclosure to the public brings the HIV+ persons in contact with diverse people many of whom he/she may not have had previous relationships with. This kind of disclosure to diverse people especially in the attempt to have them abandon their risky sexual behaviours was believed can bring with it a whole new set of benefits, challenges and aspirations to the HIV+ person. This study therefore, examined those new benefits, challenges and aspirations that HIV+ persons get after disclosing their status to the public.

1.3 Objectives of the Study

1.3.1 General Objective

The overall objective of the study was to examine the benefits, challenges and aspirations of HIV+ persons after disclosing their status to the public in Uganda.

1.3.2 Specific Objectives

1. To examine the process a positive person goes through to finally disclose to the public.

2. To examine the benefits HIV+ persons in Uganda get after disclosing their status to the public.

3. To establish the challenges faced by HIV+ persons in Uganda, after disclosing their status to the public.

4. To establish the aspirations of HIV+ persons in Uganda, after disclosing their status to the public.

1.4 Research Questions

1. What process do HIV+ persons follow to finally disclose their status to the public?

2. How does the public react to HIV+ persons that disclose their status to the public?

3. What drives HIV+ persons to disclose their status to the public?

1.5 Scope of the Study

The study examined the benefits, challenges and aspirations HIV+ persons get after disclosing their status to the public in Uganda. The study was conducted from The AIDS

Support Organisation (TASO)-Mulago Branch. The AIDS Support Organisation provided a base from where the researcher identified HIV+ persons who had disclosed to the public and he interviewed them. Data collection went on for a period of 2 months in which the researcher was able to interview those HIV+ persons who had already disclosed their status to the public.

1.6 Significance of the Study

The findings of this study will contribute information to policy makers in the Ministry of Health that are involved in the response to HIV/AIDS epidemic. It will emphasize the contribution that can be made after defeating stigmatization and discrimination in the fight against HIV/AIDS. It will also be useful to social and behavioural researchers in the field of HIV/AIDS, as it will open up new areas in which strategic research that can lead to strengthening of the available interventions can be carried out. Practitioners in the field of HIV/AIDS prevention and treatment will benefit by further appreciating the centrality of stigma and discrimination in the spread of the HIV/AIDS epidemic.

1.7 Theoretical Framework

Social Control Theory

At the heart of any social order are conceptions of right and wrong (Horwitz, 1990:1). The definition and defense of the moral order is a fundamental aspect of all social organization. Social control is the aspect of society that controls the moral order of the group (Berger, 1963:83-84). Every social action, relationship, or arrangement is permeated by normative qualities that indicate moral conduct (Horwitz, 1990). In this study, I use the normative conception of social control that is limited to the purposive actions that define, respond to, and control deviant behaviour. Social norms under here are more or less deeply rooted and widely shared (Horwitz, 1990).

Going with the above normative conception of social control, I realize that religious norms and beliefs in Uganda are deeply rooted and widely shared. The major religions here, disapprove the scenario of an individual engaging in extra marital affairs. The norm that must be upheld and which is deeply rooted and widely held by most religious groups is that of faithfulness. Any individual, who engages in extra marital affairs, having sex before marriage (fornication), is regarded as sinful. Because the norm of faithfulness in principle is deeply rooted within the religious Ugandan community, whoever now contracts HIV/AIDS is seen to have been sinful since sexual intercourse remains the major mode of transmission of this disease (BBC, 2005; Ross, 2005; Trinitapoli & Regnerus, 2006).

The “religious” community around the HIV+ individual after realizing that this individual is “sinful”, attempts to engage in acts of social control. This social control takes the form of stigmatizing and discriminating the HIV+ individual for deviating from the widely held religious norm of faithfulness (UNAIDS, 2005). At this level however, this kind of social control that the community around the HIV+ individual engages in may not benefit the individual very much, but is usually an attempt to ensure that those around can learn from the example of this individual so that they can uphold the norm of faithfulness.

Ridicule, stigma, scorn and discrimination of the HIV+ individual are therefore commissioned by most of the community onto the HIV+ individual as a means of social control. Stigma can be defined as a distinguishing mark of social disgrace (Collins, 1993; Taylor, 2001) Stigma serves to reinforce social norms by defining deviance (Black & Miles, 2002; Taylor, 2001). Stigmatization is an exercise of power over people (Gilmore & Somerville, 2000; Taylor, 2001) and a means of social control by marginalizing or excluding a group or an individual from the wider community, and so reinforcing societal values. Sotang (1991) cited by Taylor (2001:794) suggests that HIV is a metaphor for “sinful” and “evil”, therefore discrediting individuals’ claim to “moral characters” and one of “us”. So, in anticipation of this kind of treatment from the wider community, most HIV+ individuals (who are sure of their status) never disclose their status beyond their immediate partners. However, an increasing number of HIV+ individuals have started on defying this community imposed stigmatization and discrimination by going public about their HIV+ status. The unique benefits, challenges and what drives these individuals on after public disclosure to the Ugandan public is what this study focused on.

Although the social control theory is well positioned to explain the thinking behind the pervasive stigma and discrimination of HIV+ people, its major shortcomings emanate from its structural nature. Because this theory is a structural theory, it cannot easily explain why an increasing number of HIV+ individuals are defying this community imposed stigmatization and discrimination by going public about their positive status. To explain this kind of behaviour and therefore cover up for the weaknesses of the social control theory, I adopt the Social Constructionist theory that starts with the rationality of human actions in explaining behaviour.

The Social Constructionist Theory

According to the Social Constructionist theory (which is made popular by Berger and Luckmann), the scenario of people generally taking the world ‘out there’ for granted, the scenario of looking at the components of the world as being prearranged long before people arrive on the scene, merely waiting to be discovered is questioned. Robertson (1981:152) shows, that contrary to the view that the world is prearranged, the reality human beings experience is and can socially be constructed through three distinct stages:

1. Externalization: This occurs when through their social interaction people produce cultural products. These products can be of many different kinds-material artifacts, social institutions, ideas about human nature, knowledge of reality. When these products have been created they somehow become ‘external’ to those who produced them.
2. Objectification: This occurs when these externalized products appear to take on a reality of their own, becoming independent of the people who created them. In other words, people lose the awareness that they themselves are the authors of their social and cultural environment of their interpretations of reality. They are confronted by their ideas and other products as though these things had an “objective” existence like mountains or the moon. The products become just another part of reality to be taken for granted.
3. Internalization: This occurs when through the socialization process, people learn the supposedly objective facts about reality, making them part of their own subjective, “internal” consciousness. People socialized in similar cultures or subcultures share the same perceptions of reality, rarely questioning the origins of their beliefs or understanding the process by which those beliefs arose in the first place.

Reality is thus constructed through a complex process of social interaction, in which people collectively act on the world and are influenced in turn by the results of their own actions (Berger, 1963; Bryman, 2004; Robertson, 1981). In realization of this process of social construction of reality, I do highlight that stigmatization and discrimination of

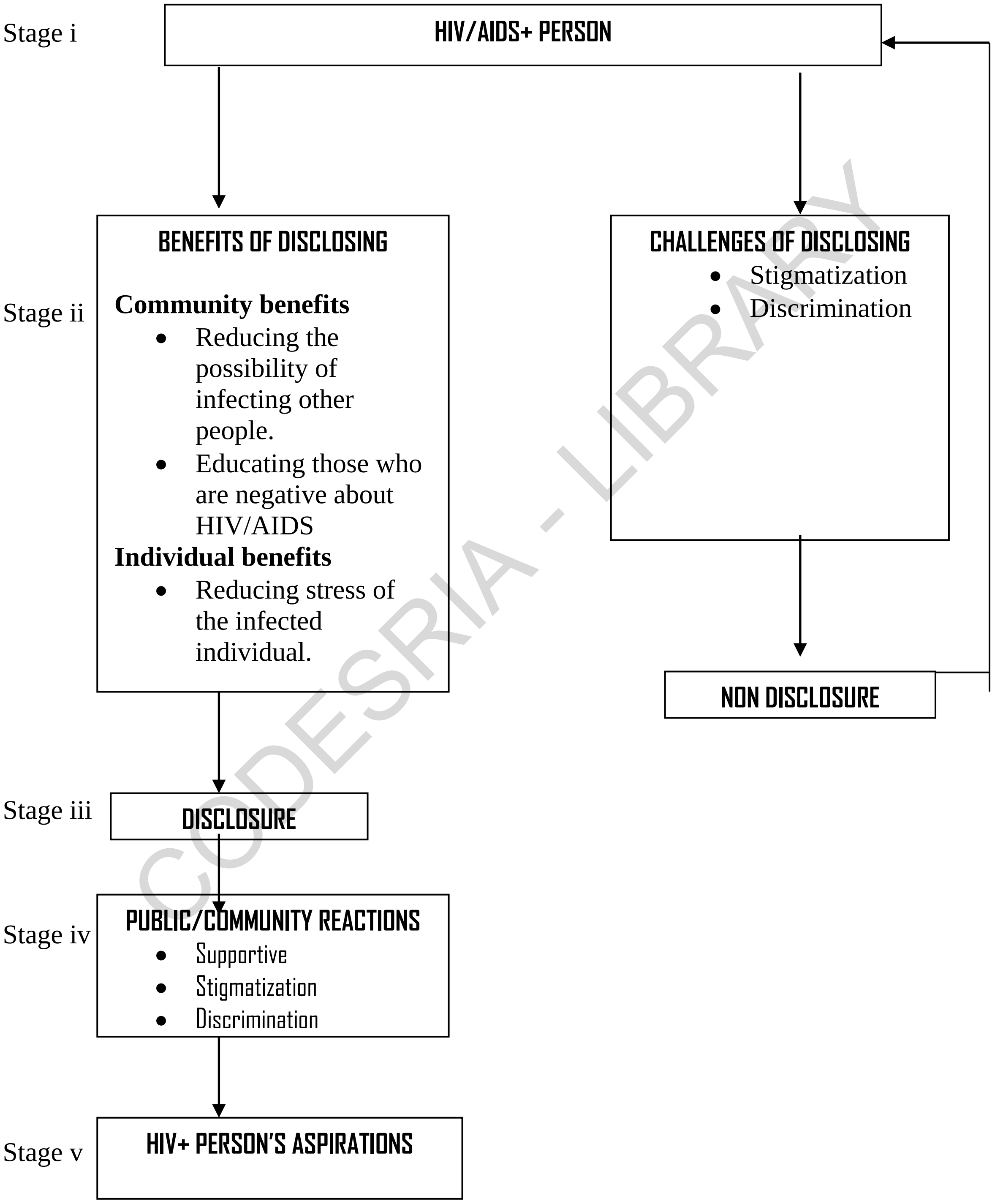
HIV+ individuals are forms of social control that were socially constructed to serve the value of faithfulness; in the early years of the epidemic, infected individuals were highly stigmatized and could not disclose their status. But because of the common good that accrues from public disclosure of the HIV+ status, such as reducing the possibility of infecting of other people, reducing suspicion of the community around, reducing the stress of the infected individual and helping in educating those who are negative about the seriousness of HIV/AIDS, those who have disclosed their status to the public today, contrary to the earlier view that they will be ridiculed, stigmatized and discriminated against seem to be obtaining acceptance and support from the community around them (African Women in Science and Engineering, American Association for the Advancement of Science, Jomo Kenyatta University of Agriculture and Technology, Association of American Colleges and Universities, & International Women in Science and Engineering, 2001:12). The act of public disclosure in these circumstances can be seen as promoting public good because of the numerous gains that go with it to the entire community. Individuals here who have gone public about their status can be seen as attempting to construct a new reality based on the desire to defeat the well documented negative consequences of stigmatizing and discriminating against HIV+ persons. Various institutions and the community at large bond with the HIV+ persons who disclose their status to the public, because their actions are seen as beneficial to every one in the community (Brinkerholf & White, 1988). It is believed it is this strong bond and the rewards associated with public disclosure, which spurs the HIV+ persons on to invest their energies further into the fight against HIV/AIDS. This study therefore attempted to examine the seemingly positive benefits to the community and the seemingly energized status in line with the fight against the epidemic that HIV+ individuals obtain after public disclosure.

Theoretical framework: Summary

People will negatively evaluate other individuals whose features and behaviours are seen as threatening or hindering the effective functioning of their groups (Neuberg, Smith, & Asher, 2000; Smith, 2007). Because of this community imposed stigma, most of the HIV+ individuals in the past could not disclose their status to many people if any. This non disclosure however is associated with numerous threats to the community too, that include; malicious exposure to the HIV risk, not seeking testing and counselling services, and support which by themselves exacerbate the spread of the disease. The act of public disclosure by a single individual is usually an act of martyrdom, so that finally the entire community after appreciating the contribution of this single individual can turn out to be more supportive and acceptive of HIV+ people.

1.8 Conceptual Framework

Figure 1: Benefits, Challenges and Aspirations of HIV+ Persons who have gone Public in Uganda.



Stage i: At this stage the individual confirms that he/she is HIV positive. At this level a number of thoughts are running through the head of this individual. Amongst these thoughts is the desire to disclose their status to people around so that the HIV+ individual can be able to get psycho-social support.

Stage ii: At this stage the individual carefully weighs the benefits and costs/challenges of his/her desire to disclose their status to the people around in order to get psycho-social support. On one hand, the individual realises that there are challenges in form of stigma and discrimination that might come from the people that he/she is contemplating disclosing to. So, in order not to face these extra challenges, the individual opts not to disclose their status to the people around. On the other hand, the individual realises that there can be benefits of disclosing such as helping to educate the younger generation about the reality of HIV/AIDS, informing one's sexual partners and potential sexual partners of the risk they face, and reducing the stress the individual faces. The bulk of the benefits under this option go to the people around the HIV+ individual (Program of International Health and Human Rights, Francois-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health et al.) rather than the individual himself.

Stage iii: After seeing the challenges and benefits that can emanate from disclosing their status to the public, some of the HIV+ persons opt to disclose their status. Here the individual believes that since most of the benefits that are going to come out of their public disclosure benefit the public (people around) much more than him/her, these people around him/her should be able to realise that this act is for their own good.

Stage iv: After disclosing his/her status to the public, the people around the HIV+ individual start reacting to his/her action. This reaction can take the form of stigmatizing or discriminating or supporting the HIV+ individual. But many times than not, the people around this HIV+ individual can turn out to be supportive.

Stage v: Depending on the reaction from the community around the HIV+ individual, (but which most of the time may be supportive), this individual gets fresh inspiration that is in line with the fight against HIV/AIDS.

1.9 Definition of Key Concepts

Public Disclosure

The Cambridge International Dictionary of English (1996:1141) defines the word public as relating to or involving people in general, rather than being limited to a particular group of people. This Dictionary shows that to disclose is to make something known publicly, or to show (something that was hidden). In this study public disclosure was taken as the revealing of a person’s own HIV+ positive status to a group that has four or more people who come from beyond his/her immediate family. This group could include friends, acquaintances and even strangers. The immediate family was taken as the members of the household (spouse, children, close relatives) in which the HIV+ person was staying and the parents of the HIV+ person who were or were not staying in the same household with the HIV+ individual.

HIV+ Sero status

In this study, the HIV+ sero status referred to the scenario where an individual had tested reactive to the virus that causes AIDS.

Benefits

The Cambridge International Dictionary of English (1996:117) defines benefit as, to receive or give something intended to help. Benefit is something that promotes well being or that is for the common good. In this study benefits, were taken as the knowledge, skills and any other material resources that the HIV+ person would have gained as a result of disclosing his/her status to the entire public.

Challenges

A challenge is a situation of being faced with something needing great mental or physical effort in order to be done successfully and which therefore tests a person’s ability (Cambridge University Press, 1996:212). In this study, challenges were taken as all demanding situations that an HIV+ person encountered as a result of disclosing his/her status to the public.

Aspirations

To aspire is to have a strong desire or hope to do or have something (Cambridge University Press, 1996:70). In this study, aspirations were taken as the ambitions or desires (in line with the fight against HIV/AIDS) that the HIV+ persons obtained after disclosing their status to the public.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of the available literature in the area of disclosure of HIV status. The gaps in this literature that this study attempted to fill are also presented in this section. The chapter is divided into 3 areas of benefits, challenges and aspirations of HIV positive persons.

2.2 Benefits of disclosing the HIV positive status

Rier (2007:1) in his study on Internet social support groups as moral agents shows that, online support groups have grown increasingly popular for diseases such as cancer, lupus, AIDS and addictions. They offer encouragement, acceptance, and “virtual” companionship to offset social and spatial isolation. Both observers and participants typically describe them as “safe spaces” in which the latter can voice their hopes, fears, and problems without stigma or censure (Rier, 2007). The groups supply information on managing the disease, its treatment, and its effects on daily life. This allows them also to be a tool of empowerment (Rier, 2007; Sharf, 1997), even displaying key aspects of a social movement (Radin, 2006; Rier, 2007). From this, it seems that the act of public disclosure fits into the paradigm that suggests that it is meant to defeat stigma and discrimination so that finally those who are positive are accepted in the community. This study will particularly look at the motivations of the act of disclosing the HIV+ status to the public in Uganda.

Serovich (2000:1) indicates, for people who are diagnosed with a chronic illness, one issue inevitably to be addressed is whether to share this information with others. Researchers have documented that some people disclose information when they feel distressed and obtain some benefit by doing so (Greenberg & Stone, 1992; Serovich, 2000). For instance, those who disclose freely visit physicians less frequently, demonstrate unimpaired immune function, and exhibit autonomic nervous system regularities to greater degrees than their non disclosing counterparts (Pennebaker, Colder, & Sharp, 1990; Serovich, 2000).

Reir (2007:3) shows that in public health terms, disclosure enables partners to notify their other partners and to adopt precautions to avoid transmitting the virus further. And with the arrival onto the HIV treatment scene of powerful HAART therapies Reir continues, disclosure can also help infected partners, postpone progression to AIDS. Rier mainly emphasizes outcomes of disclosure that is done to partners of infected people. This study attempted to look at the positive outcomes of disclosure that is made to the entire community, where many of the people here had not served as partners of the disclosing individual.

There are many reasons why people at risk of HIV infection fail to be tested: fear of discrimination, fear that the test will be positive, lack of access to treatment or lack of access to testing services (UNAIDS/WHO, 2006:129). This fear of discrimination and lack of access to treatment that UNAIDS/WHO were highlighting, were specifically as a result of disclosure at the lowest levels (partner, family, and friends). This study aimed at going over and above the lower levels (household members, parents) of disclosure to establish whether for instance the community takes it upon itself to treat the person who has gone public about his or her HIV+ status.

Stigma may inhibit some HIV infected individuals from disclosing their HIV status because of the associations regarding sexual activities, sexual orientation and contagion (Bor, 2004). Disclosure of HIV diagnosis to family members may also expose loved ones to revelations of sexuality, infidelity or illicit drug use. However, failure to disclose one’s HIV status may in turn limit opportunities for obtaining social support (Bor, 2004; Leask, Elford, Miller, & Johnson, 1997). In summary it would appear that just when HIV disclosure might be most important to help mobilize and access social support, concomitant fears of stigma and rejection may in some cases jeopardize, thwart or at least postpone this (Bor, 2004).

2.3 Challenges of HIV positive persons after disclosure

Serovich (2000:371) shows that disclosure of an HIV positive diagnosis can be very difficult and anxiety provoking. Individuals fear negative reactions in the form of rejection, shunning, abandonment, or fear. However, disclosure is often important for the acquisition of supportive services, it almost becomes inevitable. Although this study highlights some of the challenges that an HIV-positive person can face after disclosure, it was presenting these challenges within the context of disclosure to partners, family members and friends, this study was particularly interested in challenges HIV positive persons face after disclosing their status to the entire public that consists of even people that may not have known the HIV positive person if it was not his or her behaviour of public disclosure of his/her HIV+ status.

Within the context of the work place, fear of losing employment often discourages individuals from making use of available testing services. Work places with “Know your Status” campaigns administered jointly by managers and workers representatives’ report improved uptake of testing, treatment and prevention services. For example trade unions in Rwanda that maintain solidarity funds to care for workers who test positive report that nearly all their members have been tested for HIV (UNAIDS/ILO/ICFTU, 2006; UNAIDS/WHO, 2006).

In a private sector led economy, there is always a likelihood that private employers will discriminate against HIV+ employees. This is mainly because of the high costs that HIV/AIDS brings to individual companies. In this scenario, it becomes the responsibility of governments to protect the rights of HIV+ people and to provide accessible and affordable redress in case employees of private companies are fired because of their positive status. Examples of such experiences of discrimination in the literature available come from South Africa and India (Program of International Health and Human Rights, Francois-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health et al., 2004), this study particularly looked at what is on ground in Uganda, that has a weaker private led economy than South Africa and India.

Reir (2007:3) for instance shows that for HIV+ individuals, disclosing their seropositivity is often tantamount to admitting behaviours, such as homosexual relations or injection drug use that remain widely stigmatised. Disclosure may cause rejection, and emotional and even physical abuse. Yet disclosure can also bring emotional support, instrumental assistance, and relief at being candid with friends and family (Rier, 2007). Seropositives carefully weigh whom, when and how to tell, and often experience disclosure as a process, and not as an event (Cusick & Rhodes, 1999; Rier, 2007).

2.4 Aspirations of HIV positive persons after disclosure

Gary & Nicole (2000:1) in their study about HIV-Positive men's sexual practices in the context of self disclosure of HIV show of how in the US those who test positive for HIV at publicly funded testing sites as well as many private locations receive post test counseling about the importance of disclosing their seropositive status to future sex partners. They indicate for instance that, *"…disclosure to a sex partner is important because it informs that partner of his or her risk"*. This seems to point to the fact that those who finally disclose to the entire public are moved by the desire to protect the prospective sex partners and to help people to change their sexual behaviours for the better.

The above desire is further confirmed by for instance the calling Rev Johannes Petrus Heath has received after discovering that he was HIV+. Rev Johannes is an Anglican priest serving Christ Church Mayfair in Johannesburg, South Africa. He is the coordinator of the African Network of Religious Leaders Living With and Affected by HIV and AIDS (ANERELA) (UNAIDS, 2005). In his testimony to a UNAIDS Theological Workshop Focusing on HIV and AIDS-related Stigma in Windhoek after he had fully disclosed to the public remarked;

> *I must give Bishop Brian credit; he did not fall out of his chair. And I think he then really sought to help me in the best way he knew. He said to me; 'Thank you so much for telling. Please don't tell anyone else.' He also told me that he looked forward to many years of ministry with me. Bishop Brian told me that if my HIV status became known, he would have no way of guaranteeing me a job in the diocese. I really believe that what the bishop said and did, he believed to be in my best interest, but the reality is that in many senses it bound me from being effective within the field of HIV and AIDS for a number of years (UNAIDS, 2005:29).*

From his testimony, it becomes clear that his public disclosure was driven on by the desire to enter the field of HIV and AIDS and save lives. This study particularly focused on what drives HIV+ individuals in Uganda on to the extent of disclosing their status to the public.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents the research design that was used in the study, the area of the study, study population, sample size, sampling procedure, data collection and data analysis, and the study procedure.

