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# SOCIAL CONTEXT OF DISCLOSING HIV TEST RESULTS: HIV TESTING IN TANZANIA



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**Social Context of Disclosing HIV Test Results:  
HIV Testing in Tanzania**

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The authors' views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Cover photo: Iringa bus station (Joe L.P. Lugalla)

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## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical and Research Foundation
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
CDC	Centers for Disease Control and Prevention
CESTRE	Centre for Strategic Research and Development
CTC	Care and Treatment Clinic
DOD	United States Department of Defense
FHI	Family Health International
HIV	Human Immunodeficiency Virus
MOHSW	Ministry of Health and Social Welfare
NACP	National AIDS Control Programme
PASADA	Pastoral Activities and Services for People Living with HIV/AIDS in Dar es Salaam Archdiocese
PICT	Provider Initiated Counselling and Testing
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission of HIV
SHIDEPHA+	Service Health and Development for People Living with HIV/AIDS
STI	Sexually Transmitted Infection
TACAIDS	Tanzania Commission for AIDS
TB	Tuberculosis
THIS	Tanzania HIV/AIDS Indicator Survey
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WAMATA	Walioko katika Mapambano na AIDS (Ukimwi) Tanzania



## **EXECUTIVE SUMMARY**

### **Study Objectives**

This study examined the circumstances and social contexts in which individuals in Tanzania were tested and counselled for HIV, and patterns in disclosure of test results to partners, family, and friends. The research sought to discover how people experienced these processes based on their own descriptions. The overall objectives of this study were to understand people's experiences in showing their own HIV test results to others, to discover the pattern of disclosure among individuals tested (whether or not disclosure occurred, to whom, how it was done, after how long), and to discern the role of social relations in facilitating disclosure to others. A better understanding of factors that facilitate disclosure can be useful to programmes that promote disclosure of HIV test results.

Disclosure of HIV test results is critical to HIV prevention in three ways. First, disclosure to others allows the individual to garner social support for preventive actions whether (s)he is found HIV positive or negative. Individuals who keep HIV test results to themselves are isolated in their decisions to adopt new behaviours that protect against HIV infection. Second, for those who test HIV positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Counselling sessions at a VCT facility are likely to emphasize the importance of discussing test results with a spouse or regular partner, and suggest that people come for testing and counselling as couples. Finally, without disclosure, a person cannot easily access social or medical services. Although disclosure of test results does not guarantee access to such services because they may not be available, without disclosure, access to services becomes more difficult. Thus, any intervention that increases disclosure of HIV test results can improve prevention, increase the number of spouses and regular partners who are tested and counselled, and increase access to services.

### **Context**

HIV/AIDS in Tanzania (population 35 million) is considered a generalized epidemic, with more than 80 percent of HIV infections transmitted sexually. A population-based national survey conducted in 2004 by the National Bureau of Statistics found that 7 percent of adults age 15 to 49 were infected with HIV. Among the country's 21 regions, the highest levels of infection (11-14 percent) were found in Dar es Salaam, Mbeya, and Iringa. The National AIDS Control Programme (NACP) and the Tanzania Commission for AIDS (TACAIDS) direct the government's response to the epidemic, which includes activities aimed at prevention, HIV testing and counselling, care and support, and treatment with antiretroviral drugs. Individuals can get tested for HIV in stand-alone centres, in clinics with prevention of mother-to-child transmission (PMTCT) services, in care and treatment centres (CTC), or in facilities that conduct routine testing. The 2004 survey found that 14 percent of both men and women had ever been tested for HIV.

## **Methods**

This study relied primarily on open-ended conversations with individuals who had been tested for HIV. Individuals were recruited in the regions of Dar es Salaam and Iringa by contacting VCT centres and associations for people living with HIV/AIDS (PLWHA). Individuals from VCT centres were interviewed twice: once at the centre after they received their test results and again some weeks later in their homes. A second interview was necessary to give them time to disclose their test results. Five HIV testing services were contacted in Dar es Salaam and three in Iringa. Members of PLWHA associations were interviewed only once.

Because the study focused on the disclosure of HIV-positive test results, the research team interviewed only those who had tested positive for HIV. Interviews were tape recorded with the permission of respondents. The final sample included 30 individuals from Dar es Salaam and 27 individuals from Iringa who had been tested at VCT centres and were interviewed twice, and 57 respondents (30 men and 27 women) from PLWHA associations, who were interviewed once. In addition, the research teams interviewed VCT counsellors, other health care providers such as medical doctors, religious leaders, and some community leaders to discuss their views about how people are tested for HIV and disclose test results.

The recorded conversations were transcribed by the survey teams in Swahili, and then translated into English and typed in Microsoft Word. The research team read the transcriptions in either English or Swahili with certain themes in mind and wrote out a one- to two-page summary to facilitate analysis and compare responses. Ethical clearance for the study was provided by the National Institute of Medical Research in Tanzania and the Institutional Review Board at Macro International in Calverton, Maryland.

## **Getting Tested**

The large majority of persons interviewed had been chronically ill when they were tested for HIV the first time (60 percent of those recently tested, and 68 percent of those living with HIV for some time). The symptoms of illness mentioned most often were fever, chest pain, coughing, and abdominal pain. Most of the remaining individuals came for testing because their spouse or sexual partner had died of symptoms similar to AIDS, or was chronically sick. Thus, more than 90 percent of those interviewed were tested because they or their sexual partner were ill or had been ill with symptoms that suggested a possible HIV infection.

Although a small number of respondents got tested without telling anyone, the majority had discussed testing with someone before visiting a testing centre. One-fourth of married people discussed with their spouse the idea of getting tested: one-third of men and one-fifth of women. Most respondents told us that they had discussed their health situation with friends and relatives; some of those individuals urged them to get tested for HIV. The nexus of social relations of family and friends played a direct role in the decision to get tested for many of these persons.

## **HIV Counselling**

The respondents were asked about their experiences in pre- and posttest counselling when they were tested for HIV. Married couples or male/female sexual partners who came for testing were given the choice of being counselled separately or together, and of receiving test results together or separately. All eight testing facilities used rapid tests, so all testing and counselling could be conducted in one visit. The pretest counselling encouraged people to get tested, discussed basic information about HIV and AIDS, explained how HIV is transmitted, obtained consent, and explained again that the test result would be positive or negative.

The posttest counselling discussed ways a person with HIV can live a normal life, and provided a referral to see a doctor. About half of the interviews did not record the reaction of respondents to being told they were HIV positive because respondents made no comments about the topic, and about half said they were shocked or frightened and disturbed. Counsellors spent time explaining how to live with the virus: where to go for help or support, whom to see for medical care, and ways to maintain good health. Some respondents were also urged to tell someone else about their test results. A few respondents suggested ways the VCT services could be improved.

## **Social Context of Disclosure**

This research focused on the patterns of voluntary and direct disclosure as it occurred over time. The study examined whether or not the HIV test result was shown to someone, to whom, how it was done, how long after the HIV test it was shown, and the response of the person or persons to whom the test result was shown. The study also collected information about the type of individuals to whom the respondents did not wish to disclose their test results. For those few respondents who did not show their test results at all, the study tried to understand the consequences of disclosure that individuals feared or expected.

The findings indicate that respondents disclosed their HIV status selectively depending on the type of relationship in which the individual was involved. For example, mutual obligation seemed to be an underlying factor in disclosing to a family member and/or partner. Although some respondents discussed taking an HIV test with a close relative, and others made those decisions without consulting anyone, when it came time to disclosure, social relations played a very important role in determining who was told about the test results.

The process of disclosing one's results varied. Some respondents disclosed the same day they learned of their results, but others waited for a period of time. The majority of respondents disclosed their results to close relatives such as parents, spouses, siblings, aunts, and uncles. Some respondents did not want to disclose to people outside of their closest circle such as neighbours, friends, and some relatives because respondents did not trust they would keep their HIV status private. Respondents were afraid that if the news of their HIV status became widespread, they would face discrimination.

Despite some fears expressed, the study found that people generally discuss HIV tests results with people with whom they are very close and with whom they share a high level of trust. These are mainly blood relatives, such as parents (especially a mother), a brother, sister, uncle, or aunt, and sometimes close friends. The nature and strength of social ties to family, friends, and acquaintances influenced disclosure patterns. In addition, the kinds of marital ties (single, married, separated, or divorced) and sexual partnerships (monogamous, multiple, concurrent) that individuals maintain greatly affected the disclosure process.

Women were much less likely to show the test results to their spouses or sexual partners than were men. The majority of married men (55 percent) showed the results to their wives, and a minority of married women (34 percent) disclosed their results to their husbands. Also, women tended to have someone else with whom they shared information about their testing and results. Among younger unmarried respondents, five out of 11 did not disclose to anyone, fearing discrimination. Respondents who were divorced or widowed were more likely to disclose to close family members than to sexual partners.

Disclosure to a spouse or sexual partner was determined by the nature and quality of the relationship. In all relationships, expected social support and the ability to maintain confidentiality played a key role in influencing someone's decision to disclose. Most respondents disclosed to family members because they shared close relationships and expected to gain social support. It must be emphasized that the nuclear and the extended family tend to be the backbone of community-level social relationships in Tanzanian society. Finally, the study showed that very few of the individuals tested did not disclose their test results to any one at all, and this was mainly due to their fear of discrimination, loss of employment, violent retaliation, or abandonment.