3.2 Research Design

A case study design was adopted to study the benefits, challenges and aspirations of HIV+ individuals that have been able to go public. The study largely used the in-depth interview method to examine the benefits, challenges and aspirations of HIV+ persons after disclosing their status to the public.

3.3 Area of Study

The study was largely based at The AIDS Support Organisation (TASO)-Mulago Branch from where I was able to identify HIV+ persons who had already been able to disclose their status to public. Majority of the respondents that I interviewed were from the drama group that is based at TASO-Mulago, and a few of the respondents were from the TASO Mulago HIV/AIDS clinic.

3.4 Study Population

The study population were HIV+ persons that had been able to disclose their status beyond their partners, children, parents, and other immediate relatives that the HIV+ persons were living with in a household to the public. An HIV+ person would qualify to be part of the study population only if he/she had disclosed his/her status to a group of four people and above, that came from beyond his/her immediate family. This group could include friends, acquaintances and even strangers. Using this inclusion-exclusion criteria one respondent qualified to be part of the study population and therefore was included in the study sample because he had disclosed his status to gatherings of people and even over the radio, but had done everything possible to keep his mother unaware of his status. The study population was HIV+ persons that were aged 18 and above that had already been able to disclose their status beyond the households in which they lived and beyond their parents.

3.5 Sample Size

The study examined the benefits, challenges and aspirations of 30 HIV+ persons who had disclosed their status to the public. Although I had proposed to interview 45 persons that had disclosed to the public, I was able to interview 30 respondents because those were the only ones I could get from TASO Mulago drama group, TASO Mulago HIV/AIDS clinic and from the general public in the limited time for field work. This study specifically looked at the experiences of only those who have been able to disclose to the public. The study also interviewed six key informants/counsellors and these key informants were counsellors that had ever escorted the drama group to one of their sensitization sessions. The table below shows a summary of the respondents that I interviewed, and the instruments that were used to interview them.

Table 1: Types of respondents

Type of Respondent	Number	Instrument
Respondents from TASO drama group	17	Interview guide for respondents
Respondents from the TASO clinic clientele	10	Interview guide for respondents
Respondents from the general public	3	Interview guide for respondents
Key informants (counsellors)	6	Interview guide for Counsellors

3.6 Sampling Procedure

Purposive sampling techniques were used to obtain a sample of 30 respondents and 6 key informants/counsellors. Purposive sampling techniques were mainly used because not so many people have been able to come out to disclose their HIV+ status to the public. Since the study was largely qualitative aiming at establishing the experiences of HIV+ persons who had gone public with the view of recommending interventions at that level, I purposely selected those individuals that had been able to disclose their status to the public. In this case therefore, any individual aged 18 and above, who was HIV+ and had already been able to disclose his/her status to the public was included in the sample.

3.7 Data Collection

3.7.1 Research Instruments

The research instruments were of two types, namely; in-depth interview guide for the HIV+ persons who had disclosed to the public and the in-depth interview guide for care providers/counsellors. The in-depth interview guide for the HIV+ persons who had already disclosed enabled me to collect data from these persons about the benefits, challenges and aspirations they had got as a result of disclosing. The in-depth interview guide for the care providers/counsellors enabled me to obtain data from key individuals from HIV/AIDS care organizations that were conversant with public disclosure of the HIV+ sero status.

3.8 Data Analysis

Since most of the data that was collected was qualitative data, it was analysed using the ATLAS t.i Computer Programme. After the interviews were conducted, each interview was transcribed and at this stage great care was observed so that all the details of each interview got included onto the final transcripts. After all the 30 interviews (from people who have disclosed to the public and 6 interviews (key informants) were transcribed, they were uploaded into ATLAS t.i as primary documents. Thereafter, using the main themes that guided the research from the initial stages, the coding process was started. Specifically, this data was grouped into the broader themes of the benefits, challenges and aspirations of HIV+ persons after disclosing their status to the public. The sub themes under the main themes such as (benefits to the community, benefits to the individual, intrinsic benefits under benefits of public disclosure) developed later on as the coding process continued under main themes. In short, it was realised later on that if the benefits that arose from public disclosure can be looked at more closely, they can further categorised into the above sub themes. This process was undertaken for all the main themes and the sub themes emerged later as the coding process continued. After the main themes and sub themes were developed, the coding process was completed and the query reports were produced that made the writing of this report much easier.

3.9 Study Procedure

The researcher got an Introductory letter from Makerere University (see appendix III), which he was able to present to Uganda National Council of Science and Technology

(UNCST) for research clearance (see appendix IV), and to TASO head quarters (specifically the Research Division) for clearance. After the research division at TASO Uganda looked through the proposal, I was introduced to the Manager TASO Mulago (see appendix V) who gave me the necessary support to access the clients at the clinic, members of the drama group and the counsellors.

3.10 ETHICAL CONSIDERATIONS

Being HIV+ is one of the hardest experiences a human being can go through, and therefore this study took cognizant of this. This study required HIV+ individuals to narrate the benefits, challenges and aspirations that they had obtained after disclosing their status to the public. This task, I fully appreciated, may at certain times not be an easy task as some of the experiences of HIV+ individuals after public disclosure may not have been pleasant experiences. I tried my level best to empathize with the respondents so that they realized that the research exercise was not a mockery of their condition. And since most of the interviews were conducted at the HIV/AIDS facility, I had a counsellor at hand to take care of any patient who showed signs of breaking down because of the interview. I assured the respondents that the information they passed on to me was to be kept as confidential information, and was only to be used in such a way that it cannot be traced back to a particular respondent. I also informed the respondents that they had a right to decide whether to participate in the study or not. I also informed the respondents that they can also choose not to answer particular questions that they felt they should not answer.

3.11 LIMITATIONS OF THE STUDY

Although I had planned to interview 45 respondents, I was able to interview only 30 respondents because these were the only ones I could be able to access from especially TASO Mulago. This was partly because it was a bit hard to get clearance to do the study from the other two study sites that I had proposed. Although I interviewed 30 instead of 45 respondents, I feel the 30 respondents provided enough information regarding the benefits, challenges, and aspirations those who go public get.

CHAPTER FOUR

SOCIAL ECONOMIC BACKGROUND CHARACTERISTICS OF THE RESPONDENTS

4.1 Introduction

The findings of the study are presented in the following chapters, starting with this chapter four that solely presents the social economic background characteristics of the respondents. While presenting the background characteristics, an attempt is made to examine the relationship between these characteristics and the possibility of going public.

4.2 Age of the respondents

Respondents were asked how old they were and the results from this question are presented in the table below.

Table 2: Age of the respondents

Age Category	Frequency	Percentage
Young	9	30
Old	21	70
Total	30	100

n=30

The respondents that participated in the study were divided into two age categories –the young and the old respondents. The young respondents were those who were aged 30 years and below and the old respondents were those who aged 31 years and above. Acccording to the table above, majority of the respondents (21) were aged 31 years above and therefore fell in the category which this study considered as the old respondents. Although the study did not tease out the exact relationship between a person's age and the possibility of disclosing their status to the public, the study established that more older people had disclosed to the public than the young people. Those who are a bit older and had disclosed their status to the public in order to educate the younger generation on how they can protect themselves against HIV; the older persons tended to point out that they sympathised with the younger generation. One respondent aged 35 years in support of this pointed out; ”*For me, I am a parent and I have children who are already grown up and getting to the age of being sexually active,* *but when I look at them I feel they might contract HIV. Given my experiences in marriage and how I contracted HIV, I realised I should come out publicly to help other people not to contract HIV".* The older one is, the more capable they are to act as autonomous agents. Those who have disclosed publicly many times are acting as autonomous agents particularly in defiance against stigma and discrimination that the public seems to think should be born by those who are HIV positive.

4.3 Gender of the respondents

At the start of the study it was suspected that ones gender could have a significant influence on whether they can disclose to public or not. So, respondents were categorized by gender and the results are shown in Table 3 below.

Table 3: Gender of the respondents

Gender	**Frequency**	**Percentage**
Men	14	47
Women	16	53
Total	30	100

n=30

The study established that the gender of an individual was not very important in determining whether the individual could be able to disclose publicly. Being a woman seemed to have a slightly higher level of encouragement to dislcose than being a man as shown in the table above. Majority of the respondents that I interviewed that disclosed to their churches were women and majority of the TASO drama group members that sensitize communities through drama were women. The differences in the numbers of men and women that had testified in their churches and those in the drama group can be explained by the longstanding differences in church attendance and health seeking behaviour between men and women. In most countries and Uganda inclusive, majority of those who go to church/places of worship are women (Flynn, 2002) and since they are the majority in places of worship, there is a big likelihood that they will be the majority when we consider public disclosure in places of worship/churches. Still in Uganda, majority of the clients for hospitals/clinics including HIV/AIDS clinics are women (Wabwire, 2007; Ssali, 2007; personal communication) and since the drama group members are recruited from the TASO HIV/AIDS clinic the explanation for the big percentage of women in the drama group partly comes from this historical difference.

4.4 Education level of the respondents

At the start of the study, it was also suspected that an individual's level of education have a significant influence on whether they can disclose to the public or not. So, respondents were asked what level of education they had completed and the results are shown in table 4 below.

Table 4: Education level of the respondents

Education level	**Frequency**	**Percentage**
No Education	2	8
Primary	7	27
Secondary	8	31
Tertiary	5	19
Still a student	4	15
Total	26	100

Missing cases=4

According to the table above, majority of the respondents (24 respondents) that had disclosed publicly had experienced some formal education. Since majority of the respondents for this study (17 respondents) came from the TASO Mulago drama group, the education level of the respondents had two influences on it. The first influence was that, a kind donor had appreciated the work the group was doing and had therefore offered everyone in the group the opportunity to go back to school and train in whatever skill they needed; that is why a significant portion of the respondents (4 respondents) reported they were still students. After getting the opportunity to go back to school, some of the drama group members enrolled in mainstream education system and thus one reported that he was currently sitting his S.4 exams, another one reported to be enrolled in a tailoring school, and another in a beauty school to learn skills on how to operate a saloon. The other influence that was identified was that, as a result of the virtue of volunteering with TASO and being HIV positive, those members that had better qualifications had already been offered formal employment by TASO or other organisations and had therefore dropped out of the drama group.

Generally it was observed that there is no significant relationship between ones level of education and the possibility of disclosing to the public. Individuals that are well educated had an equal possibility of disclosing to the public in the same way as their less educated counter parts. One well educated respondent who pointed out that he was pursuing a Masters degree in Psychology and Community Health when asked about his level of education remarked;

> *It is very difficult to find out what my level of education is. According to academicians I may not be educated, because I do not have documents of your nature. But I have studied; I first did religious studies and I spent five years studying religion. I went to Makerere and did some courses in Economics, Political Science and Communication. I also did a bit of Mass Media. I was a news reader, I used to read on both radio and television. I am now a student of Psychology and Community Health, I am in Second year in university. I am studying at UNISA; that is the University of South Africa. But I think my experience in life, having worked for over forty years (I think I have worked for forty five years), qualifies me to be having some Ph.D if I was in another country other than this one.*

Generally, although majority of those who have disclosed according to the table above seem not to have gone very far in terms of formal education, this scenario in terms of education achievement can be explained by the earlier influence that I pointed out.

4.5 Occupation of the respondents

The respondents were also asked what their occupation was and the results are presented in table 5 below.

Table 5: Occupation of the respondents

Occupation	**Frequency**	**Percentage**
Volunteer	17	57
AIDS activist	4	13
Petty trade	2	7
Formally employed	3	10
Unemployed	4	13
Total	30	100

n=30

According to the table above, majority of the respondents (17 respondents) were volunteers. This was mainly because majority of the respondents that were interviewed for this study were from TASO Mulago drama group. The drama group recruits HIV positive persons only from the TASO Mulago HIV/AIDS clinic to work as volunteers using the concept of drama to sensitize the communities about HIV/AIDS. It is made clear at the recruitment stage that those who are only willing to work as volunteers can be the only ones recruited into the drama group. The members of the drama group after being recruited are facilitated with a monthly allowance, transport refund when they come to practice at the centre and when they converge for performances within the community. Although the money they are paid as a monthly allowance (70,000 UGX by the time of fieldwork), and the transport allowance, remains meagre and requires that before members are recruited, it should be made clear from the onset that the spirit of voluntarism is the overriding spirit, to some of the drama group members, the allowances that they are paid at first seemed a lot and was therefore seen a ”reasonable salary”.

According to the table above, a number of respondents (4) reported that they were HIV/AIDS activists and another 4 also reported that they were unemployed. Those that reported that they were HIV/AIDS activists were deeply involved in the response to HIV/AIDS, with three of these four heading fully fledged non governmental organisations involved in HIV/AIDS work at the national level. All the respondents who reported that they were unemployed (4 respondents), were clients of the TASO Mulago HIV/AIDS clinic. Even those who reported that they were involved in petty trade (2 respondents) had first reported that they were unemployed but it was the further probing of the researcher that actually unearthed that they were doing some petty trade.

4.6 How long ago did you get to know your HIV status?

Disclosure of the HIV+ status is usually a process; and those that test positive usually take some time before they finally disclose to immediate relatives and finally be able to disclose to the public. With this in mind, respondents were asked a question on how much time had passed since they got to know that they were positive and table 6 below summarises the results from that question.

Table 6: How long ago did you get to know your HIV status?

Time	Frequency	Percentage
1980-1984	1	4
1985-1989	0	0
1990-1994	8	29
1995-1999	4	15
2000-2004	13	48
2005-2008	1	4
Total	27	100

Missing cases=3

The respondents were asked when they got to know that they were HIV positive and their responses are shown in the table above. This was asked mainly because disclosure was believed to be a process, with those who get to know their status earlier having a big likelihood to have disclosed to the extent of public disclosure. According to the table above, majority of the respondents (13 respondents) reported that they got to know their status in the period between 2000-2004. The time when one got to know their status was defined as the first time when an individual tested positive. In asking the respondents when they got to know their status, and obtaining the dates in years, little could be revealed as far as the process of disclosing is concerned. So in order to comprehend how the process goes, respondents were also asked when they began going to the clinic for HIV treatment after testing positive. Again, HIV treatment was taken as a whole range of treatment an HIV positive person recieves starting with routine counselling, treatment of opportunistic infections up to starting on antiretrivoral therapy (ART). It was believed that this act of going to the clinic for treatment enabled the person to obtain adequate information on HIV/AIDS, and this adequate information tickled them to go public as will be shown later that those who go public are indeed partly driven by the desire to fight myths and misconceptions that exist out there in the communities about HIV/AIDS.

4.7 How long ago did you start coming to the clinic?

In relation to when an individual got to know that they were HIV positive, they were asked of when they started attending an HIV/AIDS clinic regularly. It was believed that those that had spent some considerable time while attending an HIV/AIDS clinic could have a more likelihood of disclosing to the public. The results from this question are summarised in table 7 below.

Table 7: How long ago did you start coming to the clinic?

Time	Frequency	Percentage
1990-1994	8	31
1995-1999	3	11
2000-2004	13	50
2005-2008	2	8
Total	26	100

Missing cases=4

According to the table above, majority of the respondents (13 respondents) reported that they started going to the clinic for HIV/AIDS treatment in the period 2000-2004. The period 2000-2004, is when HIV/AIDS treatment was becoming widely available in most of the developing countries including Uganda, and it is not a surprise that many of the respondents report that this is the period that they started getting HIV treatment. Still according to the earlier table, majority of the respondents (13 respondents) reported that they had tested positive in the period 2000-2004, so when they tested they embarked on the whole range of treatment services starting with counseling. Even testing services were getting widely available during this period.

CHAPTER FIVE

THE PROCESS AND BENEFITS OF PUBLIC DISCLOSURE

5.1 Introduction

This chapter presents the process an HIV positive person goes through to finally disclose to the public. It also presents the benefits that come out of the act of public disclosure to the individual disclosing and the communities being disclosed to. While presenting the benefits to both the individual and the communities, I attempt to weigh the benefits to these two and bring out who benefits more from the act of public disclosure.

5.2 THE PROCESS OF PUBLIC DISCLOSURE

5.2.1 The Path to Public Disclosure

Scholars that have written on the subject of disclosure within the context of HIV such as Ryan (2007) show that disclosing ones status generally takes a definitive direction with individuals that test positive first disclosing to their spouses, then to the family, then to friends, and if possible to the entire public (as shown in Figure 2, below). This study established that although this trend is followed by the majority of those who test positive, a number of other trends can be identified in the disclosure process; these trends are presented in the next paragraphs.

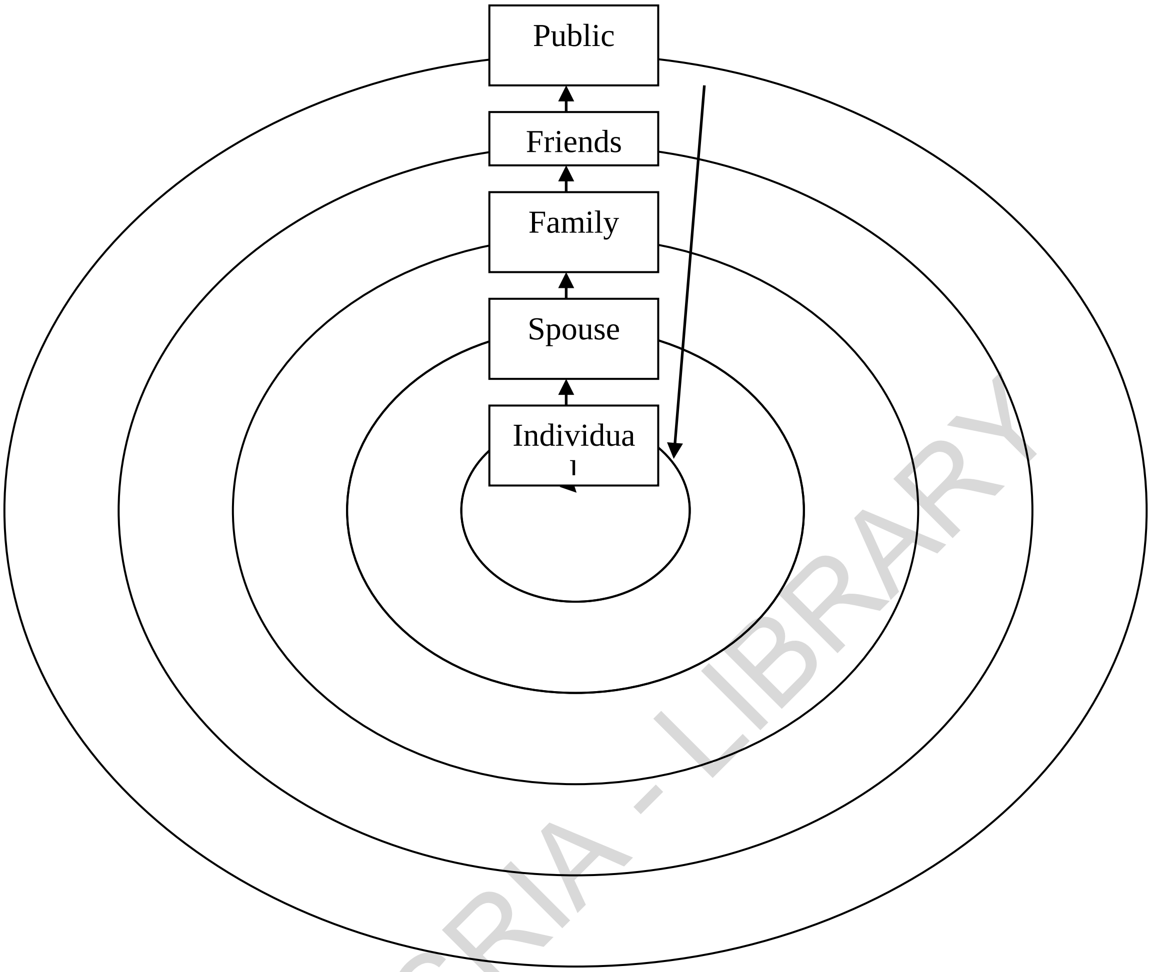


Figure 2: The path to public disclosure (Source: Ryan 2007)

As shown in Figure 2 above, most of the people that have disclosed publicly usually start the disclosure process with their immediate relatives. Most of them start with their spouses, then they disclose to their families (children, immediate relatives), disclose to friends and then go public. But this is the generic model that most of those who finally go public are believed to have followed. The study also found out that majority of those that have disclosed to the public follow the trend that Ryan (2007) identified; that is an individual first discloses to the spouse, then to the family, then friends, and finally the entire public. According to table 8, majority of the respondents, 19 reported that they followed this kind of trend where members of their immediate family were disclosed to first, then friends, and finally the general public.

Table 8: Public disclosure trends

	Public Disclosure trends	**Frequency**	**Percentage**
1	Individual→Spouse→Family→Friends→Public	19	79
2	Individual→A few relatives→Public	3	13
3	Public→Individual	2	8
	Total	24	100

n=30 Missing cases=7

This study also noted that apart from the most common trend of disclosure that follows from (the Individual→Spouse→Family→Friends→Public) that is identified by Ryan (2007), there are individuals that have disclosed to the public but some members of their immediate family members are not aware that they are positive. Here disclosure follows from the Individual→A few relatives→Public; and this happens when an individual is not interested in making some very close members of the immediate family very worried. So, the individual decides to go public before disclosing to these kinds of individuals. A respondent for instance from the drama group pointed out that he has been able to disclose to numerous gatherings and has also appeared on various radio stations over which he disclosed that he was positive, but his mother is not aware that he is positive. This proved that in certain places and at certain times, the process of public disclosure does not need to follow a strict unidirectional path.

The above disclosure trend that follows from the Individual→A few relatives→Public was also identified to happen when the HIV positive individual starts with disclosing to those who are very close because the individual knows that they will not discriminate against them and then skips those who are not very close (those that the individual judges that they will discriminate and stigmatise them most), and discloses to the public (less discrimination from those that had not known the individual before). Those who are not close, get to learn that an individual is HIV positive after he/she has gone public. Those who are potentially more discriminative and stigmatising after realising that the individual is positive, cannot be able to gossip about a person who has already disclosed to the public that they are HIV positive.

In relation to the above, most of the discrimination and stigmatisation of HIV+ individuals happens within their immediate circles of family members, friends, and work mates. The amount of discrimination an individual experiences beyond his/her immediate network of family members and friends is low compared to what they experience from the wider community. Since these individuals are finally able to disclose willingly or unwillingly to this immediate network, then public disclosure would be possible if disclosure to the immediate network (family, friends) was started much earlier. Most of the TASO drama group members that have been supported by the group to disclose publicly pointed out that they were first comfortable with disclosing to gatherings that didn't contain anybody that knew them before. Those who started their public disclosure with gatherings that had people that knew them before seeing them on stage, reported that it was like 'baptism by fire'. Since most of these group members started with communities that had not met them before, they became confident overtime to disclose even to communities that had met them before.

The other trend that public disclosure can follow, that was identified was where members of the public got to know that a certain individual was HIV+ before the individual himself/herself personally realises that they are positive. This trend however seemed to be associated with the misconceptions people have about HIV, that are indeed bases of discrimination and stigmatisation. The experience of this respondent from the drama group shows how the disclosure process can start from the public to the positive individual; he remarked;

> *Before you take time off to test, you can never get to know that you are HIV positive. But the community that you are living in may be aware that you are HIV positive when you yourself you are not aware about it. You can go to a community and get into a relationship with a girl, but the people in that community know that that girl has ever had a husband who died due to AIDS. But for you, you may not be aware that that girl lost a husband to AIDS. So, if you do not know that, the people around would be gossiping about you quite often. Even if you fall sick, they continue gossiping that, 'That one was in a relationship with the next widow, so, we are aware of what is killing him' The people cannot be able to tell you that although you are in a relationship with that woman, she is a widow and her husband died due to AIDS. Most of the time, the people around you, get to know that you are HIV positive before you get to know it. Some time ago, I had a relationship with a girl before I tested. Actually she had just joined the organisation to work with us. But as I started the relationship with her, the people around, told her, that that man has AIDS; and she also came and told me that, "I am being told that you have AIDS". So, I got surprised! But*

> *that is what the people were telling her. Let me give you an example; you said that you work with Makerere, but you can come this side of Mulago and get into a relationship with a woman, but because I too work in Makerere, I may see you in my neighbourhood with that woman, and when I get back to Makerere I can start gossiping about you that, "That man you see over there is in love with a widow!" So, the people around you get to know that you are positive before you yourself realises it. And they cannot approach you to tell you that the girl you are having a relationship with in Mulago is a widow.*

Although in not all the cases, the community can conclude rightly that a certain individual is HIV positive; their conclusion in this case was true and their conclusions in majority of the cases are always true.

5.2.2 Who Travels the Path to Public Disclosure?

After looking at the trends disclosure can take, it is quite important to look at the categories of people that can also be identified when public disclosure is being considered. Only the types of people of people that have disclosed publicly are summarised in the table below because the study limited itself to only those that have disclosed to the public.

Table 9: Categories of people that have disclosed to the public

Categories of those who have disclosed	Frequency	Percentage
Disclosed without support	17	57
Disclosed with support	13	43
Total	30	100

n=30

This study established that people are different when public disclosure is being considered. There are about three categories of people when the subject of public disclosure is being considered; the first category are those who even with support that is offered by a group such as the TASO drama group cannot gather themselves to disclose publicly, and therefore cannot even accept to enrol into such a group, the second category of people are those who with the support of such a group (13 out 30 according to the table above) finally are able to disclose publicly and they get free to disclose their status and last category are those people who disclose on their own without the support of organised groups (17 out of 30 according to the table above). In the following paragraphs, I will try to bring out how the disclosure process goes for the second and third category of people since this study limited itself to respondents that have been able to disclose publicly.

Starting with the second group of people who with the support of an organised group finally are able to disclose publicly, the study found out that when these positive individuals continued to disclose their status in the context of an organised group, they get used to disclosing publicly up to the extent of realising that there are not many negative consequences that they can face as a result of going public about their status. The end result is that they get confident and are able to disclose even to big gatherings which gatherings even have close relatives/friends within them. In support of this for instance, a respondent from the TASO drama group who is also a client of the TASO clinic had this to say;

> *I came here for treatment in 2000, and I entered the drama group in August 2004. I found they were preparing for the end of year festival. They usually have a festival with the drama groups from the other centres in order to popularise this concept of drama. During the period of the festival, the groups do not usually visit the communities, and so during that time when I joined, we did not go to the communities. After the festivals, November came and then TASO was preparing for the end of the year; so we went to the communities in January; by then I had already spent some months in the drama group. But for me to be strong to disclose to the communities, I think it took me up to two years. But when I got used to disclosing, I became so free, I became so healthy, I put on weight. I came here when I was 75 Kgs, but now I am 90 Kgs.*

Most individuals that have gone public feared discrimination and stigmatisation before they went public. But after going public they have realised that the discrimination and stigmatisation that they feared was not as widespread as they thought. The experience of another respondent from the TASO drama group exemplifies the scenario of the process most people who go public go through. In response to a question on which place they first disclosed their status publicly the respondent replied;

> *It was here in Mulago at the market place. The problem I got was that, I was once a resident in Mulago, and among the people that gathered there were people who knew me. So, when I looked at them, I felt small, I tried to look around, but I could do nothing. We had already introduced the group as the Mulago TASO group, consisted of people who are living with HIV. It wasn't easy.*

But when further asked why they could not resist going to the sensitise the gathering at the market place that was near where she had once stayed she pointed out; "*No, when we are doing interviews we are told that if you feel you cannot be open about your HIV status anywhere, you do not qualify for the task. You qualify if you are free to disclose your status to every person, so, I could not tell them, that I could not go to Mulago because of such and such a thing*". Now that she had not yet got experience with disclosing publicly and she had to start with a community that had known her before, I had to ask her, what did you tell this gathering that contained people that had known you before joining the TASO drama group? In response, she said;

> *I did not tell them anything, we performed and after performing, we came back. Then, I took some months… But when I meet them now, I tell them yes I am positive. Now, I am free I have the courage, I can tell everyone about my HIV status. I tell them that it is better to test and you get to know where you belong. You cannot know whether you are positive or not if you do not test. It is good you test and you know where you belong. I tell them like that.*

So when asked how she felt after the first time she disclosed her status to that gathering that had people that had known her before that meeting, she pointed out; "*Personally I asked myself questions, such as, 'Maybe the people I disclosed to are now laughing at me?' But later after sometime I got used and realised that some people are able to learn something from my experiences that I share with them*". She further pointed out; "*Although the first disclosure to a gathering was not easy, when I got used to going to the communities to sensitize them, it is now quite easy to tell a gathering that I am HIV positive*". This shows that supported public disclosure such as that which goes on within the context of the TASO drama group helps the individual to overcome all their fears about disclosure and they can freely disclose their status publicly on their own after the initial period of support.

Most HIV positive persons feel that it is not easy to disclose their status to the public. Even majority of those that have disclosed publicly have at one point felt that it is quite impossible to disclose their status to the public, but later on after disclosing, they have again realised that little has changed about their lives. The experience of another drama group member that I interviewed shows the process that those who get supported by groups go through to finally feel free to disclose their status to the public. She narrates how her first experience of disclosing her status to the public went;

> *To give a testimony [public disclosure] is not very easy. It is the hardest thing an HIV positive person can face. At first you fear so much, but one has to be quite strong to be able to tell people about their life and all the things one has passed through. If I can tell you, for me I feared so much when I was going to give the first testimony, to the extent that I even cried. So, when I was told that it is your turn to give a testimony, I thought about how I got the virus and cried. I got HIV when I was still young and still in school. …When I finished giving the testimony I approached my other friends who were on the same team with me. So, I shared some of my*

> *challenges with them and they told me, do not mind you will get strong as time goes by. Actually they also helped to give me more counselling.*

When the respondent was asked whether she remembered that first time she disclosed her status to a gathering of people so that the process she went through to finally disclose comes out clearly, she pointed out;

> *I remember that first time. At first, I had kept quiet about my status for two years and then later I told my sister. Then later, I even disclosed to a gathering. I gave a testimony to the community that and this testimony brought out things that concerned my life…*
>
> *Going public is not easy! Like I told you when I was tested in 2001, I remained in denial and that is why I could not come for treatment until 2003. But after some time I started falling sick because of the numerous problems I was going through, and my sister advised me to go to where I was referred to for treatment and that is when I came to register with TASO in January 2003. So, when I came to TASO, I talked with the counsellor on so many issues, including how I should look after myself. Amongst the very many issues that we talked about was the issue of the drama group, but after that discussion with the counsellor still I could not come out publicly with the drama group. For one to be able to disclose their status publicly it needs lots of sustained counselling after which you can be able to realise that you need to get out to help other people.*

Asked whether the first time she disclosed her status to the public was after she joined the TASO drama group or not, she pointed out;

> *I was already at TASO. But to go public is not easy and it can never be a one day's decision. But to finally go public is a long process that is supported by counselling. Given the experience that you have, and the counselling that you get, then, you can be able to gain enough strength to go public so that you help educate other people. For me, I am a parent and I have children who are already grown up and getting to the age of being sexually active, but when I look at them I feel they might contract HIV. Given my experiences in marriage and how I contracted HIV, I realised I should come out publicly to help other people not to contract HIV. As I told you I am a widow, so, after the death of my husband I was completely mistreated and it is this mistreatment that contributed to my going public about my status so that I can educate others and especially young people so that they do not contract HIV to experience the mistreatment that I got. My going public is also meant to help even those who are already positive so that they can reach out to places that can help them.*

The experience of the three respondents above show clearly that without the support the TASO Mulago drama group, the likelihood that these three would have gone public was very minimal. The support groups such as the TASO Mulago drama groups are very relevant in the collective fight against HIV/AIDS in general and HIV/AIDS discrimination and stigmatisation of HIV positive persons.

The next category is those people who are able to disclose on their own without the support of organised groups. I will bring out the experiences of four people that were able to disclose on their own with out the support groups such as the TASO drama group. The first experience is a retired army man that has been able to disclose his status without the support of any group. When I asked him when he first disclosed his status publicly he mentions the year 1993 at the occasion of World AIDS day, but quickly points out;

> *By the way I think I was already open about my status, as I had already started talking about my status. I remember in 1990 I went to TASO to learn about HIV counselling. This was also a hassle because I had to seek for permission from the army to go and do it; that means I had to tell whoever I was asking permission from that I had AIDS. So, I told the chief in the army who was my boss that I had AIDS, and I wanted to go and learn a little bit more about it. So, you can see I was already really open in a way. It is very uncommon for people even up to this day, to be open to their bosses because they fear that they will sack them from their employment or whatever may be. But my case was different, I went to my boss and I told him, 'Look I have AIDS, that is what I have been told after testing', so I told him the process that I went through. So, I want to go and do some course in HIV/AIDS counselling' And I was granted permission.*
>
> *Yes, 1990, I had already started talking about it. I knew I was supposed to live for 3 years and I thought with 3 years I should be able to help others understand the disease. So, I thought the best way to share this problem apart from the counselling that I was offering, I think to let these people (my clients) know that they were not alone, that we were many. I had a problem of being able to gather them because you had to keep confidentiality so I thought I will break my confidentiality in order to try and invite people. I was trying all the time to see how I can invite people so that we could form something ourselves. Because by then I was already feeling a world where I lived but did not belong. You know when you finished work you went home, and you really found out that you are not part of this world. You found that you are a dying man, and you are there alone, and you know you are dying!...*
>
> *…So, in 1992 there was a conference which happened in Amsterdam in the Netherlands, and it was an International conference on HIV/AIDS and STIs and I was supported by USAID through a certain lady I had disclosed to…*
>
> *So, I got a sponsorship to attend the HIV conference in Amsterdam and when I got there I found people demonstrating. These were people who were HIV positive and they went around demonstrating. They were strong and they were even happy; I could have joined if I was not an army man, but with this background of being an army man and a Major for that matter, I feared that if they did something wrong, and we are arrested and they realise that I am an army man, I would have problems…*

…I followed them gradually and tried to hear what they were saying and you know they were really rumbling, talking about HIV, talking about their rights, saying that all they need is that people understand they are probably part of the solution and not a problem. I said Aah!, part of the solution and they have AIDS and they can talk like this!...

…But eventually they wanted to take a rest and take some refreshments and so they sat and started talking. But they were really happy and joking and laughing. I asked myself, 'How can you have AIDS and you are happy and laughing?' Somehow, I picked on one of them and I started talking to them, one by one, and eventually I told them I was also HIV positive. But I was not as strong as they were. And I was asking them, why they thought they can be this strong. I asked them, 'Have you not been told when you are supposed to die? And they said, 'No, we are not supposed to die at all. We shall die like any other person. We are not going to die now' What a marked difference! It became so different…

…In 1993, I was invited this time because I enlisted myself among people who were HIV positive in the world to a conference of people living HIV/AIDS only. Eventually I became friends with those people, I gave them my details and so they enlisted me as one of the members of the international group of people living with HIV/AIDS. The conference happened in a place called Acapulco in Mexico. I did not know how to get there because that would cost money; so I went to the Ministry of Defence and sought for money. I asked for money, and told them, 'I have AIDS and there is a conference I have been invited to attend and I want to attend'. Again note that I am doing things in a different way, others were fearing to talk, but for me I was telling my own bosses…

…When I went to Mexico, I found 360 people who were HIV positive in that conference. And I saw how people lived, and I thought I had no reason to die any more. When I came back here I got haunted because I was so proud that now I knew I can live. I knew I was not going to die, but I knew there were so many people who were like me -in the past; they were there thinking about themselves, suffering with AIDS -as we called it, and they were waiting to die. So, what came to my mind was, how do I also rescue them? Because I had been rescued; I looked for a way but it was very complicated. Then my mind said may be you should go public, and invite those who want to join you to join you. After that you can start your own something. I had already got tired with the way things were going. People with AIDS were being used to get money…

…So, in 1993, on World AIDS day I had already made a resolution to go public, so, I told my boss. This time I was working at…

…So, I eventually thought indeed it was important to reveal my HIV status publicly in order to get others to join me. When I told my boss, he thought I was a mad man. In fact that is what he told me. "I think you are a mad man! And you are going to loose you job" And those kinds of things. I said well, after all, I could even loose life, what about a job? So, for me that was

> *not a big deal, I just ignored him. Fortunately, I happened to be in charge of public relations in that organisation; so when they invited people, I was also invited. In fact I went on behalf of my boss to attend the World AIDS day…*
>
> *…So, when they started talking I also asked the person who was the Master of Ceremonies to allow me say a few things. He asked, 'What do you want to say?' I told him, 'You know I am HIV positive, and I want to tell people that I am HIV positive' My friend when I said that, there was panic even at that place. He said, 'What? You are a Major and you want to tell people you are HIV positive?' I replied "Yes", "But I am, and I think I cannot keep it any longer"…*
>
> *…So, eventually they allowed me and I went to the pulpit and told the audience I was HIV positive. I told them I believed many people seated around here looking as smart as I do may be HIV positive but they are not actually accepting the reality and the reality is there. It is high time that we talked about it. Keeping it in the closet is not going to help and I invite any one who would like to work with me, as I had already written a proposal of starting an organisation -this organisation by the way,…*
>
> *…My biggest problem was always that if we keep quiet the disease will escalate and when it escalates it will be too complicated to manage. If we could now start looking at attacking it from even a prevention perspective, we probably could be able to get the care that we needed…*
>
> *…I always look at the thrust that Lutaaya used; Lutaaya admitted that there was AIDS, and he was ready to die; he even sung songs saying farewell, completely gave up and said okay, bye bye, I am going. I have been singing a different song, I have been saying you don't have to die; you have HIV? Yes, but you don't have to die. And I think that is a very serious message that people need. HIV is a chronic disease or a chronic infection but is a manageable disease. People don't have to die any more; I got it when I was 36, I am 60. So, if I die, I will die of age not of AIDS…*

Another respondent who went through the entire levels of disclosure until when he disclosed to the public without the support of an organised group when asked how the process like for him to finally disclose to the public, remarked;

> *…It took me twenty minutes to disclose…And by that time there were no traffic jams like we have today, so it took me about twenty minutes from the town to Mukono. That is why I said it took me twenty minutes because when I reached Mukono immediately I told my in-law. The second person I told was my Principal and then I went and I told my fellow staff members. Then finally I told my students. Within a space of about of 3 days I had finished that process of disclosing. Then after that I decided I need to disclose to my family members, so I came back to Kampala and told my brother –the one who follows me…*
>
> *…The year 1995 completed my disclosure process; in 1995 there was an International AIDS conference in Kampala and they allowed me to give a*

> *paper and talk about my status. I disclosed and it was very easy to do it because my family knew, my church knew. Once you have disclosed to people who matter, disclosing to the rest of the world becomes very easy…*

Another respondent who disclosed by themselves without the support of an organised group like the drama group when she pointed out that she disclosed her status in church and over radio was asked where she disclosed from first, and she pointed out;

> *…I disclosed to my church and also disclosed my status over the radio. I have appeared on Radio Uganda…. I disclosed first in my church and they prayed for me to heal from TB and the virus. The same church has helped me to take care of my grand daughter who was left behind by my daughter who was also taken away by this same disease…*

Another respondent who has not only disclosed to public but also pointed that he was a saved person when asked when he came out in public to disclose his status, pointed out;

> *I cannot say I started going public with TASO. In 1996, I got a problem and my skin got a terrible rash. So, on one Sunday morning I went to the church and told the congregation about issues of HIV/AIDS and went on to tell them that personally I had tested in 1993 and found that I was HIV positive. So, I told them that, "I felt should tell you about this because there is no other person who can help me to go back to the village where I have got a number of relatives who can be able to help me. So, that is how I started to go public. …When I returned in 1997 I went back to Mengo, then in 1998 I joined TASO and on 29th January 2001, I joined the TASO drama group, to start talking about HIV and my health. But before I joined I talked about it with my counsellor who asked me whether I could be able to help other people (both those who are infected and those who are not), by talking publicly about my experience so that they can be able to change the way they behave? So, I told them, that it is possible because, when I got the virus I did not feel very well and I think if any other person got the virus, they would not feel fine.*

This second category of persons who went public by themselves without the support of organised groups, were largely born again Christians or had become saved after realising that they were HIV positive. Their actions can be interpreted within the lenses of the spirit of savedees who believe that most of their troubles should be shared with the church congregations so that these congregations can learn from them.

5.2.3 Disclosure event

Respondents were asked to explain how the disclosure went after they had made up their mind to disclose to the public. Most of them especially those that disclosed their status through the drama group were at first timid to disclose their status to the public. Those who disclosed on their own without the support of an organised group on the other hand did not experience a lot of fear as they approached the ultimate time when they disclosed their status. This difference in the levels of fear experienced at the ultimate first time of disclosing to a gathering can be attributed to personality differences as will be shown later that there can be three different types of personalities when public disclosure is being considered. For instance when one respondent was asked whether he still remembers the first time he came out publicly pointed out;

> *Yes, I still remember that day. My colleagues introduced themselves first, but for me at first I refused to get out of the vehicle, so, when they got back, they remembered that I had not introduced myself. So, they got me out of the vehicle, telling me I should go and introduce myself. So, I introduced myself long after others had introduced themselves, and there was another item of giving the people information. So, I had to interrupt that item first to introduce myself. But after that, I felt, now why did I introduce myself, now if in that gathering there was somebody who knew me? And I thought about many other things of this nature.*

Another respondent that disclosed with the support of an organised group –the TASO drama group, when asked in which place she had first disclosed her status publicly pointed out; "*It was here in Mulago at the market place. The problem was, I was once a resident at Mulago, and among the people that gathered there were people who knew me. So, when I looked at them, I felt small, I tried to look around, but I could do nothing. We had already introduced the group as the Mulago TASO group, consisted of people who are living with HIV. It wasn't easy"*. When further asked why she could not say no to going to Mulago when she knew that they were going to Mulago, she pointed out; "*No, when we are doing interviews we are told that if you feel you cannot be open about your HIV status anywhere, you do not qualify for the task. You qualify if you are free to disclose your status to every person, so, I could not tell them, that I could not go to Mulago because of this"*. Another respondent who disclosed with the support of an organised group, when asked whether she remembered the first time she disclosed to the public remarked; "*Yes. To disclose to a gathering was not easy. I said what I was supposed to say to the gathering. I told them what I was going through,… The first time I disclosed, before I could be able to complete my testimony I broke down. It did not go very well"*. The first disclosure event for those who were supported by the drama group was not a good one as nearly all them seriously contemplated whether what they were going to do was right or not before the actual public disclosure.

The scenario of the first public disclosure event for those that were able to disclose on their own without the support of an organised group seems a bit different. This category of people seem to have been long convinced before the actual act of public disclosure that they will not get serious negative consequences if they disclosed publicly. In support of this for instance a respondent that disclosed without the support of any group when asked to explain how she went about her first public disclosure pointed out;

> *I stood up in the church and said to the audience, I am here praying very hard to God to continue blessing me because I have come from very far with this virus. And even now, I think God has helped me to be here. I think it is the hand of God that has enabled me to be here. After that the pastor prayed for me, and also said, you should pray for Rose (not real name) because she has HIV. He was loud enough for every body in the church to hear him. He went on saying that this lady came here to thank God because He has enabled her to live with the virus up to now. So, I do not fear to disclose my status to the public.*

Another respondent who had stood up in church to be prayed for when asked how she felt when she stood up and every one was looking at her pointed out; "*I did not feel bad because I was standing up with many other people. I was not all alone. I did not feel bad. But everyone in the church got to know that I was HIV positive. But I did not feel bad because I stood up with a number of other people"*. The difference in personalities that exists between those who disclosed on their own without any support from a group and those who disclosed with the support of a group explains the differences in the experiences that these two categories got when the ultimate time for disclosure reached.

5.3 BENEFITS RESULTING FROM PUBLIC DISCLOSURE OF THE HIV+ STATUS

The study established that public disclosure brings with it a number of benefits; and these benefits are enjoyed by the community to which the individual discloses and the individual who discloses their status. While these myths and misconceptions are being clarified –knowledge and information is flowing from the HIV+ person to the communities; in short the community is benefiting by getting increased awareness about HIV/AIDS. A comparison of the two (the community and the individual) shows that, the community benefits much more from the act of public disclosure. This is mainly because the individual disclosing has costs to meet (these are shown in a later section on challenges of public disclosure), while the community has very minimal costs to meet in relation to the act of public disclosure. In the end, the community to which the individual discloses to bags a number of benefits from the act of public disclosure and these benefits are summarized in table 8 below, and presented in details in the paragraphs that follow.

Table 10: Benefits of Public Disclosure

	Benefits of Public Disclosure	**Frequency**	**Percentage**
1	Clarifying on HIV/AIDS information/Debunking myths and misconceptions	15	33
2	Encouraging those who are HIV positive to seek treatment	9	20
3	Teaching those who are negative how to remain negative	4	9
4	Notifying potential sexual partners	3	7
5	Reduce re-infection	4	9
6	Counter individual discrimination and stigmatisation	3	7
7	Intrinsic benefits	4	9
8	Economic benefits	3	7
	Total	**45**	**100**

n=30

5.3.1 Benefits to the community

Although individuals who test positive for HIV/AIDS are discriminated and stigmatised by society, and as a result are encouraged not to disclose publicly, the few that have disclosed publicly in Uganda have generated a number of benefits for the communities in which they live. It is this contradiction that inspired the writer to investigate much more about public disclosure. The contradiction simply put is that, if a positive person is discriminated and stigmatised, it convinces other individuals who test positive in future not to disclose their status. But when they do not disclose to those around them, then those around them stand to lose things such as notification of the infectiousness of this positive person, dispelling of myths and misconceptions about HIV/AIDS and so forth. On this basis, then individuals in the community should not be discriminative of HIV+ people. However, to a big extent, the reverse is true. According to table 10 above for instance, it can be seen that the benefits the respondents bring out point to the fact that the community around the HIV+ individual benefits more from the act of public disclosure than the individual disclosing. These benefits which are brought out that show the community benefits much more from the act of public disclosure include, debunking myths and misconceptions about HIV/AIDS (33% of the total response), encouraging those who are HIV positive to seek treatment (20% of the total response), teaching those who are HIV negative how to remain negative (9% of the total response) and even notifying potential sexual partners (7% of the total response) about their HIV positive status. One respondent I interviewed had this to say in line with the overall paradox of discrimination and disclosure;

> *Everyone benefits; the individual disclosing benefits, the public benefits. You are right to say people should support disclosure because the person disclosing and the person being disclosed to benefit. So, the question you as the researcher should be interested in is, 'But if disclosure is beneficial to both the one disclosing and the one being disclosed to, why then is it still most difficult for most people?' That is where we are failing the battle!*

It is this double-sided benefit of public disclosure to the community and to the individual disclosing that encouraged the writer to venture into studying discrimination and stigmatisation of HIV+ persons, and how these two encourage secrecy.