## **Conclusion**

This research focused on individual experiences in getting tested for HIV and the challenge of managing testing results, with special attention to the social relations of respondents. The study included only HIV-positive individuals, and therefore it is not surprising that nearly all came for testing because they were afraid they had been infected with HIV: either they had been chronically ill or their sexual partner was ill or had passed away. According to respondents, counsellors at VCT centres emphasized the confidentiality of test results, but the counsellors rarely mentioned disclosure to others. Despite this lack of emphasis by counsellors, nearly all respondents showed their test results to at least one person.

Most the respondents disclosed their test results to blood relatives, and most often to a female relative: mother, sister, sister-in-law, aunt, or cousin. Respondents disclosed to their family members because of their close and mutual relationship as well as the social support they expected to gain. Most of the married men disclosed their test results to their spouses, and those who were single disclosed the results to their parents and relatives but not to their sexual partners. Married men were more likely to show their results to their spouses than were married women, for men hold more social and economic power than do women and they are less concerned about spousal rejection and

discrimination than are women. In addition, women are more vulnerable to accusations of infidelity than are men.

Fear of discrimination remains the main concern of HIV-positive individuals who seek to limit the disclosure of their test results to immediate family members and avoid spreading the news beyond the family. The majority of respondents were afraid people outside the family would “spread rumours” about their sexual relations if they heard of their test result.

Based on these findings, the most critical recommendations for improvement to HIV testing and counselling are:

- VCT counsellors discuss the importance of disclosure with their clients more often and more directly. This is an especially important conversation to have with younger single individuals who are sexually active but do not disclose their status to their sexual partners.
- VCT counsellors seek ways to tailor their counselling to the needs of their clients rather than provide the same advice to all persons, whether married or single, divorced or widowed, etc.
- Programmes train counsellors to address the different fears and social concerns of men and women regarding life with HIV and disclosure of HIV status to others.



# 1. INTRODUCTION AND SETTING OF THE STUDY

## 1.1 Introduction

The HIV/AIDS epidemic has been spreading steadily ever since the epidemic began more than 25 years ago. During the last two decades in Tanzania, the HIV/AIDS epidemic has spread to affect people in all walks of life and decimated the most productive segment of the population (TACAIDS, 2005). As of December 2005, a cumulative total of 205,773 AIDS cases had been reported since 1983 when the first three cases in the country were identified (NACP, 2007).

In response to the epidemic, the Government of Tanzania, with support from a variety of donor countries and multilateral organizations, has created a number of agencies to lead efforts to control the spread of HIV/AIDS in the country. For example, in 1987 the government established the National AIDS Control Programme (NACP) under the Ministry of Health; it formed the Tanzania Commission for AIDS (TACAIDS), which operates under the umbrella of the Prime Minister's Office, in 2000; and it developed and adopted a National HIV/AIDS Policy in 2001 with the objective of providing a framework for leadership and coordination of the National Multisectoral Strategic Response to the HIV/AIDS epidemic. Most of the interventions have focused on preventing, controlling, and mitigating the negative impact of the epidemic through health education, a multisectoral response, and community participation.

Increasing public use of voluntary counselling and testing (VCT) services has been a key mechanism for the prevention of HIV transmission in the country. The United States Government (USG) seeks to reduce HIV infection by providing assistance to TACAIDS, the Ministry of Health and Social Welfare (MOHSW), and the Tanzanian branch of the African Medical and Research Foundation (AMREF), among others. The Angaza network of VCT centres set up by AMREF has greatly expanded the number of VCT centres around the country in the past few years. The VCT centres of the Tanzanian government, along with those supported by AMREF and other donors, now provide more than 500 sites in the country where a person can obtain an HIV test along with counselling.

HIV/AIDS experts agree that knowledge of one's own HIV serostatus, combined with effective counselling, may facilitate individual behaviour changes that reduce the risk of HIV infection and protect sexual partners as well. Tanzanians can now get tested in VCT centres, in routine testing facilities, in prevention of mother-to-child transmission (PMTCT) centres, and in other types of facilities with a different blend of services. HIV/AIDS researchers also understand that the disclosure of one's serostatus, particularly if one is HIV positive, is a complex process often fraught with fear of rejection and discrimination. It is that process that this study sought to better understand. By accumulating a large number of accounts of individual experiences in learning their test results, living with that knowledge, and finally disclosing their serostatus to others, this study contributes to a better understanding of that process.

## **1.2 Statement of the Problem**

It is evident that disclosure of HIV test results is important to garnering social support and to accessing care and medical treatment. Disclosure of test results can be an effective action because it can facilitate the prevention of HIV transmission to sexual partners. In this light, it is important to encourage intervention programmes that promote VCT and disclosure of test results. These programmes can be effectively promoted only if people know the factors that compel people to seek an HIV test, as well as the circumstances under which people show their test results to others. Although there are many people in Tanzania who voluntarily take an HIV test and who may also show the results of their test to others, no systematic studies have been carried out to thoroughly understand the dynamics that characterize the nature of VCT combined with disclosure.

At present there are many unknowns: Why do people decide to take an HIV test? Under what circumstances do they get tested? How do they decide to disclose or not to disclose the test results to others? To whom do they disclose? How do those who receive the information react? And finally, what is the impact of disclosure on the infected person? We also do not know what patterns of disclosure exist and how social relations determine these patterns. Understanding these issues is critically important to promoting intervention programmes that aim not only to encourage people to take an HIV test but also to disclose the results of the test to others. Generating this kind of information and understanding was the prime objective of this study.

## **1.3 Major Research Questions**

The main research questions that guided this study were the following: What are the factors that compel people to take an HIV test? What are the factors that affect the disclosure of HIV test results to others? Are those factors primarily individual characteristics that push an individual toward disclosure or not? To what extent are those factors aspects of the social relations maintained by individuals?

The study focused not only on whether or not the HIV test result was shown to someone, but also to whom, how it was done, how long a time after the HIV test, and the response of the person or persons to the news of the test results. The study collected information about the type of individuals to whom respondents did not wish to disclose their test results. The study also wanted to find out the type of people who would take care of the respondent when he/she became sick. For those who did not show their test results, it is most important to understand the consequences of disclosure that individuals thought or feared, to understand why such people opted to remain silent.

In brief, the following were the research questions:

- How did respondents learn their HIV status?
- What form of the social relations did individuals maintain?
- What family and friends do persons interact with most often? And how did these relations determine patterns of disclosure of HIV test results?
- How did people decide to show their HIV test results to others?
- What was the response of others who learned of a person's test results?
- What circumstances keep a person from showing HIV test results?

These research questions and associated assumptions were examined and revised through discussions with stakeholders during the preparation for training field workers, and then again during the training for field workers. Because we knew that the individual assumptions of field workers collecting data through guided conversations would affect how they actually guided the conversations, the training gave the field workers the same understandings of the research strategy and of our expectations from respondents. Regarding disclosure, we assumed that individuals who were HIV negative were more likely to discuss their test results with others than those who were found to be HIV positive. Similarly, we also assumed that married people were more likely to disclose test results to their sexual partners than unmarried persons.

#### **1.4 Study Objectives**

The overall objective of this study was to understand peoples' experiences in showing their own HIV test results to others or not, to discover the pattern of disclosure (whether or not, to whom, how it was done, after how long) among individuals tested, and to discover the role of social relations in facilitating disclosure to others. Very little is known about factors related to disclosure of test results or the ways to encourage individuals to discuss HIV test results with others. A better understanding of factors that facilitate disclosure can be useful to programmes that promote disclosure of HIV test results.

## **1.5 Significance of the Study**

The significance of this study stems from the fact that disclosure of HIV test results is critical to HIV prevention. First, whatever the result, disclosure to others allows the person to garner social support for any preventive actions they may want to undertake, whether they are found HIV positive or negative. Individuals who keep HIV testing and test results to themselves are on their own for whatever they decide to do and however they decide to change their activities to protect themselves against HIV infection. Second, for those who test positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Thus, the counselling sessions at a VCT facility are likely to emphasize the importance of discussing test results with a spouse as couples. And finally, without disclosure, a person cannot easily access social or medical services that may be available. Although disclosure of test results does not guarantee access to social or medical services, because they may or not be available, without disclosure access to services becomes more difficult. Thus, any intervention that increases disclosure of test results will also facilitate access to services.