The study also established that when the act of public disclosure was carried out by an individual who was not of a high profile before, it tended to remain a localised public disclosure. In other words, the person disclosing gets known to the communities in which he/she has disclosed his/her status. This can be attributed to the low levels of literacy in the country whereby even when published information in news papers about a particular individual is available, some sections of the population do not read such news papers. So, what may be called public disclosure does not qualify to be public disclosure to some people for instance who do not read news papers. A number of respondents especially in the TASO drama group that I interviewed reported that although they have gone to very many communities giving their testimonies in relation to their positive status, many other people in Uganda do not know that they are HIV positive. It was largely those individuals that by chance were in the gatherings that benefited from their disclosure that can remember that such and such an individual is HIV+. The experience of this respondent from the drama group clearly shows that even when one discloses their status to gatherings, that act of public disclosure can remain a localised public disclosure;

> *Before I married her, I had already gone public about my status but she didn't know that I was positive. Although we have gone public and disclosed to the communities we have not been to all the communities in Uganda. Not everyone knows that I am positive, although I have been to several communities giving my testimony. I think I have gone to over 300 places giving my testimony but that does not mean that now wherever I pass in Uganda they know that I am positive. If I enter Makerere University now, nobody may be aware that I am HIV positive, although I have been there*

> *giving my testimony. The cohort that listened to my testimony has now already left university, so, if I went there now, nobody might be aware that I am positive.*

The above respondent still has been able to keep his status as a secret from his mother. Although he has been able to disclose to the public, his mother has never got to know that his son is HIV positive. This he did with the advice of his relatives so that he could be able to prevent her mother from dying when she hears the news that her beloved son was HIV positive. In his own words, he pointed out;

> *She does not know anything about my positive status nor does she know that I am going around the communities disclosing my positive status. But for her she knows that I work with TASO, but she does not know that I have gone public that I am HIV positive. She just knows that I am in the drama group that goes around educating people about HIV/AIDS. She does not know that me -the educator, I am also HIV positive.*

With the above two scenarios in mind, I now set out to discuss the benefits public disclosure can bring to a community. This study established that public disclosure brings with it numerous benefits to the community from which the individual disclosing comes from and also to the other communities that he/she discloses to, and these benefits include;

5.3.1.1 Clarifying HIV/AIDS information/Debunking myths and misconceptions

According to table 10, majority of the respondents, 15 out 30 that I interviewed pointed out that their act of public disclosure helped to clarify on HIV/AIDS information and debunk misconceptions individuals and communities around them had about HIV/AIDS. Clarifying HIV/AIDS information generally takes the form of receiving questions about HIV/AIDS from the public and answering those questions. It can not be easily separated from the other benefits of public disclosure that I will bring out later, but to many of those that have disclosed to the public it is felt that on the general level they help to clarify on HIV/AIDS information. One respondent from the drama group pointed how they helped to clarify on HIV/AIDS information;

> *When we go to the communities we find that different people have different views about AIDS;…but by the time our performances are over, most of the people would have their thinking already changed to rhyme with our own thinking. For me I am on ARVs, and I started on ARVs in October 2004, but for some they think the drugs that TASO gives out are just meant to kill a positive person very quickly. For instance today the community we were in someone told us that the type of Septrine that clients get from TASO is huge compared to the ordinary Septrine, and this huge Septrine clients get from TASO has some added virus that enables the clients to die much*

> *quickly. But when we go to the community and talk with the people about these issues, we help to dispel the myths that they have about HIV treatment. I give the people my own example where if I was not on ARVs I would have died long time ago since by the time I started on ARVs I was having only a CD4 count of 58. But these ARVs have enabled me to live longer and look after my big family, which would not have had anybody to look after it after my death.*
>
> *…These ARVs are so good because they enable us to gain strength and even those who had already lost all the strength when they start on ARVs they regain the strength and start taking care of their family once more. Then we tell them that the drug such as the Septrine they would have asked about is bought by TASO from the same market as any other clinic. Sometimes we get that big Septrine which is two in one and at other times we get the ordinary Septrine where we get two tablets under this case. I think every Septrine tablet has 480 milligrams; so when you get the big one which is two in one, it has 960 milligrams, you just swallow only that; when you get the small Septrine you have to swallow two tablets, each of which is 480 milligrams, where the two total to 960 milligrams. So we clarify this kind of thing to them and they get to understand it.*

Another respondent in the process of answering how he disclosed to his church explained why positive persons sometimes are forced to go public. He pointed out;

> *Why do we have public disclosure? Because there are so many myths and misconceptions around HIV/AIDS that require champions/people who are passing through it or living with HIV or being affected by HIV by way of nursing or loosing a spouse or a child or a father, to tell people that there are things that you talk about AIDS that are wrong.*

Individuals that have gone public about their status help the communities that surround them by constantly answering questions about HIV/AIDS. In relation to this another respondent from the TASO clinic pointed out, "*Some of them come and ask me questions. Such as, 'Are you sure you tested positive?' 'Do you think when they test you, they can't give you a drug that can kill you very quickly?'*" Another respondent from the TASO drama group pointed out, "*Some ask for instance, 'Why can't the authorities isolate all the HIV positive people from the mainstream society so that they cannot spread the disease to the rest of the population?'*" So when questions like the above are answered by the person who has disclosed to the public, you can be sure that their audiences are left with better knowledge on how to deal with HIV/AIDS.

5.3.1.2 Encouraging those who are HIV+ to seek treatment

A number of the HIV+ persons (9 out of the 30) that have also gone ahead to disclose publicly that I interviewed pointed out that they were concerned with the situation of those who were already positive but feared to seek out treatment services. It was clearly pointed out that some of those who are positive sometimes blame themselves and think that they will be completely ashamed if they sought treatment from the public HIV treatment clinics that are available. As a result of this self stigma, many of the positive persons hide themselves in their homes until when they succumb to AIDS and they die. Those who have disclosed publicly pointed out that it is part of their mission to act as examples to those who are hiding themselves by showing them that they are not the only ones suffering but there are so many other people who are HIV positive. By disclosing publicly they would have encouraged those who are already positive to also come for treatment services that are offered by various clinics in the country. By going public when one is in very good health condition, and testifying that either their health had deteriorated and it's the life saving drugs that have restored their health to the current levels (which every body would be seeing), then those who are aware that they themselves are positive, can also seek for treatment early enough or those who suspect themselves to be positive can seek for counselling and testing services that are offered by the HIV clinics.

When the above is done, those who are positive can be able to get treatment and information on positive living from the clinics, thereby prolonging their lives. When their lives are prolonged, it enables them to continue working normally, contributing to the entire economy and also looking after their children –this indirectly reduces the number of orphaned children that the community has to take care of. By seeking out treatment services and in the process getting appropriate information on HIV prevention, those who are positive have a higher likelihood of not spreading the virus further as they would have been informed of the dangers of re-infection at the clinics. Encouraging those who are positive to come to the treatment centres by those who "sacrifice" themselves by going public about their own positive status enables those who are positive to reduce their own infectiousness as it has already been shown by scholars such as Wabwire, Wagner and Ryan (2007) that some of those who start on HIV treatment can be able to reduce their infectiousness if they adhered to the treatment. In all the above, the community around the positive individual benefits as the number of orphaned children are reduced, as the person embraces protective measures to ensure that they do not get infections in future relationships and as the infectiousness of the individual is reduced because of adherence to HIV treatment. The experience of this respondent from the TASO drama group shows that those who go public act as focal points in the communities in which they live and the communities in which they give their testimonies so that the rest of the people can get advice from them. He pointed out;

> *I have even been able to bring people here to test and those who have found that they are positive, they have got the drugs and now they are working normally. I talk to a number of people, sometimes I give them my testimony, and they get convinced to come to the clinic to test. Some come here when they are very weak and already qualifying to start ARVs, they start on ARVs immediately and they get back on the road. I have helped so many people to come and seek for treatment from the clinic. Some of the people hear me talk over the radio; I have appeared on two radio talk shows, and I am preparing to do more of the radio talk shows on 20th of this Month and 1st July. I am going to talk about discordant couples. So, when I pass on my telephone number over the radio, some of those listening call me after the show saying, 'Come and help me to talk to my relative here' Then when I go and talk to them, they get convinced to come to the clinic to seek HIV/AIDS treatment services.*

Another respondent in the process of answering why she does not fear disclosing her status to the public remarked;

> *I am not the first one to get the virus nor am I the last one to get this virus. Even when I am at home I unpack my drugs when my neighbours are seeing; I want everyone to know that I have HIV. Even all the children that I have know that their mother has HIV. Even everyone in my village knows that I am HIV positive. I usually go to the village and educate them about HIV; even today, I have brought someone to this clinic and they are lying behind there waiting to start on treatment.*

Another respondent who is a client of the TASO Mulago HIV/AIDS clinic while responding to a question on why he had gone public about his status remarked;

> *All along I had been touched by the condition in which positive people were dying in. I thought that if I disclose to the public, it could help those who were just scared to get out and seek for treatment. They could seek for treatment even if they did not disclose their status. …Some people were not convinced. But after disclosing my status publicly, deep in my heart I got happy because some of the people who used to fear seeking treatment started to come to me so that I could help them get treatment.*

Another respondent from the TASO drama group pointed out;

> *By coming out publicly I have been able to save the lives of many. I have never even shifted from the community in which my husband died from. When he was down he looked very badly, but I have never shifted from that community. Some used to stigmatise me but now they are coming to me for advice. …Yes. They come and ask that, "You used to look very poorly but now you look very fine; what trick did you use to look like this?" Then I tell them that I did not get any big trick, but I am only in TASO from where I am getting treatment for my positive status. Then I tell them, "You should also come and test from there, and in case you are positive, you can start getting treatment from there". …I have surely saved the lives of some people that were already in a very bad shape.*

Another respondent from the TASO drama group when asked why she had gone public pointed out; *"…My going public is also meant to help even those who are already positive so that they can reach out to places that can help them"*. Apart from encouraging those who are HIV positive to come to the treatment centres to receive services, by encouraging everyone in the communities to come to the treatment centres for services greatly contributes to spread of the appropriate information about HIV/AIDS. Those that are encouraged by those that have gone public to approach treatment centres leave these centres with better knowledge about HIV/AIDS, and it is believed this has an important effect on the prevention and treatment of HIV/AIDS.

5.3.1.3 Educating those who are HIV negative how to remain negative

When those who are not sure of their HIV status are encouraged to approach the treatment centres by those who have "sacrificed" themselves by going public, when some of these individuals find that they are HIV negative, then they also get useful information from these centres. This information rotates around how they can continue to remain negative by being introduced to the various alternative protective strategies/methods that they can adopt. When the individual seeks HIV/AIDS services, the various myths and misconceptions that they might have had about HIV/AIDS are checked and the right information provided to this individual. If this individual after visiting an HIV/AIDS service centre aims at preserving their negative status still the community around this individual benefits as it is saved the burden of looking after HIV orphaned children. The individual continues to work productively for a long period of time and thereby contributing to the entire economy. Generally the spread of HIV is curtailed as individuals now approach the counselling and testing centres from where they discover their negative statuses but also get equipped with useful information on how they can remain negative. In relation to this a respondent from the TASO drama group when asked what motivated him to disclose his status publicly, pointed out;

> *The first thing that I think motivated me was that if I had also got the kind of sensitization like the ones the drama group takes to the communities, most probably I would not have contracted the virus. I thought it was necessary to educate the people about HIV. There are very many people out there that we assume know the basic facts about HIV but when we get there we find they know too little facts about HIV. When you ask them simple questions about HIV, and then listen in to what their replies are, you realise they know little facts about HIV. Even when we assume that people here in Kampala know the basic facts about HIV, there are communities that we*

> *have gone to and found out the contrary. So, I realised it was necessary for me to educate the people about HIV and if possible I could save lives.*

Another respondent in the process of answering the question on whether he would encourage other people who are positive to disclose publicly pointed out;

> *But why do people go public? Because they know that they have been called to help other people. Like me I am on a mission to reduce stigma, to reduce shame, to reduce denial, to reduce discrimination, to reduce inaction and mis-action, because I know that once those six evils are still in place these prevention efforts will not yield much, these treatment efforts will not yield much. You will put testing machines and people will not test, if they test they will not disclose! So, I feel called to help in that direction.*

Another respondent from the TASO drama group while answering the question on whether she disclosed her status publicly before or after joining the TASO drama group remarked;

> *Given the experience that you have, and the counselling that you get, then, you can be able to gain enough strength to go public so that you help educate other people. For me, I am a parent and I have children who are already grown up and getting to the age of being sexually active, but when I look at them I feel they might contract HIV. Given my experiences in marriage and how I contracted HIV, I realised I should come out publicly to help other people not to contract HIV. As I told you I am a widow, so, after the death of my husband I was completely mistreated and it is this mistreatment that contributed to my going public about my status so that I can educate others and especially young people so that they do not contract HIV to experience the mistreatment that I got.*

The above experiences clearly point out that a significant portion of those who have gone public have been partly motivated by the desire to educate those that are HIV negative about the reality HIV/AIDS poses to their lives.

Although observation was not part of the data collection methods that I had proposed to use to collect data on public disclosure, while I was in the field collecting data, I got the opportunity to join the TASO Mulago drama group as they were going for one of their sensitization sessions. In the two boxes below, I summarise what transpired on that particular session. In the second box in particular, I present the testimony that was given on that particular day; and this testimony not only points to how individuals in the communities should protect themselves against HIV, but also hints on how those who are positive and might still be out there should approach the treatment centres for help.

While I was conducting the interviews I got the opportunity to join members of the TASO drama group who were going on a routine sensitisation to the community. This time, they had been invited to perform and sensitize a gathering of mainly women of Kikaya (on Kampala-Mityana Road). The women in this community have organised themselves into an association. So in this particular day, this women's association had invited the TASO drama group to sensitize mostly the women about HIV/AIDS. The women here had decided to celebrate the International Women's day on this day. In order to celebrate, this women's organisation had felt that if women in Kikaya are sensitized about the reality of HIV/AIDS, then, a lot would have been achieved.

While interviewing the counsellor that had escorted the drama group for the sensitisation session, it was pointed out that in order for any community, or organisation to benefit from their sensitisation service they have to apply two months in advance. While looking at the schedule for the drama group, I realised that its services had virtually been booked for the next 3 months. This partly confirmed that the community appreciates the service that is provided by especially those that have gone public about their HIV+ status, since everyone in this drama group has gone public about their status.

Still on this sensitisation tour, one the very few men that attended the sensitisation session, asked why TASO had opted to only come and sensitize largely women, and the counsellor in charge of the out reach pointed out;

> *TASO does not go to where it is not invited. So, for you to benefit from our sensitization you must apply to us formally. These women did apply to us and because of that application, that is why we are here. For you to apply, the application should at least reach us one month in advance. If we come here uninvited, that would seem as if the HIV/AIDS problem is TASO's problem, but if you think that this problem affects you, then you should invite us formally. And when you invite us, we will be willing to provide you with all the necessary information.*

Since the service of those who have gone public about their status is on demand, this points to the fact that the communities are appreciating that the benefits that come from this act largely benefits them and not those who have gone public.

Box 1: Visit to the community with the TASO Mulago drama group on a sensitization session

Testimony

I am a married woman and a mother of four children. I got married in 1993 and in the same year in November, I produced a baby a girl. I became pregnant once again in 1995 and went to Mulago hospital for antenatal care. It is from here that I was taught a number of things including issues of HIV/AIDS. I was taught that research had already shown that pregnant women that were positive had a possibility of infecting their unborn babies. So I was advised to take an HIV test so that in case I was found positive, I could be given a drug that can reduce the possibility of infecting the unborn baby. So, I accepted to be tested for HIV. By then the HIV results could be got after a period of two weeks; so after the two weeks I went back to get the results. Unfortunately, the results showed that I was HIV positive, a fact that annoyed me so much. After that I cried for a long period. The counsellor however who counselled me was a very good counsellor who gave me all the support that was necessary. Among other things, the counsellor advised me to start using condoms so that I could protect myself against various diseases that might aggravate my situation. The counsellor also advised me that if it was possible I should not carry unnecessary pregnancies again as this could also aggravate my situation. After this, I went back home and told my husband that I have been tested and found HIV positive and that I was advised that I should encourage him to go and take an HIV test too to establish his status. So when I told him to go and test, he refused saying that since I had tested positive, there was no reason for him to test because he is already positive too. So in 1996, I was able to deliver under the watchful eyes of the doctors who were aware of my situation. But because our faith does not allow us to use condoms, me and my husband could not be able to use condoms nor any other method of family planning, I got pregnant again. So, I went back to the hospital for antenatal care and tested HIV positive once more. The doctors again advised me to convince my husband to come for an HIV test which task I fulfilled once more. After protracted convincing, he accepted to come with me to the hospital to test. When the two of us tested for HIV, unfortunately my results showed that I was positive while he was negative. The counsellor had an uphill task of explaining to us how we could be able to proceed after that. After this discovery, some of my husband’s relatives advised him to abandon the relationship since I could no longer produce children with him. Amongst the options the counsellor had given us was to take on using condoms if the status of my husband was not to convert sero-positive. So, we convinced the church Reverend to allow us to use condoms in order to save the life of my husband and this request was granted. Then later on, I went back to the hospital and delivered under the watchful eyes of the doctors. On this occasion, I got blessed with twins. My second born is now in Primary Seven and I was able to take him for numerous HIV tests until when he was four years and he is negative. The twins are now in Primary five, and they are also HIV negative. Unfortunately my first born who was produced before I got to know my status and therefore was not able to take the necessary precaution turned positive and later died. Together with my husband we have been able to resolve to continue in our marriage, but currently we are using condoms to protect my husband from contracting HIV. I end by calling on you to go and test for HIV so that you can be able to obtain the right information at the right time.

Box 2: Testimony from one of the members of the TASO drama group given during the sensitization session

5.3.1.4 Notifying Potential partners

It would be expected that if someone disclosed publicly that they were HIV+, then the number of prospective partners that approach them for sex would reduce drastically, but this study established that this is not the case. Nearly all the respondents that I interviewed reported that people of the opposite sex continue to approach them even after the respondents had already disclosed to the public that they were HIV positive. When asked whether the respondents were sure that those approaching them were aware that they have already told the world that they are HIV+, nearly all the respondents pointed out that they were sure that those who approached them knew that they have disclosed their status publicly.

In short, public disclosure does not seem to deter prospective partners from approaching the HIV+ individual for sex. Although when asked whether those approaching them for sexual relationships could have been positive too, some of the respondents pointed out that some of the people approaching them were already positive clients with the TASO clinic, but a number of respondents also pointed out that, because they are healthy and they are very beautiful/handsome, many of the people approaching them do not believe that they are HIV positive, but only think that they are in the "business" of public disclosure in order to earn a living. The scenario of potential partners that continue to approach those that have disclosed publicly can for instance be exemplified by the case of one drama group member who when asked whether men continue to approach her even after disclosing to them that she was positive remarked;

> *You see when you test and know where to go for medication, sometimes you change and your health improves. When we disclose to people like in villages, they do not accept that we are positive. They can say, "How can you say that you are positive? Can a healthy person like you be HIV positive? No, you are lying to us, you are just given money to say that you are positive". And after performing they come to you and say, "I feel I should marry you. I know you are lying about your status and I have admired you". …They think that we are deceiving them. They think that we are given money to say that we are positive.*

Another respondent in response to a question of whether men who are aware of her HIV status continue to approach her for sexual relationships pointed out;

> *Yes. Men still have a big weakness because when we go to the community we disclose our positive status; when someone discloses their positive status publicly, I do not think they can be able to get the courage to spread the disease recklessly. Some men tell us, "You are just lying to us, there is nobody who is HIV positive that can be as open as you are! And if you were HIV positive you would surely not be looking as healthy as you are. Where did you get this strength that enables you to disclose your status publicly? Now, you want to save us as who? Or you are just claiming to be positive because you are being paid?" Then you see a man approaching you for love. But for me, I just tell them that I have already told you that I am positive.*

Asked whether the men that approached her are usually serious in their moves, she remarked;

> *Yes. Very serious!. And they tell you, they will have sex with you without using condoms. Very risky! Ignorance about HIV out there is so huge!. Some people out there think that we are just playing and we are being paid, but we are just interested in saving their lives. For me, I am quite sympathetic with the rest of the community and I am not interested in spreading the virus, but there are some of the people who are aware that they are positive and they intentionally spread the virus.*

Another respondent when asked whether women who had never been his sexual partners before he went public approach him for sexual relationships remarked;

> *Ooh! Ooh! I get so many women my friend. I do. I do. I am a very marketable man, I can assure you. I think to some it is an issue of complacency that I was already talking about. Maybe others are really trying to discover whether I have HIV! And of course others do want to be associated with me may be because they are very empathetic. You know you get all sorts of people. There are people who wonder what kind of person I am! And women are quite soul searching. If I wanted to marry so many women, I would be in trouble. I do not have any problem in association with women at all, whether those I may have had sexual relations with before or even those that I had not met. I do not think I would find any problem especially from women; nothing! And I think women especially those who are knowledgeable know that I would be more protective than those [men] who deny the fact. If I was to go with a woman I would definitely put on a condom. I would not try to dodge. I would not try to tell her to do things in different way. There is no remorse. But these other men when a condom comes in, each one starts wondering does she think I have HIV, or does he think I have HIV? Things like that! But for me it is straight, there is no argument, there is no remorse.*

Another respondent when asked whether women still approach him for relationships pointed out;

> *I think there is a singer who has released a song, I think it is Ssemakula, and I think it goes like this, 'When love is in the air, it does not know…' In my personal life, I have seen that there are things that do not obey rules; I have seen things like liking, loving, hating, disliking; these things do not obey conventional rules. Even when rules are there, they break them. When you say approach, it is a very big word, but it is pregnant! Yes, you can see people making moves and trying to attract attention. Before I married again, it was even worse because they had realised I was single. I would say, 'I lost my wife in 1991, I am HIV positive and I am alone' And these young girls would say, 'Wait a minute, I think this man is not communicating the whole truth; there is nothing on his body that shows that he is positive! So, he is using the positive gimmick to distance himself from us. Up to now there are people who do not believe that I am positive! So, my stating that I am positive would not be enough to scare them away. Secondly, love does not get scared with death, and that is why I was telling you that when we are communicating we need to design messages that are*

> *in tandem with reality. Because when you say, 'Do not have sex you will die of AIDS' and these people are intensely in love, someone can even say, 'If I can die as a result of loving this person, it will be a nice thing to do' Like Jesus said that, 'Greater love has no one than this, that one lay down his life for his friends'. John 5:13. So we need to separate these things. So, by stating that you are positive, people will not get scared away if there are so many other qualities that you have that attract them to you. If there is no sign on you to show that they have to be at a distance. That is where we have a problem because people who have AIDS are not a problem; the people who have AIDS have sore lips, weak energy, they are in bed -those can't have sex! But those who are positive and well, they can have sex. That is where the problem is! I have heard testimonies from women who say, 'Even if you tell a man that I am positive, he says, "go away, you think we have seen few positive people, and do you think I will live forever"' So, people don't get scared with AIDS because there so many things that cause death in Africa. You would rather communicate a positive message that would help them look at other variables. If for example someone has children by telling them that if they cared for their life they could live longer and could see their children grow, finish university and see them at a wedding. That can motivate them more than telling them they will die. So, you are right, I am handsome, I am young, I am well educated, I am in circles that people say are above the poverty line, and that means I am vulnerable to people who would want to associate themselves to these kinds of qualities, and if possible get an intimate relationship with people with such qualities. The difference is they are dealing with some one who knows his moral convictions, who knows where he is coming from and where he is going. So, I put a bar to stop them, and when I see things getting serious I attempt to dodge. To some of these women, even being born again is not enough, they will say, 'I am also born again' They will not come as if they are looking for sex because they know you will see it, but they use other means. So, what I am saying is that there is no one who is free from vulnerability, but what Chinua Achebe taught me is, 'You cannot stop birds from flying over your head, but you can prevent them from laying eggs in your hair' So, girls can be interested in me because I can't stop them from being interested in me but at least I can prevent them from laying eggs in my hair!*

The views above, show that disclosing publicly does not stop one from being approached for sexual relationships, and therefore if any programs are to be directed on involving positive persons in the fight against HIV by disclosing their status they should be aware of this reality.

It was also observed that public disclosure has an indirect benefit to the individual disclosing because it shields them from approaching potential partners later on if the urge comes up. Because the individual would have already disclosed to the public, in case they felt they needed to get into a relationship later on, they would have to weigh what kind of relationship they need to get into, and how much safety they need to observe. Even when persons of the opposite sex seem interested in this individual who has already gone public, the very act of public disclosure that they engaged in earlier on, informs the decisions they have to take now. In relation to this for instance, one respondent who not only has disclosed his status publicly but also pointed out that he was a saved person, when asked whether women were approaching him for relationships after he went public remarked;

> *The women that I have seen, who know that I am saved have not approached me directly. Women usually do not approach men directly!. You can be friends with a woman, and she even calls you on telephone, but many times she cannot tell you directly that she loves you. And I cannot approach them because I am not only positive but I am also saved. So, as the days pass, the woman gets to realise that you are very saved. Then they realise that you cannot be able to give in easily. When I got to the tailoring school, I told my fellow students, that, 'First of all, I am a saved person, secondly, I am a married man, thirdly, I do not have sex with any person who is not HIV positive. In short, I cannot have sex with somebody who is not positive, because even the wife that I have now, is HIV positive'. Then they realised that I am not interested in infecting anybody, while they also realised I was not interested in getting infections from them. Then I told them about condoms and how they can help them to protect themselves. So, they got to know the limits within which they could be able to interact with me, and with that it becomes difficult to approach me.*

Another respondent who not only has disclosed his status to the public but is also saved pointed out;

> *I know in disclosing my status, I have not committed a sin and it has enabled me to keep my faith between myself and God. You see, if I did not disclose my status, may be I would commit a sin? Who knows? Even when you see me now, can you say that I am HIV positive? No. I was much likely to get tempted; so disclosing my status has helped me not get tempted.*

Seen in another way, public disclosure in the above two cases can be compared to building a fence around ones house to keep away thieves but which fence also limits the owner on the exit options they have in case they want to move out. Apart from this 'fence' that to some extent keeps away those that could have nurtured intentions of approaching the individual for sexual relationships, it also to some extent limits the individual that would have built it in case they wanted to engage in numerous sexual relationships.

5.3.2 Benefits to the individual

Although the individuals that have gone public about their positive status pointed out that they were motivated by the desire to help the communities, they further pointed out that individual desires partly motivated them to go public. Individual desires such as the desire to be prayed for by those who have disclosed to the churches, the desire to obtain economic help especially by those who were unemployed, and the desire to counter discrimination and stigmatisation were some of the individual considerations that motivated some of the persons to disclose publicly.

5.3.2.1 Economic benefits

Most of the respondents that I interviewed did not have formal jobs apart from volunteering with the TASO drama group. Apart from the respondents from the TASO drama group, the other respondents had formal jobs, and were actually more gainfully employed and therefore hard to interview as they were busy most of the time. A number of the respondents (3 out of 30 that I interviewed) pointed out that they had been partly motivated by economic benefits to go public. Going public was seen as an easier way of getting employment and getting the needed treatment. For instance one respondent who had disclosed her status first in church when asked what those who had come for church talked to her after the church service, remarked;

> *Yes, they asked me, 'How did you get this strong to stand up in church and disclose?' Then I told them that, 'If for you, you can't come out, for me I am strong. Now that I have finished disclosing I might get somebody giving me advice on what kind of medicine I can use!' 'I can get somebody giving me advice on which Doctor to go to or which church I can go to, to be prayed for' It is better to disclose to people so that they can be able to help you. If you disclose, may be somebody may tell you, 'Go to this and this person he will be able to help you or go to this and this office and you will be helped' Now if I keep quiet I might die because I am not working and therefore I do not have money to use. …For us positive people we are advised to do light jobs;, so now, if I do not disclose to the public, how will I get the light jobs?*

Another respondent who has not only been able to go public but has started an organisation devoted to HIV/AIDS work when asked what inspired him to start the organisation remarked;

> *What inspired us to start that organisation was that we wanted to be of help to others. …But taking this on, was also like getting something to do, it was like getting employment. Coming out helps one to get privileges because somebody after listening to you may say, oh you like this, oh you are like this. Somebody can come to your rescue and help you. In fact when we started the organisation we needed to be helped and we also needed to have a position in society; because sometime when you do not come out nobody will understand you. But we knew when we come out and say that we are these kinds of people, then we shall be recognised. As per now, we*

> *have registered the organisation as an NGO …but we know when we succeed we shall be exposed, we will be able to cater for our families, to cater for our children. Then we shall also get the job privilege.*

Another respondent brought out the treatment benefits of disclosure. If after disclosing publicly, and advising those that are positive to stop spreading the virus intentionally, there can be better treatment for those who are already positive, then individual who is positive stands to gain.

> *So, I keep telling people with HIV that, 'Each day you spread the virus, you are causing a problem to yourself, more than even to the person you have given it. First of all for you, you have already lived longer with the virus, you probably might need the drugs much earlier than the person you have infected. But by infecting this person and therefore causing the number to become bigger, you are creating a situation where the government is not going to be able to provide for medication and therefore, you will also be a looser. Because the government will reach a stage where they will say, we do not have the money, we can't do much; but if there were only a few people who were HIV positive in this country, their lives would be more guaranteed because they would be assured of drugs. But because the number has become so big, you realise that may be only 40% of those who are in dire need of treatment can access treatment… So, really that is what I meant. I meant that if we kept it to ourselves, selfishly, we probably would have had a better service than we are able to get now.*

Another respondent from the drama group while explaining how she came to join the drama group pointed out;

> *So, when I came to the drama group, I found the job that I did not like, the job of going to the communities! But I had to go to the communities because I had asked for the job willingly. I had also heard that there was some little money that those who go to the communities for outreach were being paid, by then, after every month, we would get paid 50,000 UGX. By then that money was a lot, because I had no job, and a year would even pass without me getting that kind of money. So, for a person to tell me that they were going to give me 50,000, I looked at that amount as a lot of money. So, I had to strengthen myself to go to the communities.*

As the experiences above show, there are material benefits that accrue from public disclosure that go to the individual disclosing. These benefits that go with the act of public disclosure to some extent as will be shown later encourage individuals to go public.

5.3.2.2 Intrinsic benefits

It was not only very tangible benefits such as monetary gains and employment that they got after disclosing publicly, but there were also intangible benefits such as the satisfaction that comes out the feeling that one is contributing something positive to society. When individuals disclose publicly and in the process act as focal persons to direct others to where they can get care from, and when those that are directed are helped by the HIV/AIDS care organisations, those who disclose publicly intrinsically benefited. According to table 8 above, 4 respondents out the 30 that I interviewed clearly pointed out that they were actually satisfied with the outcomes of their public disclosures. One respondent for instance when asked how he felt when he saw the people he had directed to the HIV/AIDS care organisation coming for treatment remarked; *"In fact I am very happy. I am happy. In the past people have been dying in a very bad way without any treatment. Some have been dying in a very bad state, without any hair, the skin in a terrible state"*. Another respondent when asked whether on a personal level he has ever felt that he made a mistake to go public remarked;

> *No, No, I have no regrets. First of all I could not reverse the virus. When it has gone in, it has gone in; you can't reverse it. I have no regrets that I actually went public because I think in the process I have saved so many peoples lives. What best can a man do? In this world what else do we have that we can do? I have no regrets at all. Sometimes I sit down and say 'May be this is also destiny?' Maybe if it is an issue of God, then perhaps his soul is in me that there is that quality of being what I am. Therefore my life is being useful instead of being useless. So, I have no regrets. I absolutely think, I live a happy life. I am probably one of the happiest men that live on this planet, because I do exactly what I want to do, and I do it with all my heart and soul. No remorse; nothing!*

From the above, it becomes clear that those who go public actually get satisfaction at the personal level when they see that they are being useful to society through providing useful HIV/AIDS information to the wider society.

5.3.2.3 Counter individual discrimination & stigmatisation

At the individual level, the person who discloses publicly benefits by being able to counter discrimination and stigmatisation. Discrimination and stigmatisation of HIV+ persons largely thrives on the spread of rumours and gossiping about the individuals who are suspected to be positive. So now after the individual has come out publicly about their status by themselves, the basis for the suspicion and therefore the rumours would be no more. In the end, the individual benefits after the elimination of this basis. According to table 8 above, 3 respondents out the 30 that I interviewed clearly pointed out that public disclosure had enabled them to counter discrimination and stigmatisation. In relation to this, one respondent from the TASO drama group when asked how easy it was to give her first testimony to the public pointed out;

> *It is not easy but the good thing I had gone through enough counselling. But when you get out, you have to be free, you have to get out of the denial stage and accept that you are HIV positive. You become free and open, and this to some extent helps you as some one can no longer insult you by telling you that you have HIV. At that level do you think that that kind of utterance can still affect you? No, it can't. It is not even an abuse, and if anyone says such a thing to me, it cannot hurt me, but I can just wait to look on as they get ashamed of themselves. For me already I know that I am a victim, and I have accepted it.*

Another respondent from the TASO drama group in the process of answering the question on how he felt the first time he disclosed his status to a gathering pointed out;

> *But what motivated me to disclose was that when you disclose your status to the public you do not experience much discrimination because you would be the one who revealed your status to the people. But if the people discover that you are positive by themselves when you are trying to hide it, that is where the source of the problems are going to emerge from. But if you disclose to them your status first before they stumble on information that you are positive, then they do not discriminate against you. When I looked at this, I thought I should disclose my status to the public. Although the first disclosure to a gathering was not easy, when I got used to going to the communities to sensitize them, it is now quite easy to tell a gathering that I am HIV positive.*

When asked further what he meant by saying that when you get out first and disclose publicly, people around to not discriminate against you, he pointed out; "*If you have not disclosed to the people around, that provides favourable ground to these people to start gossiping about you, saying it looks so and so is sick [having AIDS]. But if it is you who disclosed to them, it is not easy for these people now to start gossiping about you and discriminating you*". When asked further why there were differences in the amounts of discrimination an individual receives when people discover one's status by themselves and when the positive individual himself/herself disclosed it to them first, he pointed out; "*When you do not come out openly it looks as if you are hiding your status, but when you come out and disclose openly the people around get to realise that this man has a problem of this kind of disease [HIV/AIDS] and needs some kind of help. Many times this helps the person who has disclosed their status rather than waiting to have the people around to piece together the information that shows that you are HIV positive*". Most of the respondents that I interviewed were of the view that disclosing publicly helped in reducing discrimination and stigmatisation at the individual level. When discrimination and stigmatisation are reduced at the individual level, then the community stands to benefit as these two also reduce at the community level.

It is like the court process, if a suspect pleads guilty the first time the judge reads them the charges, the judge can opt to give them a lighter punishment than when they prolong the hearing and later they are found guilty after all the evidence pins them down for committing the crime. So, even those who are HIV positive, when one is able to disclose before the symptoms become very apparent, they experience less discrimination and stigmatisation from the community. Although it appears to surprise many in Uganda when someone who is healthy comes out in the public to say that they are positive, they again appreciate the fact somebody can be healthy but HIV positive. So, when such a healthy person goes public, it seems the community around this individual appreciates the fact that although this individual had the option of not informing them and infecting them intentionally, they did not take this option. And because the individual did not take the option of not informing them and remaining with the potential to infect many intentionally, then society sees no reason for discriminating against such a person because by their actions they would have shown that they are interested in the common good of society.

5.3.2.4 Helps to reduce re-infection and other infections/diseases

It was also established that public disclosure of the HIV+ status indirectly helped individuals to reduce or avoid re-infection. According to table 8, 4 respondents out of the 30 that I interviewed clearly pointed out that their engagement in public disclosure had enabled them to significantly reduce their re-infection. Those that have been able to disclose to the public showed that they were less likely to engage in risky sexual behaviours. This was mainly because their potential partners would most likely be already aware of their status and therefore cannot approach them, or would without any question use condoms if they approached them. In relation to this, a respondent from the TASO drama group pointed out;

> *…there are some people who are aware that they are positive and they intentionally spread the virus. But this kind of behaviour is very bad, the individual, that you think does not have HIV may at least have other diseases that you can be able to pick from them. When you have unprotected sex with them, then you pick such diseases because our health is very sensitive to so many other diseases. The more you expose yourself to other diseases in that way, the more you shorten you life. …While on the other hand when you disclose publicly it helps you to reduce on the number of people that can approach you for sex. (When the potential partners reduce, then, you can be sure that the various diseases that you would have obtained from these partners reduce or are avoided).*

Another respondent in the process of answering the question on whether women still approach him after he went public pointed out;

> *...And I think women especially those who are knowledgeable know that I would be more protective than those who deny the fact. If I was to go with a woman I would definitely put on a condom. I would not try to dodge. I would not try to tell her to do things in different way. There is no remorse. But these other men [who have not disclosed] when a condom comes in, each one starts wondering does she think I have HIV, or does he think I have HIV? Things like that! But for me it is straight, there is no argument, there is no remorse;…*

From the above it can be seen that indirectly, public disclosure enables individuals to protect themselves further from re-infection and from getting other sexually transmitted diseases.

CHAPTER SIX

CHALLENGES AND ASPIRATIONS AFTER PUBLIC DISCLOSURE

6.1 Introduction

This chapter presents challenges that result from the act of public disclosure. While presenting the challenges that result from public disclosure, I attempt also to show between the individual disclosing and the communities/collectives from which and to which they disclose who meets the biggest burden of these challenges. This chapter also presents the aspirations that HIV positive persons get after the act of public disclosure.

6.2 CHALLENGES RESULTING FROM PUBLIC DISCLOSURE OF THE HIV+ STATUS

Positive persons that have disclosed their status to the public do face some challenges but nearly all the challenges they face rotate around discrimination and stigmatisation. It is not only the individuals that face challenges but the communities from which they come sometimes can share in these challenges from public disclosure. These challenges are summarised in table 9 below.

Table 11: Challenges from Public Disclosure

Challenges	Frequency	Percentage
Discrimination and stigmatisation	30	40
Family related challenges	11	14
Failure to be believed	20	26
Work related challenges	11	14
Other challenges	5	6
Total	**77**	**100**

n=30

Before embarking on data collection, the researcher felt that when an HIV+ person discloses their status to the public, they are bound to face numerous challenges. The most significant of these, the researcher believed would be discrimination and stigmatisation from the community in which the positive person lives. The study showed that although positive persons are discriminated and stigmatised, the extent of these two is not widespread as the researcher had earlier thought. In the next paragraphs I bring out the challenges HIV+ persons experience after disclosing their status to the public. Amongst the challenges that I present, the issues of discrimination and stigmatisation are given due attention.

6.2.1 Discrimination and Stigmatisation

Again before presenting the challenges that exist out there for positive persons that disclose their status to the public, I present the experience of a 71 year old woman that I extracted from the New Vision, Monday August 4, 2008 p.40 (New Vision, 2008). The experience of this old woman precisely summarises the two theories –Social control theory and the Social constructionist theory that I use to inform the study. The experience follows in the box below;

Can we treat my grandmother with ARVs without her knowledge?

Dear Doctor,

My grandmother who is 71 years has high blood pressure and diabetes for which she is under care. Recently she developed herpes zoster and the doctor advised that we do an HIV test. This was done and she turned out HIV positive. We have not told her because she often says HIV affects immoral people. However the doctor says she should be put on ARVs because her CD4 count is very low. Is disclosure always necessary? Since she is on daily treatment for high blood pressure and diabetes, can we add the ARVs without her knowledge? Please advise.

Box 3: Can we treat my grandmother with ARVs without her knowledge?

Although she had engaged in discrimination and stigmatisation of HIV+ positive persons, because she thought those who are HIV+ had serious moral problems, she too later got diagnosed with HIV. As I will show later while using the public health morality model (see Figure 3), she had engaged in this discrimination of HIV+ persons as a form of social control, but if she was informed of her positive status after the test, then the reality that she was aware of should and could have been easily reconstructed.

Discrimination and stigmatisation of people living with HIV/AIDS is still widespread in the communities although it is reducing. According to table 11 (shown earlier), 30 respondents out of the 30 that I interviewed pointed out that discrimination and stigmatisation are some of the challenges that they face after disclosing to the public. The study established that those who have disclosed publicly partly aim at fighting to further reduce this discrimination and stigmatisation of HIV positive people. This was thought could be done by sacrificing themselves to show the public that HIV is out there and can be contracted by anyone, so there was no need to stigmatise anybody since anyone can contract it.

Positive persons that have disclosed their status to the public did not report facing significant discrimination and stigmatisation from the people around them. In support of this, one respondent who had disclosed her status publicly in the church when asked how she felt after disclosing in church commented; *"There was no change. For me I trust in God and even if somebody gossiped about me, I know God is the one who has enabled me to live up to today"*. Another respondent when asked what challenges she had encountered as a result of disclosing publicly, pointed out; *"I do not have so many challenges that I have got in disclosing to the public"*. But when further asked about the behaviour of her neighbours, she pointed out;

> *In my community some people think that because I have HIV if I converse with a man, that man would be trying to sleep with me. If a new person comes into the community they try as soon as possible to tell him all the information about you. They tell him that, that woman has this and that problem. Most people think that HIV positive persons do not have to have friends. If an HIV positive person converses with another person, they tend to think that this other person is trying to sleep with them. That is the thinking of some of the people. They think that if you are positive you cannot have just a friend.*

Again when further asked how she felt when such a thing was mentioned, she pointed out; "*It does not hurt me because many times the friend who is told such things usually comes to me and tells me the whole story. Then I just confirm to them that what you were told is the truth; that is my condition.* This seemed to prove that those who go public, are already convinced about what they are doing, because if it was not the further probing of the researcher, her first response pointed to no discrimination involved in public disclosure.

Another respondent when asked about the challenges he has faced as a result of going public, could not be able to refer to himself but pointed out the challenges other positive people have faced. He remarked;

> *Some of the people who go public are chased out of their rented houses by their landlords. Different people have different ways of thinking about an HIV positive person. Some HIV positive persons are discriminated against by their own neighbours by for instance stopping their own children from playing with the children of the HIV positive person. It would be good for every positive person to disclose publicly, but as it stands now, every person should be able to look at their surrounding and especially the people surrounding him/her. For some people when they learn that one is HIV positive, they mistreat your children by constantly reminding the children that your mother is HIV positive, and on that basis the children should not play with their own children. When the landlord sees that you have malaria, they complain that, "That one is going to die before I am paid my rent fees!". Then after that, they decide to chase you out of their house. The landlord gets worried that you are going to die in their house and he sees that scenario as quite disturbing to him.*

This proves that discrimination and stigmatisation of HIV positive individuals is still out there, and therefore those who come out publicly should be regarded as martyrs, as they brave these two in their everyday lives.

Because discrimination and stigmatisation of positive persons is still out there, the community around the positive individual who discloses gets amazed by their courage. This amazement has its basis within the thinking that HIV/AIDS is a moral disease and those who contract it, automatically should experience discrimination and stigmatisation. So when an HIV positive person discloses to the public, those around him/her cannot completely comprehend what motivates this individual. One respondent when asked what the people in the communities that they go to ask about, pointed out;

> *Most times they ask, "For this long, how have you been surviving? How did you get this strong so that you do not fear people to get to know your status?" They ask so many different questions.*

From the above, it becomes clear that those that have been able to go public leave their audiences amazed, because many in their audiences would expect that those who discover that they are positive keep quiet in order to avoid stigmatisation.

Discrimination and stigmatisation of HIV positive persons as pointed out earlier are forms of social control that society metes out in order to control the sexual practices of its members. But these forms of social control according to available evidence are completely counter productive, because they discourage persons from seeking out testing and treatment services; they discourage disclosure and so forth (UNAIDS/WHO, 2006). This study further established that discrimination and stigmatisation of HIV positive persons as a form of social control is counter productive as it encourages secrecy with its disadvantages; a respondent who experienced discrimination and stigmatisation after disclosing his status to the public in the process of giving more information about the reaction that he received after disclosing to the public at the national rally to mark the World AIDS day, pointed out;

> *…And I believe many of them had had sex without protection; because I was not talking to school children, I was talking to adults. But when I came here of course there were a few rumours here and there; murmuring here and there, when I would for example go to the barracks in the army, then everybody would start looking at me, pointing at me; people kept a distance. By then of course people were not very clear that you could only get HIV through sexual contact and what we now know as exchange of blood in one way or the other; or through mother to child transmission. They did not know! The best thing they could do was to keep a distance apart me! Even greeting me would be a problem, because they were scared. My heart and mind were prepared and the advantage I already had was that I had done training in HIV counselling, so I knew some of the things that I would expect. So going public was may be was a problem to other people but not me, because I knew what to expect.*

While answering the question on whether he would encourage other people to disclose their status to the public, he pointed out;

> *If people can come to their senses and see reality; it is like if you hid any other disease let's say tuberculosis which used to cause a lot of stigma. If everybody knew about tuberculosis, first of all, they would not stigmatise anyone but secondly they would also not get it. Many people get tuberculosis because they stigmatise others, because then others hide it. With tuberculosis when you under go treatment for only two weeks, tuberculosis ceases to be contagious! But people will hide because they fear this business of stigmatisation. And so those who are stigmatising and those who have it will all have problems, so is HIV really. For me I think the more we harbour it, the more we fear going for testing the more problems we create for ourselves and for the communities in which we live.*

From the above it becomes clear that discrimination and stigmatisation are forms of social control that society has constructed to regulate the sexual practices of its members. However, these forms of social control –discrimination and stigmatisation of those that are HIV positive as strategies of ensuring that societal members are faithful in their relationships, have become so external to those who constructed them and have been able to continuously bring negative consequences to those who constructed them. It would be much better if societal members can change their constructions suddenly.