## **2. THE SOCIAL CONTEXT OF HIV/AIDS IN TANZANIA**

### **2.1 Introduction**

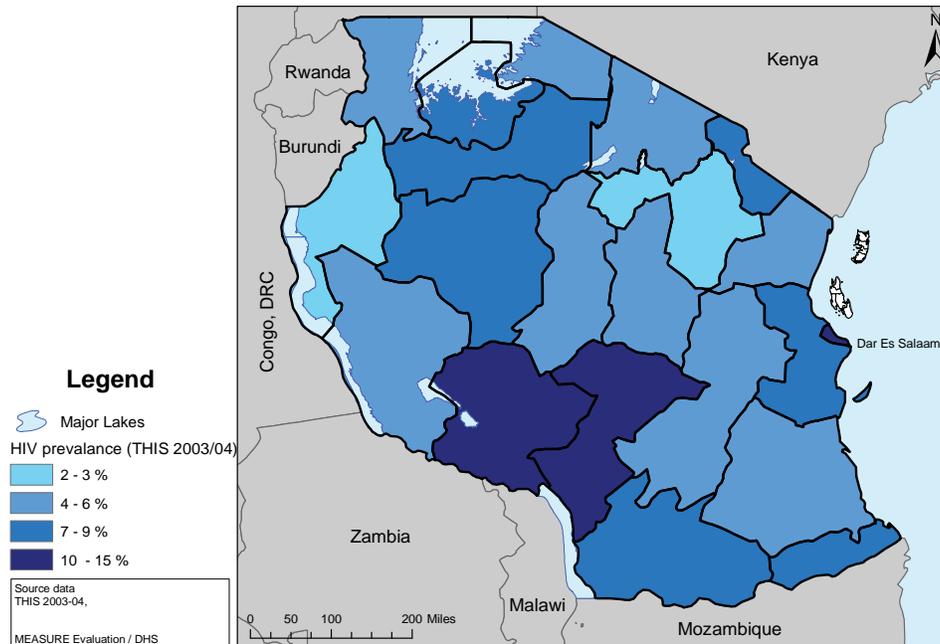
Epidemics like HIV/AIDS are both a social phenomenon and a biological reality, and therefore occur within a specific social context. The process through which individuals decide either to take or not to take an HIV test takes place in a social context. In this chapter, our aim is to situate the AIDS epidemic in Tanzania to understand not only why and how HIV infection is spreading, but also the social relations and conditions that influence people's decisions to take or not to take an HIV test, and to disclose or not disclose the outcome of the test. Like the manifestations of AIDS, disclosure of HIV test results is a social process that occurs over time; it does not take place in a vacuum.

### **2.2 The Prevalence of HIV/AIDS in Tanzania**

In Tanzania, the first three AIDS cases were clinically diagnosed and reported in 1983 in Kagera region, the northwest corner of the country situated between Rwanda and Lake Victoria (TACAIDS, 2005). By 1986, AIDS cases had been reported in all 21 regions of Tanzania. Since then, the prevalence of HIV/AIDS has been increasing. In 2003, Tanzania mainland was estimated to have about 1,800,000 people living with HIV (840,000 females and 960,000 males) (NACP, 2005; TACAIDS, 2005). Tanzania began monitoring HIV infection rates through its sentinel surveillance system data in 1990. The MOHSW now uses about 30 antenatal care sites for prevalence data.

In 2004, the National Bureau of Statistics, in collaboration with TACAIDS and the NACP, and with technical assistance from Macro International, conducted the Tanzania HIV/AIDS Indicator Survey (THIS) to obtain population-based estimates of HIV prevalence for the country. This was a survey of the adult population (men and women age 15-49) of mainland Tanzania using a two-stage sample design that produced a nationally representative sample of 6,900 households. The survey also assessed levels of knowledge about HIV and AIDS in the sample population and collected information on sexual practices. Figure 1 shows the distribution of HIV prevalence by region in Tanzania.

**Figure 1. HIV Prevalence by Region in Tanzania**



It is important to note the regions where the HIV prevalence is the highest (dark gray) as well as those regions where HIV prevalence is very low (light gray).

Data from this survey showed that 7 percent of Tanzanian adults age 15-49 were infected with HIV, with prevalence among women slightly higher (8 percent) than among men (6 percent). Survey results also showed strong variations among regions: Mbeya, Iringa, and Dar-es-Salaam were the regions with the highest HIV prevalence of 14, 13, and 11 percent respectively. The regions of Manyara and Kigoma showed a prevalence of only 2 percent. The survey also showed that women are more highly affected at younger ages compared with men. Except for ages 15-19, at which prevalence for both men and women was 2 percent, prevalence for women was higher than for men ages 20-39. At ages 40-49 the pattern reversed and prevalence was higher among men than women.

The survey also shows that urban residents have a significantly higher risk of HIV infection (11 percent) than rural residents (5 percent). Prevalence among urban women was 12 percent compared with 6 percent for rural women, and 10 percent among urban men compared with 5 percent for rural men. HIV prevalence also increases with the level of education, and it varies with marital status. For example, formerly married individuals had a higher HIV prevalence rate (18 percent) than other groups. Those who had never been in a union had a relatively low prevalence rate, and those who were currently in a marital union had intermediate HIV prevalence levels (7 percent among women and 8 percent) among men). Young women who were divorced or separated were much more likely to be HIV positive (18 percent) than women who were currently married (4 percent) or those who had never been married (2 percent).

### 2.3 Social and Cultural Construction of HIV/AIDS in Tanzania

Understanding how people socially and culturally construct an epidemic like AIDS is important precisely because it shows how people perceive the epidemic, and it suggests ways of coping with it. Because more than 80 percent of people in Tanzania who are HIV positive get their HIV infection via heterosexual relationships, sex and sexuality are at the centre of Tanzanian understandings of the AIDS epidemic. Most people associate HIV/AIDS with sex and believe strongly that if you are infected with HIV, then you must have acquired it by having had sex with someone. At the same time, Tanzanian traditions have surrounded sex with many taboos and have rules to regulate sexuality as well as sexual relationships. In most societies in Tanzania, sex is rarely discussed openly with children. Most people approve of sexual relationships that take place within marriage, but premarital or extramarital sexual relationships are considered immoral.

These associations are clearly summarized in the study of stigma and discrimination conducted in Ethiopia, Tanzania, and Zambia (Nyblade et al., 2003). As they state, "HIV and AIDS are intimately linked with sex and death. Our research shows that stigma around HIV and AIDS persists so tenaciously because it is deeply enmeshed with social and personal views, beliefs, fears, and taboos around sex and death" (ibid). People associate HIV infection with the violation of sexual taboos as well as certain death, and people with the infection may suffer from discrimination in Tanzania. AIDS is seen as a shameful and life-threatening disease that is the result of personal irresponsibility or immoral behaviour. These negative responses to people living with HIV and AIDS (PLWHA) reinforce the dominant ideas of good and evil with respect to sex and symptoms of AIDS and proper and improper behaviours (Avert, 2008). The consequence of stigmatizing AIDS in Tanzania has far reaching implications. Some of the consequences include the following:

- Stigma can function as a powerful tool of social control. It can lead to marginalization and discrimination against people who are HIV positive or have AIDS.
- Stigma instils hostile attitudes towards people who have HIV, AIDS, or show symptoms of having HIV or AIDS.
- Besides rejection and discrimination, some individuals, particularly women, experience violent retaliation or even divorce/abandonment from their sexual partners once their HIV-positive status is known.
- Stigma leads to secrecy and denial that hinder people from seeking counselling and testing, the crucial first steps in fighting the epidemic (TACAIDS, 2005).
- Due to their own fears about discrimination, people who know that they are HIV positive may not disclose their test results and thus cannot access care, treatment, and support.

Stigma tends to affect men and women differently. Decades of changes in economic activity and gender relations have placed women in increasingly difficult situations, making them vulnerable to HIV/AIDS. Traditionally, women managed households and acted as primary caregivers; now they must contribute significantly to their household incomes. Those who lack options to do so have turned in increasing numbers to sex work—a practice that has facilitated the spread of the epidemic (Thaxton, 2005; Silberschmidt, 2004). At the same time, the traditional norm of virginity for unmarried girls that exists in many societies paradoxically increases young women’s risk of infection because it restricts their ability to ask for information about sex out of fear that they will be thought to be sexually active. In addition, the social construction of masculinity compromises men’s health by encouraging men to equate a range of risky behaviours with manliness and to regard health-seeking behaviour as unmanly (Mwaluko et al., 2003). For instance, images of masculine ideals encourage multiple sexual partners and more sexual activity, and promote sexual practices that do not include the use of condoms, or the use of condoms inconsistently (Kapiga and Lugalla, 2002).

#### **2.4 Characteristics of HIV/AIDS Interventions in Tanzania**

As the number of people living with HIV/AIDS was increasing in Tanzania, national and international commitments were put in place to control the further spread of the epidemic and to assist those who have already been infected. National commitments included the establishment of the NACP in 1987 under the MOHSW, the Presidential Declaration of HIV/AIDS as a disaster in 1999, and the establishment in 2000 TACAIDS with a mandate to provide strategic leadership and coordination of multisectoral responses, as well as monitoring and evaluation including, research, resource mobilization, and advocacy (MOHSW, 2004; TACAIDS, 2005).

Besides forming these policy programmes, the government with support from donors also increased the budget for supplies and other commodities (e.g. condoms) and educational and advocacy materials; the logistics for their distribution was also put in place. At present, educational and advocacy materials have been and continue to be distributed throughout the country to educate people about AIDS. As a result, accurate knowledge regarding HIV transmission and prevention has increased tremendously in Tanzania during the last few years.

#### **2.5 Availability of VCT and CTCs**

The use of VCT services has been considered as a key component in the prevention of HIV transmission in many countries. It is believed that knowledge of one’s own HIV serostatus, combined with effective counselling, can facilitate individual behaviour changes that reduce the risk of HIV infection and protect sexual partners as well.

To encourage people to know their HIV serostatus, the government, in collaboration with nonprofit organizations, has established many sites where individuals can get tested for HIV. Tanzanians can now get tested in VCT centres, in routine testing facilities, in PMTCT centres, and in other types of facilities with various types of

services. VCT and CTC sites are located in every regional and district hospital in Tanzania. Those who test positive are referred to a CTC or PMTCT clinic for further checkups, treatment and care.

In 2005, a total of 217,116 new clients accessed VCT services in mainland Tanzania, as reported by counsellors from 21 regions managed by the MOHSW (NACP, 2007). This number does not include those managed by AMREF through the Angaza Project, which served 106,669 clients in 2005 (AMREF, 2008). Among the more than 215,000 clients served by MOHSW facilities, 27 percent tested positive. Because the national prevalence of HIV is 7 percent, this figure indicates that many VCT clients have a good reason to think they may be HIV positive. The number of people taking advantage of the services offered by VCT centres has increased tremendously in the past ten years. However, as an intervention, VCT services might not become effective if those who are tested are not willing to disclose their HIV test results.

Another service that the Tanzanian government has made available in recent years is care and treatment services to people who are HIV positive or have AIDS. With the availability of antiretroviral drugs that prolong the life of people living with HIV/AIDS, the government has now opened many CTCs where people who are HIV positive or have AIDS can access treatment and care. By 2007 there were a total of 200 such CTCs in Tanzania.

## **2.6 HIV/AIDS Testing and Counselling in Tanzania**

There are basically five different forms of HIV counselling and testing in Tanzania. The first and most common one is the “client-initiated” VCT which takes place in most cases in stand-alone sites like the ones under Angaza that are run by AMREF. There are counselling and testing services that seek to prevent the transmission of the virus from mother to child through testing the blood of pregnant women in antenatal clinics. A more recent type of testing is known as provider initiated counselling and testing (PICT), when a health service provider can encourage a patient to take an HIV test if he/she has symptoms that suggest possible HIV infection. Then there is HIV testing that is conducted for medical research and surveillance purposes. Finally, in some contexts, HIV screening is mandatory. In this study, we dealt mostly with client-initiated VCT clients.

## **2.7 VCT: Problems and Challenges**

Despite the number of VCT sites that have been established across the country, and the increasing number of people who access VCT services, problems abound. Many people are not willing to undertake an HIV test through stand-alone VCT centres, because they do not want to be seen being tested. Even when they are tested, people may fear disclosing their HIV test results to others. Less than 10 percent of the country’s late teen and adult population are aware of their HIV status, making it impossible to contain the disease and difficult to care for those who have already been infected (AMREF, 2008).

The other challenge that VCT facilities in Tanzania face is that most people are reluctant to go with their sexual partners. Most people who seek VCT services go to these facilities as individuals and very rarely as couples. Even in situations where they have sexual partners, some of these people decide to be tested for HIV without informing their sexual partners, and this creates complications when it comes to disclosing or not disclosing the test results, particularly if the results are positive. Even in a situation where the results are negative, disclosure can lead to questions about why testing was necessary.

### **3. STUDIES OF DISCLOSURE: A BRIEF REVIEW OF LITERATURE**

#### **3.1 An Overview of Studies of Disclosure**

The disclosure of HIV test results is critical to preventing HIV prevention and for maintaining good health and continuing social relations (Nsabagasani and Yoder, 2006). Whatever the result, disclosure to others allows the person to garner social support for any preventive actions they may want to undertake, whether they are HIV positive or negative (ibid). Disclosure may also help break stigma surrounding the disease and have a positive effect on antiretroviral adherence (Skogmar et al., 2006). Disclosing one's HIV status may, however, also confer risks to the individual, particularly for women, because negative social effects such as rejection, discrimination, and violence may follow (Gielen et al., 1997; Rothenberg and Paskey, 1995). Parsons and his team have identified both negative and positive consequences of disclosing one's serostatus to sexual partners. According to them, negative consequences include stigma, rejection by sexual partners and others, loss of intimacy, and threats to personal well-being (Parsons et al., 2004; Paxton, 2002; Skogmar et al., 2006). Positive benefits include increased social support and intimacy with partners and reaffirmation of one's sense of self.

According to Nsabagasani and Yoder (2006), disclosure of HIV test results is critical to HIV prevention for many reasons. First, individuals who keep HIV testing and test results to themselves are on their own for whatever they decide to do to change their activities to protect themselves against HIV infection. Second, for those who test positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Thus, the counselling sessions at a VCT facility are likely to emphasize the importance of discussing test results with a spouse or regular partner, and suggest that people come for testing and counselling as couples. Third, without disclosure, a person cannot easily access social or medical services that may be available. Although disclosure of test results does not guarantee access to social or medical services, because they may or may not be available, without disclosure, access to services becomes more difficult. That notwithstanding, any intervention that seeks to promote disclosure is likely to facilitate an increase in the number of people who are HIV positive who may have a chance to access social and medical services. In such a situation, disclosure is indeed an important intervention in controlling the further spread of HIV/AIDS.

The majority of published studies of disclosure have used survey methods with questionnaires to measure whether respondents showed their serostatus or to their sexual partner(s) or to others. Such methods can indicate the proportion of individuals who disclosed to someone, or not, but are unable to collect data on individual experience with disclosure or with what occurs over time. A recent audit of 46 peer-reviewed studies on HIV disclosure indicated that 30 had focused on the United States and Europe, often on "high-risk groups," such as men who have sex with men or intravenous drug users, and 10 were devoted to populations in Africa (Varga et al., 2005; Nsabagasani and Yoder, 2006). Studies vary tremendously in the terms used to describe disclosure, the populations they examine, and their ultimate objectives. Some scholars have focused on disclosure as a dichotomous variable: respondents disclosed or did not, or they disclosed

to their sexual partner or did not (Antelman et al., 2001). A few have focused on the reaction of spouses or sexual partners to disclosure (Maman et al., 2003). In east and southern Africa, one finds more studies of disclosure among pregnant women in antenatal clinics than studies of the general public (Kilewo et al., 2001; Nsabagasani and Yoder, 2006).

Disclosure studies have found that pregnant women tested in a PMTCT centre are much less likely to disclose their serostatus to their sexual partners than are women who use a VCT facility. As Suzanne Maman and colleagues explain, discussing findings from their study in Dar es Salaam, women who use VCT facilities have thought about getting tested for quite some time, they often discussed going for a test with their partner, and they perceived themselves as at high risk for HIV infection (Maman et al., 2003; Nsabagasani and Yoder, 2006). Pregnant women who are offered an HIV test in PMTCT centres, on the other hand, may not feel at risk for HIV, they may not have thought much about getting tested, and they are not likely to have discussed their acceptance of a test with their partner. Thus, the prospect of telling a partner that they have been tested, no matter what the outcome, is a very different matter.

### **3.2 Disclosure as a Social Process**

The process of disclosure has been found to be quite complex to describe, measure, and evaluate. Disclosure may be voluntary or involuntary, direct or indirect, full or not at all. Most studies of disclosure have examined disclosure that is voluntary and direct, that is, situations in which an individual voluntarily tells someone else directly of his or her serostatus (Nsabagasani and Yoder, 2006). Disclosing HIV test results is a complex, very difficult personal matter that entails communication about a potentially life threatening, stigmatized, and transmissible infection. The decisions about disclosure vary across different people, cultures, age groups, types of social relationships, situations, and contexts. These decisions sometimes change with time and one's experiences with HIV/AIDS, and in some cases they also depend on the state of health of the individual.

Disclosure of HIV-positive status may be inhibited if individuals live in neighbourhoods and/or ethnic communities that stigmatize someone with HIV (Castro et al., 1998; Mason et al., 1995) or if cultural rules discourage the disclosure of distressful facts and feelings (Argyle et al., 1986). Communities have "rules and scripts for appropriate conduct" (Cupach and Metts, 1994) that influence HIV disclosure/nondisclosure (Derlega et al., 2004).

Viewed in this light, disclosure is a social process that occurs over time with certain people and not others. As Cusick and Rhodes (1999) have pointed out, "Disclosure is therefore best envisioned as a social process which is 'situated' within particular social relationships and contexts" (Nsabagasani and Yoder, 2006). Individuals who have just been tested consider to whom they may want to show their status as well as people they do not want to tell about the results. The process thus may involve revelations to some people along with active concealment from others, including people known to gossip a lot, people who will blame the individual, or those who may react violently (Nsabagasani and Yoder, 2006). Therefore, to properly understand disclosure,

we must consider the time elapsed since testing, the social relationship of the respondent to the persons told, the manner in which disclosure occurred, and the identity of people from whom the respondent wants to conceal the results.

In his study of the consequences of disclosure, Serovich (2001) tested the theory of disclosure as a selectivity process or a cost-benefit analysis of consequences. He recommended that research should not focus only on looking at determinants of disclosure, but also on consequences and effects of disclosing when examining factors that influence disclosure and nondisclosure. In his study, disclosure risk was associated with rejection, loss of control, low personal integrity, and limitation or embarrassment. According to Serovich, there are three levels that a person reckons with when contemplating disclosure: the self, the other, and the relationship between the two. Discussing and disclosing HIV status is a two-way process. Whether it is right or wrong, many people say that a person who knows that he/she is HIV positive has an obligation to tell the other person with whom they have an intimate sexual relationship. Most public health officials and counsellors follow this line of reasoning and encourage people in this process. This reasoning assumes that HIV infection is the result of sexual relations. Therefore, anyone who is HIV positive must have had a sexual partner. In some countries laws have been enacted that require disclosure of HIV-positive status prior to sex (Galletly and Pinkerton, 2006).