In order to show how discrimination and stigmatisation of those who are HIV positive have become so external to those who constructed them and ended up being counter productive, I bring out the experience of one respondent that has gone public about his status. Below is an excerpt of an interview with a respondent who is not only positive but also a priest; the excerpt starts after the respondent has gotten his results;

Int: When you came from Baumann house and reached Mukono; how did the people that you disclosed to first react?

Res: My sister in law whom I started with did not react with any surprise. After all she knew that my wife had died of HIV…She was not very surprised because my wife died in 1991; she had handled that process and she is the one who had told me that my wife died of an AIDS related illness, for me I did not know. She had said that it would be good for you to go and check to find out whether you are positive or not. She told me to go and test in October and I went for the test in January; so when I came back I thought it was natural to begin with her. And she reacted with very nice words which probably made me to continue getting the courage to disclose, because she said, "Well Moses (not real name), we loved you before HIV, and we will love you after HIV. HIV is not going to change our relationship with you" She impressed me; we prayed together and we cried together. It was a tough moment, but she reacted in a way that did not discourage me from disclosing. Again that is an important fact that you will note in your research, 'The person you disclose to first, his/her reaction will determine whether you will continue on the journey of disclosure or whether you cut it short and say, if everybody is going to react like this, I would rather keep it to myself' That is why when a person is considering to disclose he must calculate; he will say, 'where do I begin?. Who is the most likely person to give me a warm reception and if it is not a warm reception an understanding or empathetic response?' So, if you have ten brothers then you ask yourself, 'Whom do I begin with? Who is likely to be the most supportive?' Because if one is supportive, he can change the attitudes of the others. If you have two parents, the mother and the father, who is likely to be supportive? So, you calculate; it's a tough thing, because the moment you start and someone reacts violently, then you cut the disclosure process very short.

Int: When you disclosed to the church, what was the reaction?

Res: The reaction was mixed. There were people who were so disappointed and shocked that a priest can have a disease of prostitutes. They asked, 'And you told us you are born again? And you are positive?' So the two scenarios could not be linked. There is somewhere in Rwanda where I was preaching in the Cathedral and during the preaching I told people that I am positive; after the end of the service we usually line up and people shake our hands, saying; 'That was a good sermon. That was a good sermon. Thank you pastor', even when it was not, but people will congratulate you saying that, 'Pastor, that was a good sermon' But there was one sincere man who refused to shake my hands, and said 'I can't shake your hands'. He said, 'They are filthy! You are positive and you still climb our pulpit to preach?' You know, it was like to, 'Contaminate our pulpit?'. There was a group that was disappointed and shocked at the same time.

Box 4: Experience of discrimination and stigmatisation

May be up to now there is still a group that feels embarrassed about me, and I think in their reasoning they would say; 'Now that he is positive, he should keep quiet about it. Why does he continue to disclose his status to the public to embarrass us?' So, you are not so sure that probably even among my close friends or members of the family there could be people who feel like that! But I am not sure. But whenever you do something, you will never get a uniform response. There will be people who will feel embarrassed and say; 'If it happened, he should keep quiet about! Why does he continue talking about it?' Then there is a group that was very happy that they could have such an honest person. Like my brother was very happy that I could tell him and you could see from the way he reacted that he is happy. By joining the search for care and support; if he would go to his office he would ask his colleagues, 'do you people have HIV positive people in your homes? How do you look after them?' Then they would for instance tell him, 'Buy for him garlic' and he would come back home with many cloves of garlic telling me that, 'I have been told that these ones work'. So, in the church there were people who were supportive, and then in the church there is still a group that is undecided. In the church there is a group that likes me, loves me, supports me, and enjoys what I do. If I appear in the news papers they cut out the picture and hang in the sitting room. They are proud of what I do. There are people who are embarrassed by what I do. Then there is a third group, which doesn't know what to make about me! When they find the person who loves me talking good about me, they join in. When they find the person who does not like me talking about me, they also join because they are not sure of their position. You will always get them in any society. So, the reaction is not uniform. Generally, the church's reception to me has been very loving, very caring, very supportive. If it was not, how would I have become a Canon? If it was not, how would I have spent 7 years living with the Bishop in the same house? If it was not, how could I have become a head of Department in the Bishop's office? I know priests who are harassed and sent away. In the Catholic church, you become positive, chances are that your future might also be in jeopardy. This is mainly because they are not so sure on how to deal with you. But in my church, ooh my God! I have been well received. Very well received! Even tomorrow, I am leaving to go and facilitate the Bishops conference. Every time there is a function I am invited to come and speak. So, I have been well received.

Int: If you look at people who are not comfortable with you telling the world that you are positive; why do they want you to have kept quiet about it?

The people who look at HIV as a moral issue; as a disease which you get when you are morally loose will always feel awkward. Every time you open your mouth and say I am a Reverend and I am positive, then they feel like, 'Ooh my God, now, the society will get to know that our church is not as 'upright' as it is supposed to be' You know the English say, 'Don't wash your dirty linen in the public'. That is why I do not hate these people; if they knew the basics about HIV, then they wouldn't be embarrassed! If they knew the accurate facts about HIV, they wouldn't feel awkward, they wouldn't feel embarrassed. But because there is missing link in the information they have then they feel awkward. It is like if he is a thief, why does he continue saying that he stole something? If he has AIDS that means he committed adultery; so why does he continue to remind people that he has AIDS? Why does he continue to remind people that he committed adultery? He would rather keep quiet! That is why in many Pentecostal churches the best way of getting out of that 'shame' is to say that I am completely healed. That saves them the embarrassment. I was positive, I prayed and now I am miraculously healed! That has a double advantage; first it saves them of the embarrassment of always talking about their positive status, like me who has been doing it since 1992. And it is not easy. Two, it gives them a positive bonus of showing that they are super Christians -people who have too much faith and they pray and things happen miraculously.

So, the solution which I am helping people to understand that when people talk about HIV (they shouldn't think about promiscuity is here below);

Box 5: Experience of discrimination and stigmatisation –continued

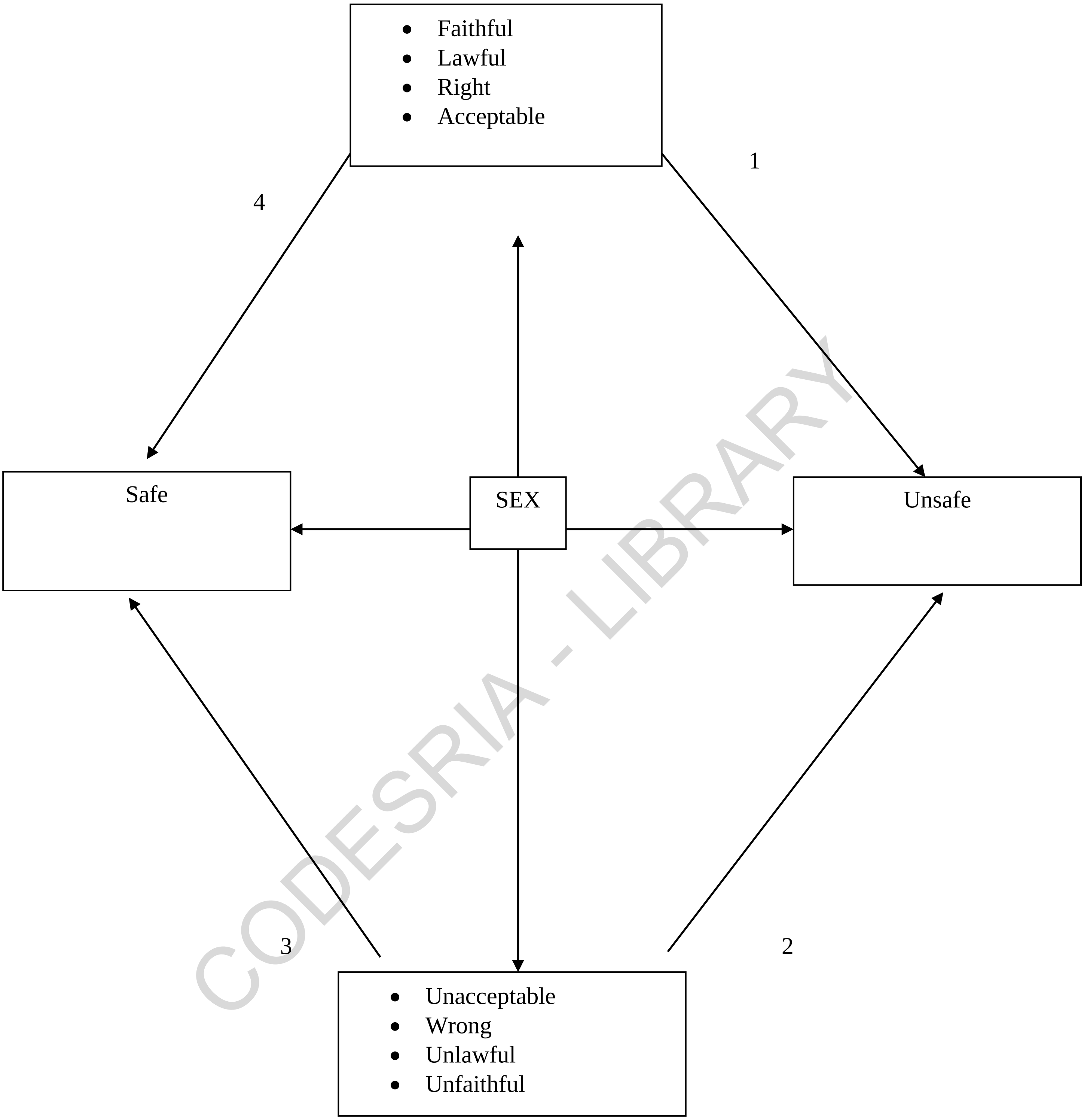


Figure 3: Morality-Public Health Model (Source: Respondent)

The figure above shows the relationship between morality and public health issues. Specifically it shows the relationship between morality and the spread of HIV/AIDS; and finally the resultant discrimination and stigmatisation of HIV+ persons. Because the major mode of HIV transmission remains sexual intercourse with infected persons, and sexual intercourse is associated with numerous moral issues, those who contract HIV many times are discriminated and stigmatised. One side of the figure is what is regarded as a sexual relationship that is characterised by faithfulness, a sexual relationship that is lawful, right and acceptable to society –sex within marriage. Individuals that are involved in this kind of relationship are considered normal and even rewarded by society, through giving them respect. On the other side of the figure 3, is the sexual relationship(s) that society regards unacceptable (adultery, fornication, homosexuality). These sexual relationship(s) are considered as unacceptable, wrong, and unlawful by the wider society. Those who engage in these relationships are considered abnormal by society and are therefore supposed to be "corrected" by society so that they can behave as expected. This correction takes the form of discrimination and stigmatisation of these individuals so that they can behave in a normal way.

The different numbers (1,2,3,4) on figure 3 however, show that the rigid classification of sexual relationships into normal and abnormal relationships, and the resultant discrimination and stigmatisation (as forms of punishment), many times may be un called for and even counter productive. Starting with number 1, on the figure 3; although an individual can be involved in a sexual relationship that is legal, light, and acceptable to society (marriage relationship), if in this relationship unsafe is the norm, there is a likelihood that this person can contract HIV. In this case what becomes important is whether the sexual intercourse that went on in this relationship was safe or unsafe rather then whether the relationship was 'normal' or 'abnormal'.

Number 3 on figure 3, for instance shows that even those individuals that engage in sexual relationships that are not approved of by society, can have safe sex. When this happens, they do not contract HIV; and because they do not contract HIV, they do not experience the discrimination and stigmatisation that those who are positive experience. For example a person can have protected sex with a prostitute who is HIV positive, but because it was protected sex/safe sex, this person does not contract HIV. In moral terms, this person that has had protected sex with a prostitute is not morally upright, but in public health terms, because this person had protected sex, they are upright.

When you talk about HIV, people think about faithfulness -you have seen even our bill boards bringing out faithfulness, lawful -have lawful sex ie within marriage, do not have sex before marriage, do things that are right -I think you have heard that from the Seventh day Adventists when they are de-campaigning condoms they say, 'Try conduct not condoms', they are looking at right behaviour. And when you hear people bashing gays, they are looking at what is acceptable and what is not acceptable. So, the opposite of acceptable is unacceptable, the opposite of right is wrong, the opposite of lawful is unlawful, the opposite of faithful is unfaithful. We also have a variable called safe and the opposite of safe is unsafe. When you say Pastor Moses (not real name) is positive people's minds run to the unacceptable, wrong, unlawful things. They start asking themselves, 'What unacceptable thing did he do? What wrong thing did he do? What unlawful thing did he do? What unfaithful thing did he do? So, he had sex outside marriage or he had sex before marriage or he committed adultery. All these things will come into peoples minds; I am telling you why they get embarrassed. So, when you say I am positive, you are bringing these things to the public. Now you can also see why it is wrong attitude on the part of the public because they should not be asking, 'What wrong thing did you do?' They should be asking, 'What unsafe thing did you do?' Because when you meet a person who is positive, either they are in this group; they did faithful things in a very unsafe way, they did lawful things in a very unsafe way, they did acceptable things in a very unsafe way. You drink your un-boiled water, the result is that you get typhoid. You sleep in your bed but you do not put a mosquito net, the result is that you get malaria. You drive your car but you do not wear a seat belt, you die when you crush. Then there is this group; these ones steal water and they drink it un-boiled. They steal people's cars and drive without belts and when they crush they die. The reason why they are dying after the crush is not because they stole the car! Now, you know why I am not ashamed of my being positive. Now you know why it is easy for me to disclose.

From the model above, when people want to shame me, I know where their thinking is from but inside me I accept myself because I know what explains my status. Because inside me I also know a group, (group number 3) which does wrong things but they do not have HIV. They commit adultery in a safe way. They have sex before marriage in a safe way. So, they have committed adultery but they are not positive. So, it is not true that being positive equals adultery. And that people who are negative equal to sexual saints! Those ones have never done anything wrong. No, that is not true.

The following equations are not true, but society thinks that they are true;

HIV Positive = Adultery

HIV Negative = Sexual saints

As you can see these people (faithful, lawful, acceptable sex but in an unsafe way) when they die, they go to heaven because they have done right things in an unsafe way. The only problem is that they will go to heaven very early!. So, why do people get disappointed or feel embarrassed when you say that you are positive? Right now some people are saying that your Bishop is soon retiring and among the names that should be considered for the office of the Bishop should be your name. But I am sure those people who are saying that your name should be considered will not go very far, because they will meet a strong opposition from the people who look at HIV as sinful. So, they will say, 'How can we have a Bishop who is positive?' 'A sinner?' But the people who have understood these variables will see nothing wrong with having a Bishop who is positive. If that was the case, people who have suffered from malaria would never be elected Bishops.

Box 6: Experience of discrimination and stigmatisation –continued

The Ministry that I am working in is meant to help born again people to get a language that talks about HIV prevention, HIV care and HIV treatment in a way that does not stigmatise, in a way that does not make people who are already suffering to suffer more. And one needs to help them by asking yourself for instance, 'Where do they have a problem?' For example these condoms here; why do people have problems with condoms? It's because in their mind, condom is equal to fornication. You should be there when I am buying my condoms from the shop in Mengo! One day, when I said can I have two condoms? The woman looked at me and she was totally shocked!

Int: In a hospital or a supermarket?

Res: No, in the pharmacy.

Int: And you are putting on a collar…

Res: Then she said, 'Excuse me, did you say condoms?' In her mind condoms are used when you are going to fornicate. My Ministry is trying to help people appreciate that condoms are neutral morally. They fall in a category of things we call amoral and the opposite of amoral is moral. Amoral things are like stones, with a stone when you put it here twenty years later you will find it there. If you decide to hit the car with it, it will hit the car. If you decide to put it on the house, it will build a house. So, that is the same thing with the condom. If you decide to use the condom on a prostitute, it will work; if you decide to use it with your wife it will work; if you decide that today I am not going to use it for sex I am going to use it as a balloon at my celebrations, it will work!. So, it is the person who is going use it that should be questioned, what are you going to use it for? The condom does not answer the question, 'Who are you going to have sex with?' But it answers the question, 'How are you going to have your sex?' Whether you are going to have sex with your wife or with the prostitute the condom will not know! The condom surely will not know that now I am on a prostitute and now I am on a wife or now I am on the mistress! But you the user is the one who knows. So, I am trying to help people understand the fact that the problem is not with the condom, the problem is with the user. We need to train our children to appreciate that we do right things not because we fear getting AIDS but because of their intrinsic value. So, people should appreciate that having sex before marriage is wrong, with or without a condom. They should appreciate that whether you put on ten condoms they do not reduce the sexual sin you have committed! But when we are preaching we tend to forget that! We should also teach people that faithfulness does not protect you from infection, if you are having sex with a spouse who is already positive.

I teach people in the shops when I see them getting confused. I tell them, 'For me, I am positive, my wife is positive and we have to use these condoms correctly, consistently every time we are having sex. And because I am a born again Christian even when I have condoms in my pocket or in my bag, they never force me to have sex outside marriage. Using the condoms in that case will answer the question of being safe, but will they answer the question of being faithful? No. So, now my moral standards is here (will put a number); I have to do what is lawful in a very safe way. Like -I boil my water and drink it; I sleep in my bed but I also put a mosquito net; I drive my car but I also put on a seat belt. But in Africa, we have this confusion, for instance you hear sometimes Pastors teaching, 'Be faithful to your wife otherwise you will get AIDS'.

Box 7: Experience of discrimination and stigmatisation –continued

A person who is a student of science surely should laugh at this pastor, because it is not the unfaithfulness that causes infection. If the pastor preaches that, so that people fear AIDS, what will he preach if there is a vaccine for AIDS? If you tell people don't commit adultery because if you do you will get AIDS, what will you preach when AIDS has been overcome by a vaccine? Remember after the vaccine is here, adultery will continue to remain a sin! You would rather say, do not commit adultery; whether you get AIDS or not, that is not the point. The point is committing adultery is wrong in front of God and in front of society. It has emotional problems, it has economic problems, and it has spiritual problems. But I am telling you all this because I want to make it clear that the process of disclosure has been made very tough by this misconception. There are people who will die with their pain rather than disclose, because the moment they disclose they know people will think, 'They did unfaithful things; They did unlawful things' So when I say I am positive, people ask me, 'Did you become positive before you became a priest or afterwards? So, what do you think they are looking for? To judge me! They want to establish, 'Did he commit adultery when he was already a priest?' Actually there is another one who asked me a funny question; they asked, 'Pastor, you have said you are positive?' I said, yes. Then they asked, 'Have you ever repented about it?' How this person can be helped is by showing them that even people in Group 1 can get HIV and even people in Group 2 can also get HIV! But not all people who do wrong things (Group 3) get HIV! We need to make this clear so that the stigma goes down so that people can go for testing, and after testing disclose their status. Every time I explain this model, people say, 'We wish you had come here earlier, we wouldn't have made all these mistakes!' Especially the pastors, they say, 'We had never seen it from that angle before' Because when you talk about AIDS, they think of immorality, or sex outside marriage. Unfortunately even virgins can get HIV! And if people can get this, the process of disclosure becomes easy.

When people are asking me, 'should I disclose or not?' They want me to tell them that it is going to be a nice experience, it is going to be roses! But disclosure has costs, it can cost you promotion, it can cost you family love, it can cost you prestige because like in Uganda our president and others do not have high esteem of people who are positive. People who are positive are looked at as useless people. You know that if I disclose publicly, and I want to campaign to be a member of parliament chances of passing through are limited. So, in terms of self interest, everyone is called to shared confidentiality; so that you are able to survive, you are able to cope at the work place, in your home, or in the church.

Box 8: Experience of discrimination and stigmatisation –continued

6.2.2 Failure to be believed

Since being HIV positive is considered as having done something wrong or immoral by society and those who have done wrong things are supposed to be punished by society, public disclosure would be equated to reporting oneself for committing a crime. Since it is very rare that when people commit crimes they go ahead to report themselves to the authorities, those who have disclosed their status to the public seem to be surprising their audiences. All the respondents that I interviewed pointed out that a bigger section of their audiences remained unconvinced that they were HIV positive. The experience with the TASO drama group was that, most of those who did not believe that the members were positive pointed out that since TASO is an HIV/AIDS care organisation, it hires largely negative people to work in the drama group while pretending to be positive so that they convince the people in the communities to come for TASO services.

To some of my respondents, this failure to believe what they told the communities was one of their biggest challenges and one of their most disturbing scenarios that seem to be working against their morale in the fight against HIV/AIDS. The feeling of some of the respondents was like, now when we go to the communities to the communities and tell them about HIV and also tell them that we are positive, they think we are lying. The reality HIV poses to them is dangerously enormous, but our messages seem to be ignored because they do not believe that we are positive.

A counsellor from TASO that I interviewed in relation to the above pointed out;

> *The only challenge I have seen is that whenever we go out we these drama group members, the public does not get convinced that they are positive. Very many people don't agree that they are positive. You hear somebody say, 'They can't be sick because they look nice' For the people in the communities they think that these drama group members are employed by TASO to go and preach the gospel referring to themselves as HIV clients and yet they are not. So, it is a big challenge to them; it is difficult to convince somebody that the members are positive, if you look at those people in the drama group. We have beautiful ladies there! People do not accept that they are positive! There is one who appeared on WBS one time, and people were calling and saying, 'No, you can't be positive! You are just employed by TASO to convince the public but you are not positive!' So, that is the only challenge I have seen.*

In relation to the above, a respondent from the TASO drama group pointed out;

> *They think that the disease came for specific people such as me or some other people who have gotten out to disclose their status publicly. So, to tell them that you should go and take a test for HIV is quite a problem; after telling them that HIV is out there killing people, and I myself, I tested and was found positive, it is hard to take them now from that level to finally go and test for HIV. They just fear that if I get told that I am HIV positive, what will I do? The problem I have got is that the people that we have disclosed to seem not to appreciate that this disease is quite painful. When we tell them, to go for tests, they sometimes refuse. You also tell them that I am sick, and they also refuse to get convinced and they just tell you, you are deceiving.*

Another respondent from the TASO drama group when asked whether women who are aware of his status still approach him, pointed out;

> *For the women especially in the community, if I do not disclose to them that I am HIV positive, they cannot suspect that I am positive given the good condition I am in. …But for these people that we meet in the communities, where we even move in TASO vehicles, they might believe us that what we*

> *are saying is true. But if I went out and disclosed my status to the people on my own, they might not get convinced that I am telling them the truth. They might actually think that I am trying to hoodwink them, win their sympathy, so that I get free support. …'He just wants to present himself as someone who is ill so that they can get free support'.*

Another respondent from the TASO drama group when asked what kind of questions people in the communities ask her after giving them her testimony, pointed out;

> *…Then others point out, "As you look very well?" "It seems you are just paid money to come here and convince us so that we can be able to go to TASO!". They can't believe that when you look healthy you can be having HIV.*

Then another counsellor when asked whether when the people in the communities do not believe a person who discloses publicly pointed out;

> *Not everyone believes that they are doing kiwani [pretending] or they have been bribed. Like I said earlier, for them their sole purpose is prevention so, even if a large section will not believe them, there is that section that will believe them. People are now educated abour ARVs and they know that if you are on ARVs you can still look as healthy as somebody who is not infected. So, usually people who disclose publicly have a purpose to protect those who are negative. I do not think it really affects their morale because for the drama group members some would have left long time ago, but they are continuing with the fight!*

From the above, it becomes clear that many people in the communities where those that have gone public have disclosed from do not easily get convinced unless the person disclosing has signs of AIDS. Individuals that do not get convinced are bound to give those that have gone public comments that do not fully support their cause which sometimes is discouraging.