Because the process of disclosing one's serostatus—directly or indirectly—occurs over time, discussions of disclosure must consider the time elapsed since testing. The time elapsed is important, particularly for those who test positive, because of the need to take measures to protect their sexual partner(s) from HIV infection and to bolster their own health. In addition, most individuals disclose to a wider circle of persons as time passes, sometimes voluntarily, sometimes indirectly as a result of their illness or use of social or medical services.

### **3.3 Disclosure and Social Relationships**

Although studies have shown that disclosure is a process that occurs over time and that may involve family friends and other relationships, describing and measuring the effect of social relations on disclosure, and vice versa, continues to challenge researchers. The important questions asked are: (1) How do social relations influence the process of disclosure? (2) How does disclosure itself affect social relationships? And (3) How does disclosure affect sexual relationships?

Regarding the first question, many studies have shown that decisions to take an HIV test are usually not individual decisions. Many different factors lead individuals to make such decisions. In many cases, the social context within which one lives and the kind of social relations that one maintains does facilitate getting an HIV test. People may discuss the decision to take an HIV test with people who are very close to them. Once tested, most HIV-positive or HIV-negative persons disclose their status to some, but not to all of their partners, friends, and family. Disclosure or nondisclosure (including perceptions of benefits and costs) are linked with the type of close relationship that people who want to disclose or not have with significant others (Derlega et al., 2004).

Disclosure to significant others can help increase support for HIV-positive persons. A study of Latino gay men found that disclosure was related to greater quality of social support, greater self-esteem, and lower levels of depression (Zea et al., 2005).

Disclosure also can lead to support that facilitates initiation of, and adherence to, HIV treatment and medications (Stirrat et al., 2006; Klitzman et al., 2004). According to some studies, disclosure generally becomes easier the longer someone has been living with HIV, as she/he becomes more comfortable with an HIV-positive status. Disclosure to sexual partners is more likely in longer-term, romantic relationships than in casual relationships like one-night stands, anonymous partners, group scenes, etc. (Duru et al., 2006). Disclosure also varies depending on perceived HIV status of partners, level of HIV risk of sex activities, sense of responsibility to protect partners (personal or shared responsibility), and alcohol or drug use (ibid).

The relationship between disclosure, sexual risk behaviours, and potential transmission of HIV varies widely. Different studies have ended up with different results. Parsons and his team argue that increased disclosure is indeed associated with a reduction in sexual risk behaviour (Parsons et al., 2003), but Crepaz and Marks (2003) have shown that disclosure does not always alter risk-taking behaviours. According to them, even with disclosure, unsafe sex sometimes occurs. Some people engage in safer sex behaviours even without discussion of HIV status (Klitzman et al., 2007). Some studies have also shown that disclosure tends to provide some psychological benefits. A study carried out by Parsons and colleagues (2004) observed that HIV-positive injection drug users who disclosed their status experienced increased intimacy with partners and reaffirmation of their sense of self. It is believed that many people who are HIV positive who disclose their status find that it reduces anxiety about transmission, so sex can be much more comfortable and relaxed.

Other studies have focused on particular persons disclosed to: sexual partners, family, and friends. For studies that look at the social context of disclosure, the family context is seen as an important factor because surveillance, treatment, and care are seen to be family oriented issues, and hence HIV is seen as a family infection (DeMatteo et al., 2002). Disclosure has been characterized not as a yes or no event, but rather a process of steps, with concealment, limited retractions for fear of rejection, and admission.

Varga and colleagues (2005) report on several patterns of disclosure to a sexual partner in their summary of disclosure studies among mothers. Some reports have found that sexual partners are the most likely target for showing serostatus. For reasons easy to understand, disclosure rates appear higher among HIV-negative than HIV-positive individuals. Rates of disclosure to sexual partners vary from 20 percent to about 80 percent, which may indicate wide variation in the samples and methods of measurement. Disclosure may be influenced by disease progression when it involves family members, but it may not when it involves sexual partners (Serovich, 2001).

A recent study by Linda Niccolai and colleagues (2006) has suggested a strategy that uses a survey questionnaire to measure disclosure to one's sexual partners. Survey respondents were asked if they disclosed their HIV status to their sexual partner and if

that disclosure occurred before or after having sex. Those who disclosed before sex were engaged in full disclosure, those who disclosed afterwards had delayed disclosure, and others did not disclose at all. The authors propose this method for large samples to measure variables associated with these three types of disclosure.

Although researchers most often focus on voluntary disclosure and on seeking ways to persuade individuals to discuss their serostatus with others, involuntary disclosure also often occurs. Women who have just given birth may show their HIV status by how they breastfeed or do not nurse their infant. Attending certain specialized clinics or clubs for HIV-positive persons or being seen buying or taking ARVs may also indicate a person's HIV status. With increasing knowledge of HIV/AIDS and the symptoms of opportunistic infections that are associated with AIDS, most people are likely to recognize a person who might be in an acute stage of suffering from AIDS. In this case, the sight of HIV/AIDS opportunistic infections may involuntarily show the serostatus of an individual.

The process of disclosure also includes the response of the person(s) told the news, because sometimes an announcement is not accepted as true. The actual and perceived health of a person also has an impact on how the news is received. In Uganda, chronic illness or the loss of a spouse to an illness that appears AIDS-related often suggests HIV infection, so individuals who are affected may be commonly considered sero-positive no matter what they say. Telling someone directly that one is positive or negative does not have the desired effect if the person hearing the news does not believe it. The process of disclosure must be one of mutual acknowledgement of HIV test results and their implications so that all parties involved share the same understanding of the situation.

Disclosing HIV-positive status sometimes does result in rejection, discrimination, or violence. In some cases, disclosing to some persons can be more of a burden than a benefit. A study done by Medley and others noted that barriers to disclosure identified by women included fear of accusations of infidelity, abandonment, discrimination, and violence (Medley and Garcia-Moreno, 2004). Other studies have found that friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members (Kalichman et al., 2003).

In the context of HIV as a family infection, DeMatteo and colleagues (2002) found that disclosure could lead to relationship changes, such as divorce, separation, or abandonment of intimate partners. It also leads to difficulty in coping as a family, because children have to tend to themselves when parents get ill.

Although disclosure is highly encouraged in HIV prevention programmes, the promotion of disclosure is not without controversy. Opinions vary as to whether partners have the right to know if their partner is HIV positive, in order to be able to make a fully informed decision about sexual relations. Some people say that as long as sex is done in a safe way (protected sex), there is no need for disclosure, especially with casual partners,

and that encouraging disclosure only serves to further stigmatize HIV-positive persons (Galletly and Pinkerton, 2006).

### **3.4 Implications for the Study of Disclosure in Tanzania**

A better understanding of factors that facilitate disclosure can be useful for programmes that promote disclosure of HIV test results, yet very little is known about the factors related to disclosure of test results or ways to enable individuals to discuss HIV test results with others. Achieving a better understanding presents many methodological challenges. Longitudinal studies are the most effective, provided they allow respondents to relate to the circumstances surrounding their acts of disclosure, but they are time consuming and expensive. One can, of course, ask individuals a few months after testing if they disclosed to anyone, and to whom, and at what moment, but the usefulness of that information is quite limited without a social context. A more effective approach for cross-sectional studies would be to conduct loosely structured, extended interviews with respondents who are free to talk about their own social situation and the circumstances that have facilitated or hindered the revelation of their HIV status to those around them.

In east and southern Africa, one finds more studies of disclosure among pregnant women in antenatal clinics than studies of the general public (Kilewo et al., 2001). There are also more studies of disclosure among women as opposed to men. This study therefore was conducted with a sample of individuals who have come to VCT centres and to routine testing centres rather than with clients of PMTCT centres in order to obtain a variety of clients: male and female, young and old, those who are well and those who are ill to discover the pattern of disclosure (whether or not, to whom, how, after how long) evident among individuals who have recently taken an HIV test, to identify the kinds of social relations that increase the probability of disclosure, and to describe the role of gender in the process of disclosure.

AMREF has been implementing the Angaza Project, a VCT programme, during the last five years. Many VCT centres have been established in different parts of Tanzania and statistics show that the number of people who use the Angaza services has increased since the project began in 2001. Similarly, there are many other VCT services that are being provided by CTCs that are run by the government as well as other NGOs. However, as we have already argued, VCT can only become an effective intervention if the VCT clients are encouraged to disclose their HIV test results. The question then is: To what extent has the increase of VCT services been accompanied by an increase in the number of people who are willing to disclose their test results to significant others? Addressing this question was one of the purposes of this study.

Although HIV testing and disclosure of test results is seen to be critical to HIV prevention, there are few studies on disclosure in Tanzania. Antelman and colleagues (2001) conducted a study of disclosure among pregnant women in Dar es Salaam from 1995 to 2000 to discover when and to whom HIV serostatus was shown over time. They found a clear and regular increase in the number of women who showed to their sexual partner and to a female relative over a period of four years (Antelman et al., 2001). In a study to investigate how counselling of couples can facilitate HIV disclosure, it was

found that disclosure has increased from 27 percent in the 1990s to 64 percent (Best 2002).

The disclosure study carried out in Dar es Salaam by Antelman and colleagues (2001) assumes that the nature of social relations—evaluated through an examination of household composition and friendship network, daily activities, and a discussion of their social ties and obligations—will affect the ability to show test results. Because each person has his or her own network of social relations (family, friends, and acquaintances), it is important to consider these relationships as well as the characteristics of individuals in thinking about the potential for disclosure (Antelman et al., 2001). The methodological challenge in evaluating this assumption lies in the way findings about social relations are collected and the way they are assessed.

The studies discussed in this chapter have been used to inform the design and frame key issues for this study of disclosure in Tanzania. The study sought to discover the pattern of disclosure (whether or not, to whom, how, after how long) evident among individuals who had recently taken an HIV test. The study also tried to identify the kinds of social relations that increase the probability of disclosure, and to describe the role of gender in the process of disclosure. The research was conducted with a sample of individuals who came to VCT centres and to routine testing centres rather than with clients of PMTCT centres in order to obtain a variety of clients: male and female, young and old, those who are well and those who are ill. Very little is known about the factors related to disclosure of test results or the ways to encourage individuals to discuss HIV test results with others. A better understanding of factors that facilitate disclosure can be useful in programmes that promote disclosure of HIV test results.



## 4. STUDY DESIGN AND METHODS OF DATA COLLECTION

### 4.1 Study Design and Methodology

Several methodological challenges related to both sampling and data collection had to be addressed in this study. The first was how to obtain information about the social relations of individuals that inform how they make decisions about their own health. The second was how to ethically identify individuals who have used VCT services, given the importance of confidentiality and anonymity. The third was how to identify individuals who have been tested some months earlier and arrange an interview with them. In other words, what entry points could the study use?

The method for describing social relations follows the lines of early research in social networks. A description of social relations has several components that may be elicited in different ways. There are the participants, members of households, and close friends who are identified with regard to their relationship to Ego (respondent). There are accounts of recent activities of the respondent—yesterday and during the past week—that show interactions between the respondent and others. There are accounts of participation in social groups (clubs, associations, churches, etc.) that indicate personal interest. Finally, there are the respondents' own descriptions of their social ties. Information about all these aspects of social life was solicited as well as the extent to which these aspects influenced the pattern of disclosure of HIV test results.

The attention paid to social relations stems from several assumptions made by the study team. First, we assumed that the nature of social relations evaluated through an examination of the household composition and friendship network as well as daily activities and a discussion of the social ties and obligations would affect their ability to show their HIV test results. Since each person has his or her own network of social relations (family, friends, and acquaintances), it was considered important to consider their relationships as well as the characteristics of individuals in thinking about the potential for disclosure. The methodological challenge in evaluating this assumption lies in the way findings about social relations are collected and the way they are assessed.

The ideal respondent for such a study would be an individual who was tested for HIV some months earlier, for they would have had time to discuss their test results with others in the interim period. However, it is not possible to identify such persons from records of testing facilities because they usually contain only a minimal amount of personal information about their clients to ensure the confidentiality of the consultation. In addition, even if it were possible to identify clients from facility records, such identification may be considered as a breach of confidentiality on the part of the facility. At the same time, some of the VCT centres in Tanzania do not keep any information of people who volunteer to take an HIV test at their centres. Hence, simply relying on records kept in VCT facilities would not have yielded the kind of information that was necessary for this study.

In view of these considerations, this study used two methods to identify eligible respondents. First, the study contacted clients of testing facilities right after they had completed their HIV testing and counselling and asked if they would be willing to discuss their testing and counselling experience. In this way individuals were free to refuse, and those who were willing could talk to the research assistants after having signed an informed consent form. This approach helped us to get research subjects who were categorized as new cases. In a somewhat similar study conducted at VCT centres in Uganda in 2005, VCT clients readily agreed to be interviewed in their homes at a later date (Nsabagasani and Yoder, 2006). Second, we visited a variety of associations of people living with HIV/AIDS and post-test clubs to recruit research subjects who had been living with HIV/AIDS for a while and who may have already disclosed their HIV test results to others.

## **4.2 The Nature and Type of Study Sites**

The study was carried out in two regions of Tanzania, namely, Dar es Salaam and Iringa. A total of eight VCT centres were identified (five in Dar es Salaam and three in Iringa) for inclusion in the study. Only one post-test club (SHIDEPHA+ of Iringa) was included in the study.

### *4.2.1 Brief Profiles of the Study Sites in Dar es Salaam*

#### (a) PASADA Upendo VCT Centre

PASADA is an acronym for Pastoral Activities and Services for People Living with AIDS in Dar es Salaam Archdiocese. It is a social service operating under the Roman Catholic Archdiocese of Dar es Salaam. PASADA provides VCT at the Chang'ombe Upendo Centre (where some of the respondents of this study were interviewed) and at 18 other satellite sites throughout the Archdiocese. The total number of people who have accessed the VCT service from 2001 to 2006 is 62,977.<sup>1</sup> Currently, PASADA has 25 counsellors who have been trained in VCT.

#### (b) Angaza VCT Centres

In 2001, AMREF was awarded a grant from USAID to enhance counselling and testing services across Tanzania. Thus, Angaza,<sup>2</sup> a VCT programme managed by AMREF, was launched in 2002. From the programme's inception, Angaza's communication strategy has focused on influencing knowledge about VCT availability, attitudes toward knowing one's HIV serostatus, and HIV prevention behaviours, including participation in VCT. The programme emphasizes counselling more than

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<sup>1</sup> PASADA. 2006. Holistic HIV and AIDS service provision: Building on hope – PASADA best practices. Old East Graphic (T) Services, Dar-es-Salaam.

<sup>2</sup> Means “shed light” in Kiswahili.

testing to side-step the stigma associated with testing.<sup>3</sup> Therefore, the key message communicated is “Come, let’s talk.”<sup>4</sup>

By March 2007, Angaza had 53 static VCT sites, eight mobile units, and six PMTCT sites across Tanzania. The number of first-time clients using Angaza services also increased from 21 in 2002 to a cumulative total of 504,000 individuals.<sup>5</sup> Angaza VCT centres are the most accessible resources for Tanzanians seeking quality counselling and testing. AMREF has trained about 900 counsellors, 53 laboratory staff, 55 accountants, and 110 receptionists for Angaza VCT centres.<sup>6</sup>

#### (c) WAMATA VCT Centres

WAMATA is an acronym for “Walio katika Mapambano na AIDS (Ukimwi) Tanzania.”<sup>7</sup> Founded in 1989 as a self-help organization for affected families, WAMATA quickly grew into a broader support network, both supporting people directly and fighting stigmatization and discrimination. It employs a multi-faceted strategy and uses a participatory approach that distinguishes WAMATA from other NGOs in Tanzania. The WAMATA Dar es Salaam branch VCT centre has tested more than 7,000 clients.<sup>8</sup> Each branch has a VCT centre where the blood test costs about US \$1.00.<sup>9</sup>

#### (d) Massana Private Hospital

Massana is a privately owned hospital that has been operating since 1995. The hospital is located in Mbezi Area on the outskirts of Dar es Salaam city. Massana hospital provides a number of services such as an antenatal and postnatal clinic, a tuberculosis (TB) clinic, a CTC that started in 2004, and a VCT centre.

#### (e) Temeke District Hospital

Temeke is a government owned hospital that is managed by the Dar es Salaam City Council. Besides offering many other hospital related services, this is the only hospital in Tanzania where routine testing, particularly for TB patients is taking place. This hospital is included as a study site precisely because of that status.

### 4.2.2 *The Dar es Salaam Respondents*

A total of 70 interviews were conducted in Dar es Salaam of which 38 were first interviews and the remaining 32 were second interviews. Of the 32 respondents interviewed a second time, 22 were female and 10 were male. In most cases, the interviews were conducted in VCT sites that are run and managed by the following organizations: WAMATA, Angaza, PASADA, and Massana hospital. We also included

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<sup>3</sup> <http://www.amref.org/index.asp?PageID=63&PiaID=2&countryID=2&ProjectID=71>

<sup>4</sup> Original Swahili is “Njoo tuzungumze.”

<sup>5</sup> <http://www.amref.org/index.asp?PageID=63&PiaID=2&countryID=2&ProjectID=71>

<sup>6</sup> *ibid*

<sup>7</sup> In English meaning “Those in the struggle against AIDS in Tanzania.”

<sup>8</sup> *ibid*

<sup>9</sup> <http://www.ms.dk/sw35283.asp>

one routine testing site that was located at Temeke District Hospital. We chose these sites because they offered rapid HIV/AIDS testing services. Table 4.1 below shows the number of interviews conducted in the Dar es Salaam sites.

Areas	Interviewees
WAMATA	14
Angaza (Mnazi Mmoja)	9
Temeke District Hospital (routine testing)	5
PASADA	6
Massana Hospital	4
Total	38

From the 38 respondents interviewed in Dar es Salaam, after the data cleaning exercise was completed there were 30 clean transcribed first and second interviews with 10 males and 20 females.

Most respondents were between the ages of 20 and 39. Only six of the respondents were between 40 and 49 years old. Two-thirds (67 percent) of the interviewees were females. Of the 30 respondents, 11 (37 percent) were married, 9 (30 percent) were single, and 7 (23 percent) were separated or divorced. In terms of their occupation, two-thirds (67 percent) worked as petty traders. Ten respondents (five men and five women) lived with their spouses and a total of 16 (53 percent) respondents lived with their children. Single female respondents were more likely to live with their children than single males. Nine respondents lived with their sisters and seven stated that they lived with their brothers.