6.2.3 Family related Challenges

Members of a family are supposed to take care of one another without due consideration of how much they will get in return. The adult members of the family are supposed to take care of the children and the elderly in the African context, so the family is a closely knit group of members who are related by blood. Because these members are supposed to take care of one another without due consideration of how much they will get in return, even in the scenario of one member being HIV positive, the family is expected to be there for this member. Because of the family influence, family members many times are believed to share a number of behaviours including sexual behaviours. The family as a social unit is believed can rub its characteristics on the individual members. These characteristics that a family can rub on the individual members can include the sexual behaviours that 'run' through the family. If for instance, the father of a child is a womaniser, society would not be very surprised if the child later on turned out to be a womaniser too. Society in this case would think that the child learnt the behaviours from their father.

Since sexual behaviours and beliefs are also believed that they can be rubbed onto other people, family members are bound to suffer when one of their very own turns out HIV positive. Because the wider society to a large extent believes that those who are HIV positive are promiscuous, then the belief that they should be coming from a promiscuous family becomes true since the individual partly portrays the characteristics of the family they come from. On the basis of this, public disclosure of the HIV positive becomes extremely hard as the other family members of the positive person are bound to share in the discrimination and stigmatisation that follow after the act of public disclosure.

The experiences of the following respondents show how much the family shares in the discrimination and stigmatisation when one of their own turns positive and discloses to the public. A respondent from the TASO drama group pointed out; *"For my daughters they do not mind that I disclosed my status to the public. But when I go to their schools they do not want me to disclose that I am HIV positive because they fear to face discrimination from their colleagues within the schools".* Another respondent when asked how his family reacted when he went public remarked;

> *My family was then made of young people; children. I had children; I think my eldest son was about eleven and the girl who followed him was about eight and the last born was probably about five. So, it was not a very big problem. …The advantage I had was that the children were young; but they eventually started getting the thrust of stigma later on because people would tell them, "Look your father has got AIDS". And they would fight back! Yah, my son was quite tough he would fight back. Eventually they were just like me and they were able to overcome the problem. I talked to them very openly. I think they came to learn that this was the reality in the family; it ceased to be a problem. …I think I took HIV by the horns. This does not happen with many people but that is the direction I thought I needed to take.*

Another respondent from the drama group when asked how her family reacted after going public pointed out;

> *My parents especially my mother got very annoyed that I went public. I had already disclosed my status to her before I went public. So, when I shared my testimony over the radio and she heard me, she got very annoyed. When I shared my experience over the radio, it was replayed a number of times on different days, and when she listened in, she got very annoyed that I could*

> *share my experience over the radio. So, when my mother listened in to all my details including my names, how I got the virus, and how I tested to realise that I was positive, she did not like it. She told me, that it was not good for me to have gone public. The other thing is that my children are affected by my going public. When they read about my experience in news papers, they get annoyed. They ask for instance, "Mummy, how much money are you given to continue exposing your status in news papers?". My children already knew that I was HIV positive, but they did not like my going public.*

When asked why her children did not like her going public, she pointed out; *"I think they get ashamed because their mother is HIV positive. But I told them I have to educate people so that they do not fall into the same trap that I fell into. Up to now, they are not happy about my going public. I continue to share my experience with the public but my children do not like it".* This clearly shows that surely family shares in the experiences of the HIV positive person who finally decides to go public about their status. So when the person is considering going public they have to consider what the consequences are for their immediate family and whether the family will be able to handle those consequences.

Another category of the respondents did not seem to have their families share a lot in the stigma and discrimination that the individual who disclosed to the public was "supposed" to get. In relation to this a counsellor from TASO when asked what the reaction of the immediate family usually was, if a person disclosed to the public remarked;

> *There are families that will not want any of their family members to say anything negative; you know people look at HIV as a negative part of life that they wouldn't want other people to know about. It would be seen as a weakness in the family and they wouldn't want their family members to tell other people about it. So, such families exist. And there other families that are able to support their family members.*

And indeed when some respondents were asked how their families reacted after they went public, their responses did point out that their families were not disturbed by their actions. For instance when one respondent from the TASO drama group was asked how her family reacted after she went public, she pointed out;

> *It seems they have never seen me on stage. But even, I appear on Televisions. No body has ever come out to tell me that I saw you some where disclosing your status. Maybe my children would react differently to the disclosure, but they are still very young to know what is going on. Every time I tell them about HIV/AIDS, they say things like, 'But mummy we have been told that those who suffer from HIV loose their hair, scratch themselves endlessly'; and other things of this nature. So, when they tell me*

> *this, I realise that they are still young and they can't be able to understand what I am doing. But when I told my husband that I went public about my status, he only reacted angrily for a while but later on he kept quiet about it. He only commented that, you have been attracted by the money! He owned a motor cycle, and he would even bring and drop me here at TASO as I came to do practice. But now after some years have passed, he comments, "When you told me that you had Slim [AIDS], you were small even up today you still tell me you have Slim [AIDS] when actually you are growing fat! Now, what is Slim?" That's how he responds to me. But as you know, you have to handle a person quite carefully. You can't rush.*

Another respondent when asked whether his family was affected by his going public remarked;

> *No. No. After going public, my family is still okay. My family do not fear my talking in public. Even this vehicle of TASO has been coming and parking at my home. And people say, 'that vehicle is for positive people'. My family has no problem with my going public.*

Another respondent when asked how her husband took it after going public pointed out;

> *Actually, going public may point to the fact that the two of us are infected. And amongst the principles that we need to follow is never to give a testimony on behalf of other people and even when we are giving testimonies we are not supposed to mention other peoples names. When you include the name of another person, you would have given a testimony on behalf of that other person. Like I told you, I do not understand whether my relatives have never seen me disclosing or not, because nobody has ever come to me, to tell me that I got you in such and such a place, speaking on such and such a thing. The other thing is that we do not usually get so many invitations from communities around Kampala to sensitize them about HIV/AIDS, most of the invitations that we get are from the villages that are far away from Kampala. Most of my relatives are here in Kampala, and because of this I think that no person has come out to tell him that I have seen your wife with the TASO people preaching these kinds of things. If someone has ever told him that kind of thing, I think it would add to what I had already told him to bring another kind of reaction, but as per now, I have not seen any other reaction.*

With this category of respondents whose families seem not to have experienced discrimination and stigmatisation, it can be attributed to the fact that these two are generally reducing within the communities.

6.2.4 Work related Challenges

In the era of increased privatization and HIV/AIDS prevalence, numerous controversies surround individuals' work lives and being HIV positive. When the AIDS stage comes in, the individual weakens and becomes unable to contribute significantly at their workplace. Although most of the individuals that I interviewed had no formal employment, some few had been in formal employment, and disclosed publicly when they were still in formal employment. One such respondent that disclosed to the entire world that he was HIV positive when he was still in public service, pointed out the following in relation to his work life;

> *So going public was may be was a problem to other people but not me, because I knew what to expect. Eventually, I think there were a lot of openings for me to be able to do my work in HIV/AIDS much more. Because eventually when I discovered something I wanted to do, and whoever the boss I went to, would not refuse me permission to go and do it. There was no argument about it if I wanted to go and start an HIV activity, nobody would say no. And indeed I think that is how I managed to do so much and start this organisation. May be things that I missed were for example, I wouldn't be nominated to go and do more training as a solider or as an army officer and as a result I wouldn't be promoted because I was known to be a man that was supposed to die. I have never died but, many others who kept quiet actually died. I have no regrets about that though, because I think this was my destiny. And I think I have done probably better work than I would have done even if I was to be a General just in the army because I think I have been involved in a real life saving scheme. And I am very happy about it.*

When asked for specific challenges that he could attribute to his public disclosure, the respondent pointed out; "*In the beginning of course I got the challenges. I have told you for example that I could not get an opportunity to be trained more in the army. I ended where I had reached in terms of military training, probably I would have been better.*" Available literature authored by the Program of International Health and Human rights *et al* (2004) also shows that employees are bound to be discriminated against if their employers learn that they are HIV positive.

In relation to the above it also becomes clear that although the HIV+ person can be discriminated by their employers, other openings come up to replace the opportunities that the person enjoyed before. Recently, when a person discloses their positive status to the public, a number of organisations involved in the response to the HIV/AIDS epidemic get willing to help this person. The challenge that the individual faces is to organise themselves to have a significant change in their "careers" at a later stage in life. Going public in this case can be taken as a career since when one has disclosed publicly, they cannot undisclose, and their act of public disclosure has an influence on most of the life chances they obtain their after.

The challenges the HIV+ person who discloses to the public has to endure are a sum total of the challenges that can be experienced at the various levels of disclosure. As shown earlier while referring to the works of Ryan (2007), disclosure can be done at different levels, the first one being to a partner, the second to the entire family, the third to friends, the fourth to acquaintances and lastly to the entire public. So by going public, it does not exempt the individual from the challenges they would have experienced if they only disclosed their status to their partner. In relation to this when one respondent was asked what other challenges she had faced as a result of disclosing publicly, she pointed out;

> *Before I tested, I was teaching somewhere in a nursery school, when I tested, I thought I should disclose to the headmistress of the school. But when I disclosed to her, this headmistress chased me away from her school telling me that I would infect the children. I tried to convince her but she insisted and chased me away. So, disclosing is good, but sometimes, we loose a lot of things, because I was chased out of the school, and that is where I was getting some money for survival. And to other people when you disclose to them your status, you are rejected, you are abandoned; people start calling you a prostitute. They ask, "How did she get the virus? She is a prostitute. Look at her!". There are so many things that you face.*

Although when this respondent got problems at her workplace she had not yet disclosed her status to the public, most of the challenges that can be experienced at the lower levels of disclosure can also be experienced by those that have gone to the highest level of disclosure –public disclosure.

Still in relation to the above, when a care provider/counsellor was asked what challenges he envisaged if an individual working with public service disclosed publicly that they are HIV positive pointed out; "*There is the HIV policy at the work place these days; people are not tortured, people are not retrenched because they are positive. But there are some places for instance the army and the police -we have clients there, and they face challenges*". From the experiences of the respondents above, it becomes clear that public disclosure affects the individual's work life. It is because of the above consequences that those who have disclosed to employers have faced that discourage the majority of employees who are aware of their status not to disclose to their employers. Public disclosure is the highest level of disclosure and therefore encompasses all the lower levels of disclosure, and because it is the highest level, it has the potential to bring out all the consequences of disclosure.

6.3 ASPIRATIONS

It was believed before going to the field that the act of public disclosure of ones status to the public brought with it a renewed motivation to accomplish certain goals in response to the HIV/AIDS and this belief was confirmed true during the process of fieldwork. This renewed motivation was seen as the aspirations an HIV positive person who discloses to the public get after the act of public disclosure. Aspirations were seen as the strong desires to have some things done in response to the HIV/AIDS epidemic. These accomplishments that those who disclosed to the public desired to have completed included the following;

6.3.1 Encouraging others to disclose

Majority of the respondents were of the view that, disclosure is one of the effective ways to fight stigma and discrimination of HIV positive persons. When asked for instance whether they would encourage their colleagues who were sure that they themselves are positive to disclose their status to the public two categories of responses came out. The first category of responses (13 out of 30 respondents) emphasized that all the positive persons should first look at their immediate environment and measure the likely costs and benefits if disclosure, and if the benefits outweigh the costs, they can go ahead to disclose. In support of this for instance a respondent from the drama group pointed out; *"It would be good for every positive person to disclose publicly, but as it stands now, every person should be able to look at their surrounding and especially the people surrounding him/her"*. Another respondent pointed out;

> *... I have said that public disclosure is a calling. Not everybody is called to that type of life, it is tough, its really tough. You know once you have disclosed you cannot undisclose. You cannot get in the middle and say, 'I have now failed with this project, let me abandon it' You have already disclosed and everyone knows about it! So, it involves your emotions, it involves your future…*

With this kind of thinking the kind of disclosure that would be encouraged is what can called beneficial disclosure. With this kind of disclosure the individual disclosing does not have to go up to the level of public disclosure because when they do it becomes extremely hard to keep ones status a secret from certain categories of people.

The other category of responses to the above question was that public disclosure is encouraged without reservations. Those who are aware that they are positive can be able to disclose publicly no matter the consequences they are bound to face. This category of responses seemed to be hinged in the spirit of a revolution whereby when an individual finds out that they are positive and they go ahead to disclose publicly; the idea that goes through this is, “You can gossip about us that we are positive, but you need to be ashamed of yourselves because you know too little about HIV!” A respondent from the TASO drama group in support of this, remarked; “*…if someone said you have HIV, you can reply so what? You are just reminding me of it; I have it; so what?*” When seen in this kind of spirit, encouraging other people to disclose their status is meant to encourage the development of a movement to clamour for the rights of HIV positive persons and to further dispel the myths and misconceptions the wider community has about HIV/AIDS.

6.3.2 Continue the fight against HIV/AIDS and HIV/AIDS stigma and discrimination

Although those that have disclosed to the public faced some challenges as shown in the earlier section on challenges after public disclosure, a good number of respondents (16 out of 30) when asked what their aspirations in line with the fight against HIV were pointed out that they will continue to fight against HIV/AIDS stigma and discrimination. Although they did experience some discrimination and stigmatisation after going public, these respondents pointed out that none was surprised by this kind of reaction from their audiences. It is not only HIV/AIDS stigma and discrimination that those that disclosed to the public pointed out that they will carry on fighting but also the spread of HIV/AIDS itself. In support of this one respondent from those that were drawn from the general public, pointed out;

> *Now, if you have not disclosed people will not know that there is hope against AIDS. They will continue hearing that bad news about AIDS such as, ‘AIDS has no cure and has no vaccine’ But there are people like us who have a positive story to tell! A story of hope!. A story that emphasizes that we are not incapacitated against AIDS; that when we think carefully, AIDS is more vulnerable than us! Because if you have accurate information, you have attitudes, you have skills, you have services, and you have a supportive environment around you, what is AIDS? It becomes very vulnerable! But it feeds on misinformation, it feeds on mis-attitudes, it feeds on lack of services, or skills of protection. I was in Gulu and I asked the youths, ‘How do you protect yourself against HIV?’ Then they replied, ‘This side condoms do not reach. So, we get polythene bags and tie them and use a rubber band to tie them on the penis. That is vulnerability! That is vulnerability! If I keep quiet, then people won’t be able to hear those dynamics. Public disclosure comes with conviction; it comes with a mission in life. There are people who will say, ‘If I am able to make my*

> *money, feed my children, and build a house the other things in society should cater for themselves!' But there are others who will say, 'What does it benefit me to be well off when the rest of the people are suffering?' Those go into society, to change the status quo. For me, I am happy when people get information.*

Another respondent (a counsellor from the TASO Mulago clinic) when asked how utterances such as "You have been bribed by TASO so that you should come here to tell us about HIV/AIDS" from the community to those that have gone public influence their morale remarked;

> *Not everyone believes that they are doing kiwani [pretending] or they have been bribed. Like I said earlier, for them their sole purpose is prevention so, even if a large section will not believe them, there is that section that will believe them. People are now educated about ARVs and they know that if you are on ARVs you can still look as healthy as somebody who is not infected. So, usually people who disclose publicly have a purpose to protect those who are negative. I do not think it really affects their morale because for the drama group members some would have left long time ago, but they are continuing with the fight!*

Despite the challenges that they face after going public many of those that have gone public vow to continue with the fight against HIV/AIDS stigma and discrimination in particular and HIV/AIDS in general. This seems to originate from the fact that when one has already disclosed they cannot turn around and undisclose.

6.3.3 Strengthen Organisations and Institutions involved in the response to HIV/AIDS

Individuals that disclose their status to the public were closely linked to the organisations and institutions that are intensely engrossed in the response to HIV/AIDS. A number of the HIV positive persons (3 respondents) that were interviewed for this study after going public had gone ahead to start up organisations specifically devoted to HIV/AIDS work. So when these persons were asked what their desires for the future –in line with the fight against HIV/AIDS, a number of them pointed to strengthening the organisations that they had helped to found. A respondent for instance pointed out;

> *My organisation had a drama group that used to go to communities to people about HIV/AIDS, but because of financial constraints the drama group could not be sustained. What I would want to see done in the next two years is revamping that drama group so that the message continues to sink into the communities.*

Another respondent that heads an organisation working in the HIV/AIDS field pointed out;

> *I am looking for a way to increase the corporate members of my organisation. I would encourage the university to join my organisation as a corporate member, so that I would give them an opportunity to get free discussions when they want, to send their students to come and we share.*

From the above, it becomes clear that most of those that have disclosed publicly have not been discouraged by the challenges that emanate from public disclosure and are determined to continue with the fight against HIV/AIDS. This they hope to achieve through strengthening HIV/AIDS organisations so that they can better respond to the epidemic effectively.

CHAPTER SEVEN

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

This chapter presents the summary of findings and conclusions drawn from the findings. Also presented in this chapter are recommendations both for further research in the area of disclosure and for possible programs to strengthen the greater involvement of people living with HIV/AIDS in response to the AIDS epidemic.

7.2 Summary of Findings

This study established that people are different when public disclosure is being considered. Three categories of people can be identified when public disclosure is being considered and these are: those that can be able to disclose by themselves without the support of any organised group, the second category are those people that finally disclose to the public with the support of organised groups, and lastly is the category of people who can never disclose to the public even with the support of an organised group. Although these categories become apparent when public disclosure is considered, most individuals that have gone public have feared discrimination and stigmatisation before they went public.

The study also established that public disclosure brings with it a number of benefits; and these benefits are enjoyed by the community to which the individual discloses and the individual who discloses their status. When the benefits that come out of public disclosure to the individual and to the communities that are disclosed to are put on a weighing scale, the study revealed that the communities which the individuals disclose to benefit much more from the act of public disclosure than the individual disclosing. On the basis of this analysis on who benefits much more from the act of public disclosure, the study made it clear that discrimination and stigmatisation of positive persons convinces individuals who test positive never to disclose their status up to the level of public disclosure thereby enabling the same communities that stigmatise the individuals to loose out on the benefits that they obtain from public disclosure.

The benefits from the act of public disclosure that go to the communities the individual disclosing come from or disclose to the study revealed include clarifying on HIV/AIDS information/debunking myths and misconceptions about HIV/AIDS. When those who have disclosed to the public especially within the drama group go to the communities, they answer many questions from the community members related to HIV/AIDS. People’s opinions and beliefs about HIV/AIDS treatment, care and prevention that are completely negative and out of touch with reality are checked and clarified when for instance the TASO drama group goes out for sensitization sessions.

The other major benefit which the study revealed comes out of the act of public disclosure is encouraging those who are HIV positive to seek treatment from the available treatment centres. While clarifying on HIV/AIDS treatment, those who have been able to go public pointed out that specifically what had motivated them to go public is to encourage those who are HIV positive to come to the public treatment centres available to obtain the tested treatment and care. Because of discrimination and stigmatisation associated with HIV/AIDS, a number of positive persons never want to come near the public treatment centres; and those that have gone public pointed out they are partly motivated by the desire to convince this category of people to come for appropriate treatment from the HIV treatment centres.

Other benefits that the study brought out that come out of the act of public disclosure include, educating those who are HIV negative how to remain negative; and this is done through teaching their audiences about safe sex, encouraging those who are not sure about their HIV status to approach the testing centres to ascertain their statuses. The other indirect benefit to the community around the individual that the study brought out is notifying potential sexual partners about the infectiousness of the individual who has gone public and in the due process those who would have otherwise engaged in risky sexual behaviours with them to think twice.

It is not only the community around the individual disclosing that benefits from the act of public disclosure but the study revealed that the individual disclosing too benefits from this act. Public disclosure enabled the individual disclosing to counter discrimination and stigmatisation mainly because those who would have gossiped about the individual can never have a basis for their gossip. This is especially when the individual that discloses to the public discloses earlier on when they are still in good shape physically.

Other benefits that come out of the act of public disclosure that the individual disclosing enjoys include, economic benefits whereby those who disclose sometimes expect support to obtain better treatment and better employment opportunities, and intrinsic benefits such as the feeling that the individual is contributing something very positive to the society from which they come. This intrinsic benefit works in such a way that some of those who have disclosed to the public reported that they were absolutely happy that when they go to the communities with their messages, people respond to them and approach the treatment centres where they obtain professional help. The other indirect benefit to the individual who discloses to the public, the study revealed, was reducing re-infection of the person that discloses to the public. The reduction in re-infection of the person disclosing comes up through the pressure that now the individual faces after disclosure to lead an exemplary life after disclosure.

The study also established that discrimination and stigmatisation of people living with HIV/AIDS is still widespread in the communities although it is reducing. The study established that those who have disclosed publicly partly aim at fighting to further reduce this discrimination and stigmatisation of HIV positive people. And because they aim to fight stigma and discrimination and because they engaged in public disclosure much more willingly, they experience less discrimination and stigmatisation from the people around them. The less discrimination and stigmatisation that these persons experience is partly explained by the amazement that a number of those around them experience as a result of the extent of their courage.

On a more specific level, the study established that the family from which the person who discloses to the public comes from to some extent shared in the outcomes of this act of public disclosure. On the whole, since the individuals who have disclosed to the public did not experience extensive discrimination and stigmatisation from the wider communities in which they live, the families from which they come do not experience extensive discrimination and stigmatisation. The family like other close knit collectivities from which an individual can come from such a church group, has the potential to be blamed for the individual’s positive status. And indeed a small portion of the respondents pointed out that their families were not comfortable with their going public about their statuses.

Still, at a much more specific level, the study established that discrimination and stigmatisation of those that have gone public in their work places was not very prevalent. This could be attributed to the earlier fact that stigmatisation of those who are positive is decreasing, and partly because those who have gone public about their statuses have nearly changed their careers to devote their attention to the response to the HIV/AIDS epidemic. A significant portion of the respondents were volunteers working with the TASO Mulago drama group which was involved in carrying out sensitization sessions to the communities, and those that were in formal employment were mainly employed by organisations involved in HIV/AIDS work.