#### 4.2.3 *Brief Profiles of the Study Sites in Iringa*

The interviews on HIV testing and disclosure were carried out in three different sites namely Iringa Regional Hospital, Alamano Health Centre, and Angaza (AMREF) VCT centre. In addition, interviews with PLWHA were conducted at SHIDEPHA+, a post-test club in Iringa. Below is a brief profile of these sites.

##### (a) Iringa Regional Hospital

Some of the interviews with PLWHA were conducted in the CTC located within Iringa Regional Hospital. This particular CTC started its operations in November 2004. The number of people receiving care and treatment in this centre has now risen to 4,900 of which 4,250 receive ARVs and the remaining 650 are on septrin.<sup>10</sup> This CTC is funded by the government of Tanzania in partnership with USAID through Family Health International (FHI).

<sup>10</sup> Information obtained on September 2007 from the CTC in Iringa Regional Hospital

(b) Alamano Health Centre

Alamano Health Centre was opened in 2004 and is owned and managed by the Roman Catholic nuns of Saint Alamano, Italy. The centre offers VCT and care and treatment services to 1,850 people with HIV/AIDS, of whom 1,250 receive ARVs. In the area of home-based care, the centre receives funds from Care International and from FHI through its new programme called TUNAJALI.<sup>11</sup>

(c) Angaza VCT Centre

The Angaza VCT centre is a standard branch of Angaza that offers the services mentioned earlier relating to Angaza. Only three respondents plus one counsellor were interviewed in this branch.

(d) SHIDEPHA+

SHIDEPHA+<sup>12</sup> is a post-test club for PLWHA with a head office in Dar es Salaam and five branches in the Iringa region. The Iringa branch located in the Iringa municipality was launched in 2005. The club has 250 members who meet once every week to discuss economic and health issues. SHIDEPHA+ receives funds from the Global Health Fund.

4.2.4 *Iringa Respondents*

A total of 100 interviews were conducted in Iringa, 40 with individuals who had just received their HIV/AIDS test results, plus three counsellors, and 57 with people who live with HIV/AIDS. Informants were randomly chosen with collaboration from counsellors, health care providers, and post-test club supervisors. Only 30 individuals among the 40 interviewees who had just received their test results showed up for the second interview. Two informants passed away before the second interview, and one was severely sick and was hospitalized. The remaining seven did not appear for the second appointment, and we were unable to trace their locations.

The study was carried out at three different testing sites in Iringa, all located in or near the town of Iringa (Table 4.2).

Research site	Interviewees
Iringa Regional Hospital (CTC)	35*
Alamano Health Centre	5*
Angaza VCT	3*
SHIDEPHA+	57
Total	100

\* Includes 1 counsellor

<sup>11</sup> A Swahili word literally meaning “we care.”

<sup>12</sup> Service, health, and development for people living positively with AIDS.

Because some respondents dropped out and others could not be traced, after the process of cleaning data, there were first and second interviews of 30 respondents. Of these 30, only 27 were suitable for analysis.

Among the 27 respondents, 12 were males and 15 were females. The majority of respondents (70 percent) were between 20 and 39 years old. Most of the respondents had completed primary school education, and only five indicated that they had dropped out of secondary school education. Nineteen of the respondents (70 percent) were married, four were divorced or separated, and only four of the respondents were single. Unlike in Dar es Salaam where most of the respondents were petty traders, about half of the respondents in Iringa (48 percent) were peasant farmers. Petty traders accounted for only one-quarter of the respondents (26 percent). Only four stated that they were officially employed.

The majority of the PLWHA (74 percent) were between 30 and 49 years old. Of the 57 PLWHA, 30 (53 percent) were married and 14 percent were single. More women were single (19 percent) than were men (10 percent). Twenty-three respondents (40 percent) earned their living through peasant farming and 17 (30 percent) were petty traders. Only 12 percent of the respondents were employed. There was no significant difference between men and women with regard to employment. In addition, more than a half had completed primary education and only 2 percent had completed secondary education.

#### 4.3 Demographic Characteristics of VCT Respondents (Dar es Salaam and Iringa Sites)

Table 4.3 below shows the age categories and marital status of the respondents in the two sites combined (Dar es Salaam and Iringa). One-quarter of the respondents (26 percent) were between 20 and 29 years of age, and nearly half of the respondents were between 30 and 39 years. Nine respondents (16 percent) were age 40-49 and only two were more than 49 years old.

Characteristic	People living with HIV/AIDS					
	Female		Male		Total	
	Percent	Number	Percent	Number	Percent	Number
<b>Age</b>						
Below 20	2.9	1	0.0	0	1.8	1
20-29	31.4	11	18.1	4	26.3	15
30-39	45.7	16	45.5	10	45.6	26
40-49	8.6	3	27.3	6	15.8	9
50+	2.9	1	4.5	1	3.5	2
Not stated	8.6	3	4.5	1	7.0	4
Total	100.0	35	100.0	22	100.0	57
<b>Marital status</b>						
Married	40.0	14	72.2	16	52.6	30
Single	25.7	9	13.6	3	21.1	12
Separated/divorced	22.9	8	13.6	3	19.3	11
Widow/widower	11.4	4	0.0	0	7.0	4
Total	100.0	35	100.0	22	100.0	57

Twenty-five of the respondents (44 percent) had completed only primary school education and 9 percent indicated they dropped out from secondary school. Although there was no significant difference between men and women with regard to completing primary education, women were more likely to drop out from secondary school than men. About one-third did not state their level of education. Thirty respondents were married (16 men and 14 women). Twelve respondents (three men and nine women) were single and three men and eight women were either separated or divorced. More women than men were single, separated, divorced, or widowed. About half of the respondents earned their living through petty trading (47 percent) and about one-quarter through peasant farming. Although only eight respondents were officially employed, seven indicated that they were unemployed. Twenty-seven out of thirty married respondents were living with their spouse.

#### **4.4 Sampling of the Study Population (Inclusion and Exclusion Criteria)**

During the development of the protocol, the research team discussed the issues of site selection for fieldwork, sample size, and the criteria for accepting respondents into the study. The team selected Dar es Salaam and Iringa to involve both urban and rural respondents. In addition, Dar es Salaam and Iringa rank third and second, respectively in terms of regional HIV prevalence. The team initially expected to visit mainly Angaza sites to identify VCT clients. However, practical problems led the team to visit a variety of VCT centres that were popular in the study areas.

Three main groups of potential respondents were contacted. The first group included individuals who had received their HIV test results recently, and were 18 years old or older, and who were HIV positive. This group of research subjects was recruited in both sites (Dar es Salaam and Iringa). They were interviewed two times if available. The second group of research subjects was recruited only in the Iringa site, and included only people who were living with HIV/AIDS. The third group of respondents was made up of health care counsellors who had worked in participating VCT centres for at least one month.

In addition, a number of individuals in positions of authority and who were likely to be knowledgeable about HIV/AIDS were interviewed to discuss their experiences in talking to people about disclosure of HIV test results. In Iringa these included one medical officer from the Iringa Regional Hospital, one Lutheran pastor, one sheikh, one ward counsellor of Mkimbizi Ward (Iringa Urban), a representative of the Iringa Regional Facilitating Agency for HIV/AIDS activities, and the Iringa Rural District Council HIV/AIDS Coordinator. In Dar es Salaam the group included the person in charge of PMTCT at MOHSW, two imams, one pastor from the Anglican Church, an official from NACP, and one official from TACAIDS.

#### **4.5 Development of Instruments and the Training of the Research Assistants**

Research assistants were recruited who were knowledgeable about HIV/AIDS and who had experience with qualitative methods of data collection. Training for one week took place in a conference room of the Tanzania Institute of Adult Education. The

training was directed by Dr. P. Stanley Yoder of Macro International and assisted by Prof. Joe L.P. Lugalla from the Centre for Strategic Research and Development (CESTRE). Also participating in this training was Mr. Charles Mlwande Madihi from the Dar es Salaam Institute of Social Work (sociologist and demographer); Dr. Huruma L. Sigalla from the Department of Sociology at the University of Dar es Salaam; and Nipael E. Mrutu from CESTRE (medical anthropologist). The last three were also responsible for field supervision in both sites.

The training focused on the principles and usefulness of qualitative research, the general approach of the study, and the important research questions being pursued. The trainees were exposed to different methods of interviewing, how to motivate respondents to talk, and the skills of running a good conversation that motivates the respondent to talk about issues that are of great importance to the study. They were trained how to introduce themselves to the respondent, how to establish a personal connection, and how to carefully listen throughout the conversation.

During the training the topics and questions were revised in group discussions. The topics and questions were arranged to begin first with general issues such as demographic characteristics, family ties, hobbies, and social relationships, followed by more specific questions about knowledge and practices related to HIV/AIDS. Because the original interview guidelines were in English, translation of topics and questions into Swahili was done during the training so research assistants could participate in finalizing the instruments. All interviews were to be conducted in Swahili. The English version of the interview guidelines can be found in Appendix 1.

#### **4.6 Methods of Data Collection**

The conversation guides developed were structured and open-ended so the interviews would follow normal styles of conversation more than a question-and-answer sequence. These conversation guides made it possible to listen to narratives and accounts about social relations, the taking of an HIV test, and thoughts about showing or concealing their test results. The guides were sufficiently flexible for the interviewers to encourage interviewees to discuss questions in any order that they desired. Although they all followed a similar form, three types of conversation guides were developed to direct discussions with three groups of respondents:

- A conversation guideline for respondents who had just recently taken an HIV test (new cases).
- A conversation guideline for people living with HIV/AIDS.
- A conversation guideline for health workers, particularly counsellors working in VCT centres that were included in this study.