On the side of aspirations that an HIV positive person gets after disclosing to the public, the study established that majority of those who have gone public would encourage their colleagues who are positive too to disclose so that a movement like spirit is created to counter discrimination and stigmatisation HIV positive persons are subjected to. This movement like spirit would make it clear to those who discriminate and stigmatise positive persons that HIV/AIDS is much more of a societal problem rather than an individual's problem, and so, solutions must be sought for it collectively rather than stigmatise those who are positive with a hope that should control the spread of HIV.

The study further established that those that have been able to disclose to the public aspire to continue the fight against HIV/AIDS in general and HIV/AIDS related stigma and discrimination despite the challenges they had encountered in the business of disclosure. The challenges they had encountered that included discrimination and stigmatisation did not seem to have broken their spirit to continue the fight, mainly because they had anticipated these two in the first place before they got involved in public disclosure.

7.3 Conclusions

One thing that became very apparent while using the social control theory to explain stigmatisation and discrimination of those who contract HIV/AIDS is that, there is a tension that comes up when the various modes of HIV transmission are thought about. On one hand, while discrimination and stigmatisation of HIV+ individuals especially those who profess to have had numerous sexual partners and therefore suspect that they got HIV because they had sex with numerous partners is seen by society as okay, there are those who point out that they were sticking to one partner but still contracted HIV. Although, the discrimination and stigmatisation that society commissions is meant for the former category, even those who claim to have contracted HIV because their partners had multiple partners alongside them, cannot escape this discrimination and stigmatisation, as the society around the couple cannot tell exactly who ‘brought’ HIV into the relationship.

The scenario above also goes for other adults that test HIV positive, but could have contracted HIV through the other modes of HIV transmission apart from sexual contact. Because sexual contact remains the major mode of HIV transmission, society presumes that whoever is HIV positive contracted it through sexual contact with numerous partners. The individuals around this positive person now engage in acts of discrimination and stigmatisation whose sole purpose are meant to control the presumed unacceptable behaviours of the individual who is positive and the other individuals around this positive individual.

When we consider the multiplier effect HIV transmission enjoys, then one can comfortably point out that the idea of apportioning blame inherent within discrimination and stigmatisation of HIV+ individuals further contributes to the spread of HIV. It should be uprooted in all its traces, and in its place support and love for people who are HIV+ ploughed. The Social Constructionist theory that I use to explain how social reality including the reality of discrimination and stigmatisation of HIV+ individuals is constructed is meant to explain how this other reality of love and support for HIV+ individuals can be constructed to replace discrimination and stigmatisation of these individuals. When this is done, both the community around the HIV+ individual and the HIV+ individual themselves will all end up as winners.

How will it happen that everybody ends up as a winner? Those HIV+ individuals that would otherwise have spread HIV intentionally will not have the motivation to do that because nobody will be blaming them. HIV+ individuals will not feel ashamed to disclose their status because discrimination and stigmatisation will now have been replaced with support and love; so everyone who is positive would be craving for love and support and in the process would disclose their status.

Most of the discrimination and stigmatisation of HIV+ individuals is carried on by the people around the HIV+ individual rather than the wider public. Disclosing to the public would not be a big problem, but most of the HIV+ persons cannot disclose publicly because this would in the process expose them to people like their immediate friends, family members and so forth who they may not want to get to know that they are HIV positive.

7.4 Recommendations

This study was largely qualitative and has identified a number of issues such the relationship between gender and public disclosure, age and public disclosure, benefits of public disclosure, challenges from public disclosure and so forth. But because this study was largely qualitative, it is felt that the various issues that the study identified can further be followed up to test the relationship amongst key variables such age and the possibility of disclosing publicly using a quantitative approach. Future researchers can also do a comparative study that includes both those that have gone public and those that have not in the study sample in order to precisely establish what causes what in this whole area of disclosure.

The Ministry of Health should increase its efforts in the fight against HIV/AIDS related stigma and discrimination. This can be done by first quantifying how much HIV/AIDS related stigma and discrimination contributes to the further spread of HIV, and after this quantification is done, budget estimates devoted to the fight against discrimination and stigmatisation can be increased without much questioning.

Organisations involved in the response to the HIV/AIDS epidemic such as TASO Uganda should continue to support the drama group as a strategy to sustain increased awareness in the communities about HIV/AIDS. The benefits that such an approach is bringing to the communities are numerous, and even those HIV/AIDS organisations that have not yet adopted it should consider it. This way, the vast amounts of information on

HIV prevention, treatment and care available to the professionals at these organisations can be transferred on a sustainable basis to the communities.

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Appendix I: Interview Guide for HIV+ Persons

CONSENT FORM FOR HIV+ PERSONS

My name is Christopher Tumwine. I am a graduate student from the Department of Sociology, Makerere University. I am doing a study on the benefits, challenges and aspirations of HIV+ persons who have disclosed their status to the public as part of my requirements to complete a Masters programme.

You have been selected to participate in this study because you as an HIV+ person has already been able to disclose your sero-status to the public. I do request you to help me answer the questions that follow.

Participation in this study is purely voluntary and your participation or refusal to participate shall not affect the kind of treatment you receive from this institution.

You have a right not answer any question you feel you shouldn't and also to end the interview at any time.

There may be risks associated with your participation in the study; you may feel anxious, angry or depressed during the interview.

The benefits arising from your participation include gaining additional knowledge that may be used to further improve HIV/AIDS programmes

Information that you provide to me shall be kept as confidential information and no one including your service provider will know who gave what responses. The response that you provide will be tape recorded, and will only be used for the purpose of this study. The tapes will be destroyed at the end of the study.

Do you have any questions?

Do you accept to participate in this study?

a. Yes ☐

b. No ☐

If you do accept to participate in this study, please sign or thumb print here below.

……………………………………… or ☐
(Signature) Thumb print

INTERVIEW GUIDE FOR RESPONDENTS

Background Characteristics

Age
Gender
Occupation
Level of education
How long ago did you know your HIV status? …..Years……Months
How long ago did you start coming to an HIV clinic for care? …..Years…….Months

Benefits:

1. **Tell me about the process that you went through to finally disclose your status to the entire public.**
2. **Can you describe for me the first event when you disclosed your status to a gathering/public?**
3. **How long after diagnosis did this disclosure to the public take place?**
4. What inspired you to disclose your HIV+ status to the public?
5. Can you describe to me your first experience of how you went about disclosing your status to the public (people you are not related to)?
6. What happened after your first public disclosure?
7. How did you feel after your first public disclosure of your HIV status?
8. What were the reactions of your immediate family when you disclosed your HIV+ status to the entire public?
9. What is your experience with people you are not related with after disclosing your status to them?
10. Tell me about your sexual life after disclosing your status to the entire public. Have you been able to make sexual advances to people who had never been you sexual partners before you went public?
11. Do people who had never been your sexual partners make sexual advances to you after you went public?

Challenges:

12. What challenges have you got that you can attribute to your disclosure of your HIV+ status to the public (**probe for work place, family issues**)?

Aspirations:

13. What aspirations in line with the fight against HIV/AIDS did you get after your disclosure of the HIV/AIDS+ status to the public?

14. Would you encourage other people who are HIV+ to disclose their status to the public?

15. Is there any other information that is relevant to this study which you would want to share with me?

16. Do you have any questions for me about what we have talked about?

Thank you so much for your information and time.

Appendix II: Interview Guide for Counselors

CONSENT FORM FOR CARE PROVIDERS

My name is Christopher Tumwine. I am a graduate student from the Department of Sociology, Makerere University. I am doing a study on the benefits, challenges and aspirations of HIV+ persons who have disclosed their status to the public as part of my requirements to complete a Masters program.

You were selected to participate in this study because you are in touch with HIV+ people some of whom have disclosed their status to the public. I do request you to help me answer the questions that follow.

Participation in this study is purely voluntary. You have a right not answer any question you feel you shouldn't and also to end the interview at any time.

There may be risks associated with your participation in the study; you may feel anxious, angry or depressed during the interview.

The benefits arising from your participation include gaining additional knowledge that may be used to further improve HIV/AIDS programmes

Information that you provide to me shall be kept as confidential information and no one will know who gave what response. The response that you provide will be tape recorded, and will only be used for the purpose of this study. The tapes will be destroyed at the end of the study.

Do you have any questions?

Do you accept to participate in this study?

c. Yes ☐

d. No ☐

If you do accept to participate in this study, please sign or thumb print here below.

……………………………………… or ☐

(Signature) Thumb print

INTERVIEW GUIDE FOR CARE PROVIDERS/COUNSELORS

Benefits

1. **Tell me about the process that an HIV+ individual typically goes through to finally disclose his/her status to the entire public.**

2. What inspires an HIV+ individual to disclose his/her status to the entire public?

3. What usually are the reactions of the HIV+ person’s immediate family when they disclose their status to the public?

4. What usually are the reactions of the public (people the HIV+ individual is not related to) when the disclosure is made?

Challenges

5. Tell me about the challenges HIV+ individuals obtain at the work place after disclosing their status to the entire public?

6. What other challenges do HIV+ individuals get after disclosing their status to the public?

Aspirations

7. What aspirations in line with the fight against HIV/AIDS do HIV+ individuals obtain after disclosing their status to the entire public?

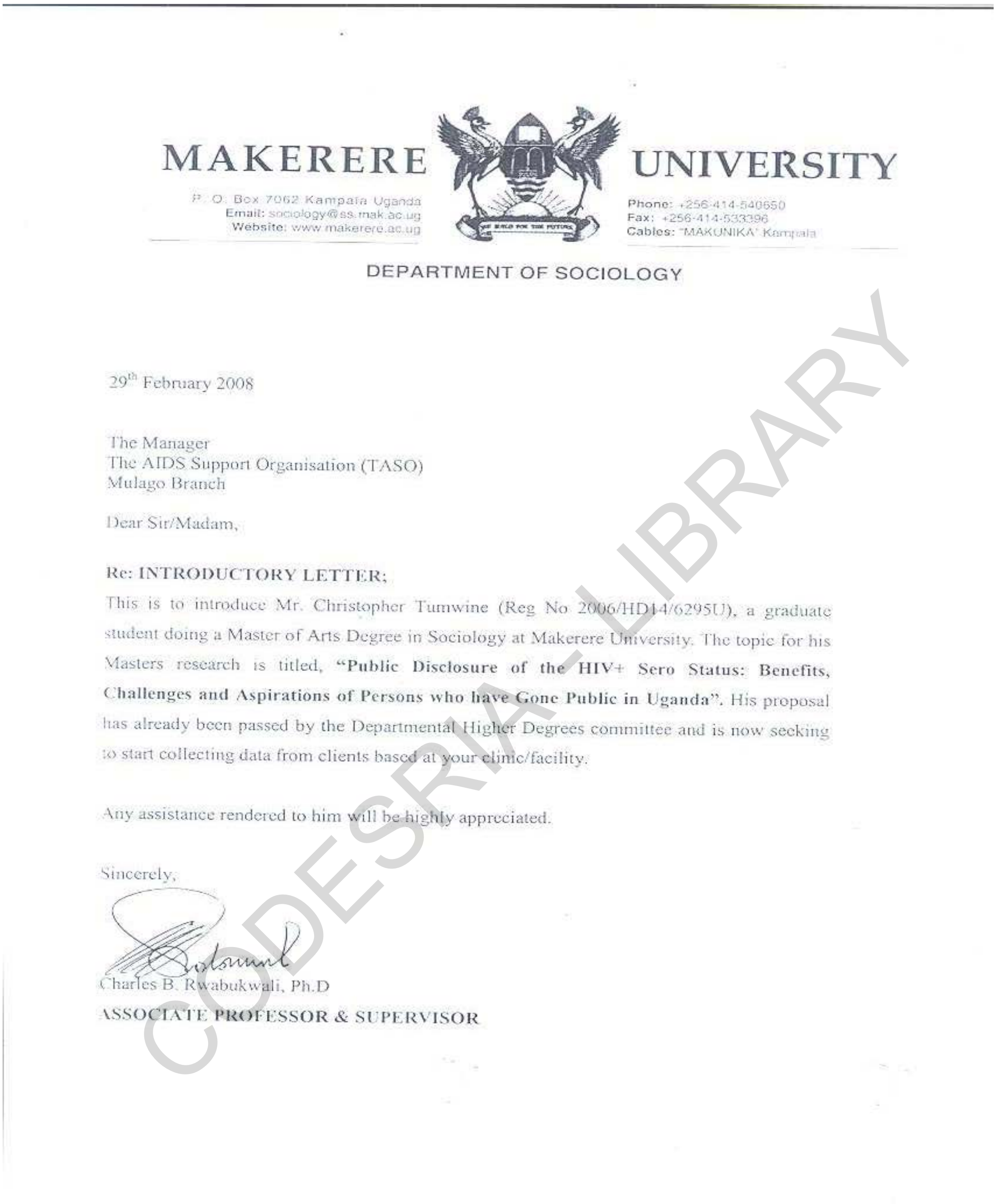
8. Do you think an HIV+ individual after the experience of declaring their status to the public would encourage other positive people to declare their status to the public?

9. Is there any other information that is relevant to this study which you would want to share with me?

10. Do you have any questions for me about what we have talked about?

Thank you so much for your information and time.

Appendix III: Makerere University –Clearance



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DEPARTMENT OF SOCIOLOGY

29th February 2008

The Manager
The AIDS Support Organisation (TASO)
Mulago Branch

Dear Sir/Madam,

Re: INTRODUCTORY LETTER;

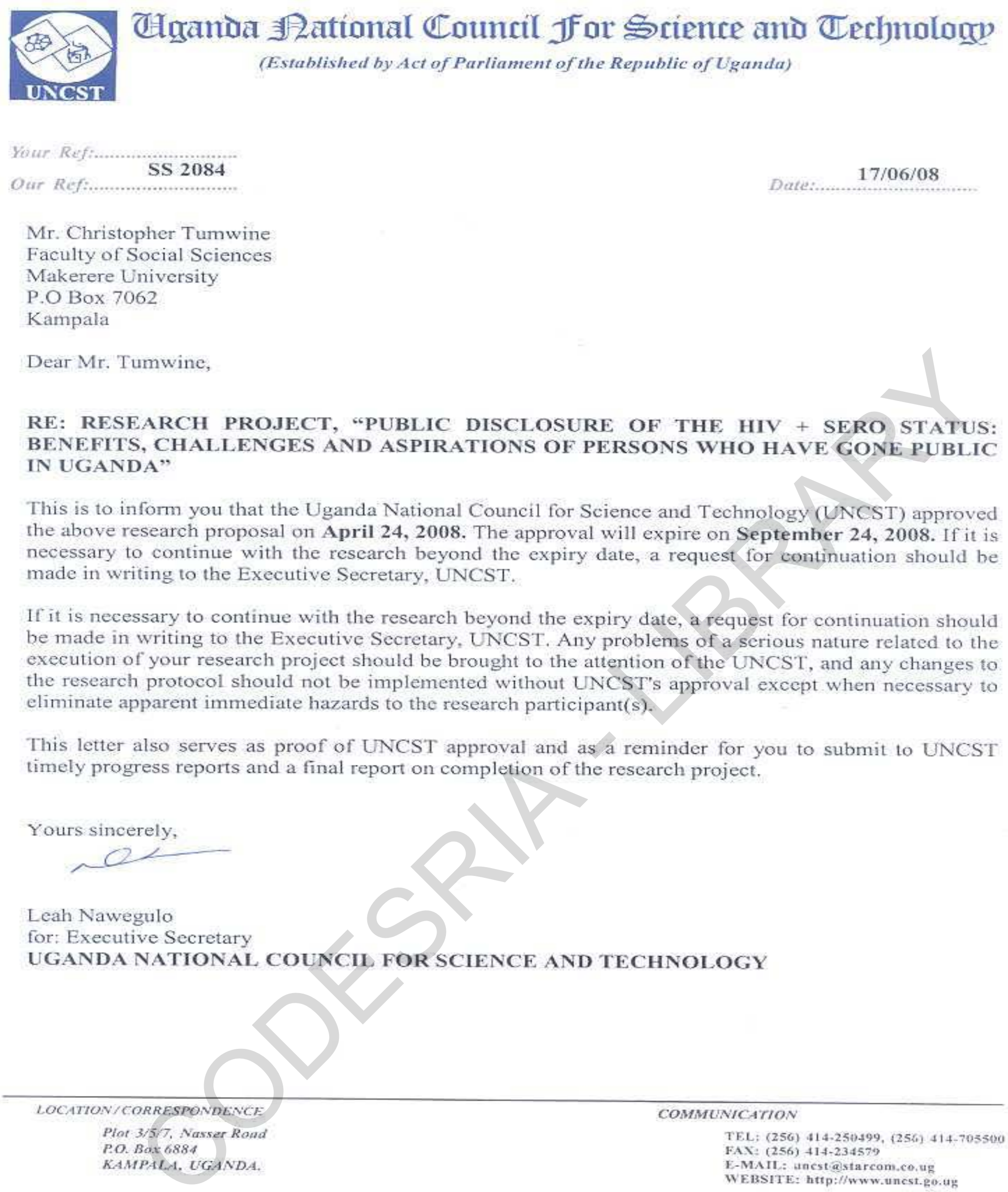
This is to introduce Mr. Christopher Tumwine (Reg No 2006/HD14/6295U), a graduate student doing a Master of Arts Degree in Sociology at Makerere University. The topic for his Masters research is titled, **"Public Disclosure of the HIV+ Sero Status: Benefits, Challenges and Aspirations of Persons who have Gone Public in Uganda"**. His proposal has already been passed by the Departmental Higher Degrees committee and is now seeking to start collecting data from clients based at your clinic/facility.

Any assistance rendered to him will be highly appreciated.

Sincerely,

Charles B. Rwabukwali, Ph.D
ASSOCIATE PROFESSOR & SUPERVISOR

Appendix IV: Uganda National Council of Science and Technology –Clearance



UNCST

Uganda National Council For Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Your Ref:..........................
Our Ref: SS 2084

Date: 17/06/08

Mr. Christopher Tumwine
Faculty of Social Sciences
Makerere University
P.O Box 7062
Kampala

Dear Mr. Tumwine,

RE: RESEARCH PROJECT, "PUBLIC DISCLOSURE OF THE HIV + SERO STATUS: BENEFITS, CHALLENGES AND ASPIRATIONS OF PERSONS WHO HAVE GONE PUBLIC IN UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **April 24, 2008.** The approval will expire on **September 24, 2008.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST. Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

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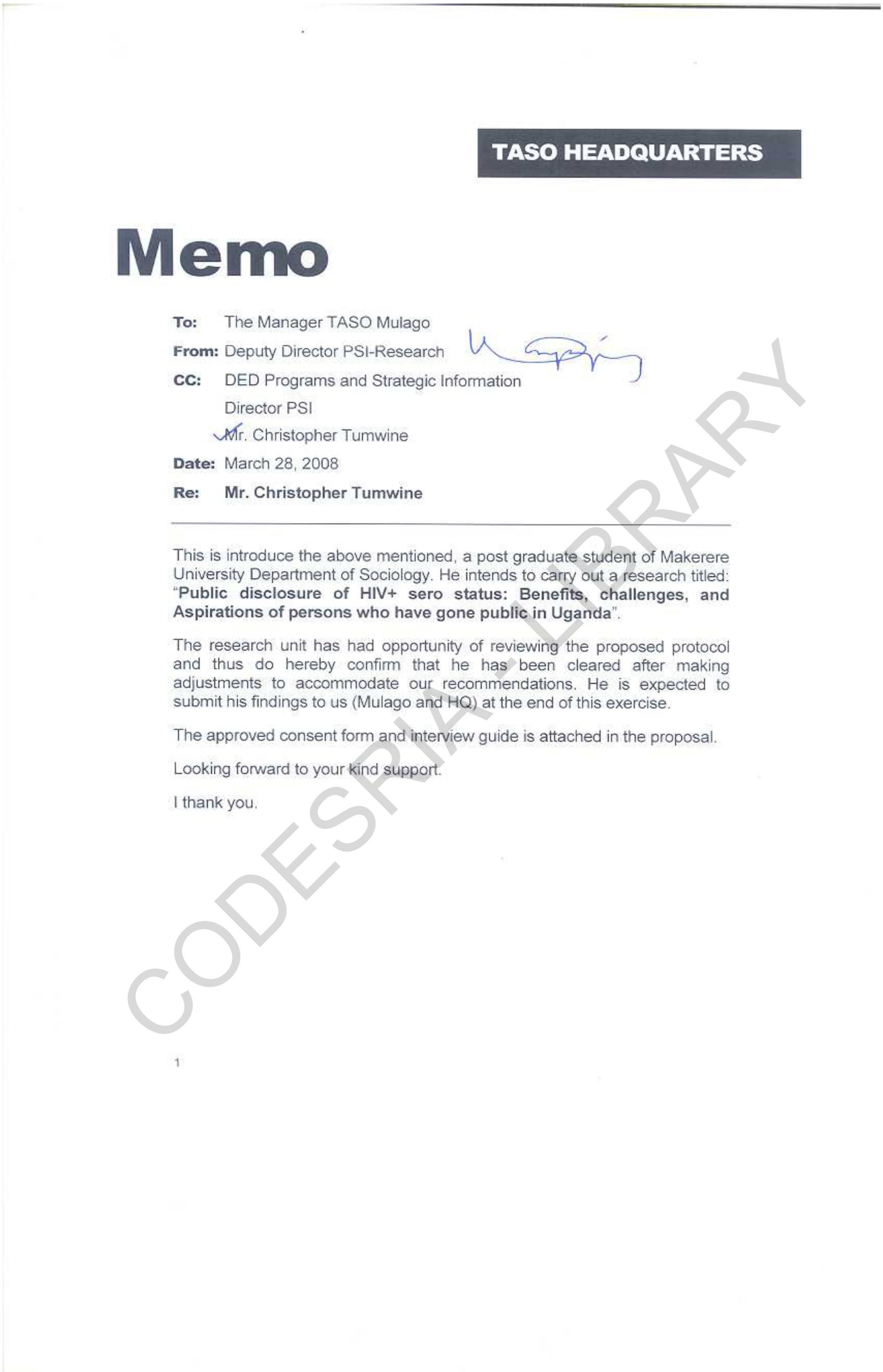
Appendix V: TASO Headquarters –Clearance



TASO HEADQUARTERS

Memo

To: The Manager TASO Mulago

From: Deputy Director PSI-Research

CC: DED Programs and Strategic Information

Director PSI

Mr. Christopher Tumwine

Date: March 28, 2008

Re: **Mr. Christopher Tumwine**

This is introduce the above mentioned, a post graduate student of Makerere University Department of Sociology. He intends to carry out a research titled: "**Public disclosure of HIV+ sero status: Benefits, challenges, and Aspirations of persons who have gone public in Uganda**".

The research unit has had opportunity of reviewing the proposed protocol and thus do hereby confirm that he has been cleared after making adjustments to accommodate our recommendations. He is expected to submit his findings to us (Mulago and HQ) at the end of this exercise.

The approved consent form and interview guide is attached in the proposal.

Looking forward to your kind support.

I thank you.