#### *4.6.1 Conversation Guide for Respondents Who Had a Recent HIV Test*

This guideline was divided into two parts because two interviews were needed. The first interview took place at the VCT facility immediately after the respondent had taken an HIV test and had been given the results of the test. The first interview dealt with social and demographic information and work experience to understand the social context and social interactions, and with the process of how the respondent went for an HIV test and how that occurred, including counselling. In other words, it dealt with the circumstances that led the respondent to undertake an HIV test. The second interview took place after four to eight weeks and the venue was either the home of the respondent or a neutral place agreed upon by the respondent and the research assistant. This interview focused mostly on their overall impression of the VCT services, their views about pre and post-test counselling, their recent experiences in talking to others about their HIV test results, activities taken to conceal their test results, and how those people reacted when told about the respondent's HIV status.

#### *4.6.2 Conversation Guide for PLWHAs*

PLWHAs were included in the study because some of them had six months or much longer to have disclosed their test results to others. This conversation guide followed the guide used for recent testers for several sections: social and demographic information, getting tested the first time, and changes in their health status over time. Another section focused more in depth on the extended period of time living with HIV infection including the process of showing their situation to others over time, particularly to a sexual partner. For those who were on ARVs, we asked about their experience in taking medication and the effect that it had on their health. Finally, we invited them to talk about their participation in activities for PLWHAs, the process of becoming a member, the kind of activities they did, the advantage of being a member of PLWHA groups and activities in the community to prevent HIV transmission.

#### *4.6.3 Conversation Guide for VCT Counsellors*

The conversation guide for counsellors encouraged them to talk about the reasons clients come for testing, the different kinds of clients they serve, the advice they give to those who test positive and those who test negative, and the referral they give to those who are HIV positive. Also of interest were their descriptions of pre- and post-test counselling and any discussion they might have related to showing test results to others.

#### *4.6.4 Observation at Health Facilities*

Data collection also included some observations of interactions at health care facilities and households, a study of records and reports of client consultations at testing facilities, and participation in meetings among VCT clients and members of PLWHA organizations. These observations proved valuable in establishing the context of interactions related to HIV/AIDS.

#### **4.7 Organization of the Fieldwork**

Data collection in the two field sites was carried out simultaneously from late May through July 2007. Individual interviews were recorded with the permission of respondents. The research assistants were divided into two teams. One team under the supervision of Mr. Madihi and Dr. Sigalla remained and collected data in Dar es Salaam sites, and the other team went to Iringa and collected data there under the supervision of Ms. Nipael Mrutu. Professor Lugalla took the responsibility of overseeing both teams periodically and remained in contact with the supervisors of the two teams by telephone, emails, and periodic visits. Dr. Yoder continued to be in touch with the Tanzanian team by telephone and emails throughout the study period.

#### **4.8 Data Processing and Analysis**

The process of analyzing the recorded interviews consisted of the following steps. First, all the interviews were transcribed into Swahili verbatim. Second, the transcriptions were translated into English and typed in Microsoft Word. Transcribing the interviews verbatim and then translating them into English was a cumbersome and time-consuming exercise. Professor Lugalla and Dr. Yoder then prepared an analysis plan that had specific themes of particular importance for the study and summarized each interview according to this framework with the exception of the interviews that were conducted with counsellors and religious and community leaders. Examples of themes included in the framework of analysis are: demographic information of respondents, family situation, social contacts and social relations, current activities, hobbies, association membership, health status and use of health services, knowledge and experience of HIV/AIDS, respondent's experience with HIV testing, disclosure of HIV test results, experience of being on antiretroviral therapy, and life situation after disclosure. Guided by these themes, we then prepared a profile of one or two pages for each respondent. These summaries helped provide an overview of each respondent's individual situation. All this information was then linked to the socio-demographic characteristics of the individual as well as his or her social context. For example, an attempt was made to describe and classify different types of social relations of respondents to see how the types match with disclosure of getting an HIV test and discussion of test results. Logically, we expected to find four types of respondents classified by their pattern of disclosure:

- 1) Those who learned their HIV test results but told no one about the results.
- 2) Those who told only their sexual partner(s) and no one else.
- 3) Those who told only some authority figure such as a doctor, nurse, counsellor, or pastor.
- 4) Those who told family members and a few friends.

However, we also envisaged a situation where the data might indicate other categories or themes that are more relevant than those derived from our own expectations. For example, we assumed that a discussion of HIV testing or test results would be different if it involved a family member or close friend, compared with

showing such information in confidence to a doctor, pastor, imam, or other person who played a particular role in the community but who was not a close friend of the respondent. Our overall goal in the analysis was to understand the social interaction through which individuals keep information about HIV testing to themselves or share it with someone else and also how their social environmental (social context) influences this process.

#### **4.9 Informed Consent and Ethical Clearance**

The ethical obligation to protect the privacy and confidentiality of the contents of any conversation between respondents (VCT clients) was a major concern for this study. Before initiating any interview we carefully explained the nature of the study, the objectives and the overall goal. We also explained that participation was voluntary and that they were allowed to withdraw from the study at any particular moment, that the information they provided would be kept confidential, and the information would not be linked to their identity in any way. Once everything was clear to the respondents, we asked them to sign an informed consent form as proof that they decided to participate in the study willingly and voluntarily. All data were processed anonymously and confidentially. The research protocol was submitted to two ethical review boards: the Institutional Review Board of Macro International in Calverton, Maryland, and the National Institute of Medical Research in Tanzania. Both institutions provided their ethical clearance. We also secured research permits from regional authorities of the Dar es Salaam and Iringa regions.



## 5. HIV TESTING AS A SOCIAL PROCESS

### 5.1 Introduction

Many people in Tanzania are leading their lives unaware that they are HIV positive. This has implications both for the risk of further transmission of the virus and for the care that these people should be receiving. HIV testing is used to confirm whether a person has HIV or not. Thus, VCT can play an important role in HIV prevention, providing early diagnosis of HIV infection and the initiation of therapeutic or prophylactic interventions (Gage and Ali, 2005). In such cases, VCT is a pivotal entry point to help people avoid HIV and cope better with existing infection, enable pregnant women to reduce the risk of HIV transmission to their babies, and to increase openness about the epidemic (Jackson, 2002).

Although HIV testing has to be seen as a process that offers many benefits, it may be a very stressful process. According to Ransom et al. (2005) as quoted in Fako (2006), it is a process characterized by a pattern of anxiety involving three phases of the experience: first, deciding to be tested; second, being tested and counselled; and third, thinking about what is next. The process of HIV testing starts when an individual begins thinking about the possibility of going for a test, a consideration of the factors that suggest testing may be important. Next, a person may consult with others to get their perspective on getting tested; some do not consult anyone, however. Then, a person will decide to get tested or decide to just forget the idea. For those who decide to be tested, they must find out where to go, how to arrive, and whether or not they will try to get tested without being seen by those who know them.

Most discussions of interest in HIV testing have focused on the “reasons” that people gave in a survey for getting tested. Most of those reasons cited involve either sexual relations or health. Factors related to sex include planning a marriage, initiating a new sexual relationship, lacking trust in a sexual partner, or desiring to protect others from HIV infection. Factors related to health include having symptoms of chronic illness oneself, having had a sexual partner who died from causes that might have been AIDS, or the need for medical treatment.

In this chapter, we present findings that help us to understand that HIV testing is a social process that needs to be contextualized in order to understand it well. We examine how the respondents of Dar es Salaam and Iringa decided to take an HIV test, the people they consulted with before testing, and their general experience of HIV testing. We also examine problems and challenges of HIV testing. However, because we interviewed only individuals who had tested positive for HIV, the majority of individuals explained that they came for testing because of health problems: they themselves had been sick for a time or their spouse had passed away without the specification of a cause of death.

## 5.2 Conditions under Which People Seek an HIV Test

In this study, respondents who had just taken an HIV test and those who were living with AIDS were asked what had motivated them to get tested for HIV. Respondents were allowed to mention more than one factor. The table below shows their responses. The row labelled “poor health condition” includes anyone who talked about symptoms of illness they had been suffering from for some time. The phrase “to know HIV status” refers to individuals who said they had lost a spouse and were concerned that they were HIV positive.

Table 5.1 PLWHA and respondents who were tested recently by sex and reasons for HIV testing

Reason for HIV testing	People living with HIV/AIDS						People tested for HIV recently					
	Female		Male		Total		Female		Male		Total	
	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.
Poor health condition	56	15	80	24	68	39	57	20	64	14	60	34
To know HIV status	41	11	10	3	25	14	34	12	23	5	30	17
To answer a call for HIV testing	4	1	10	3	7	4	0	0	0	0	0	0
Peer influence	0	0	0	0	0	0	3	1	9	2	5	3
Not mentioned	0	0	0	0	0	0	6	2	5	1	5	3
Total	100	27	100	30	100	57	100	35	100	22	100	57

The table above shows that poor health condition was the main reason for both categories of respondents in deciding to be tested for HIV: 68 percent of those who had been living with HIV infection for some time and 60 percent of those recently tested. The data also show that 25 percent of PLWHA and 30 percent of respondents who were tested recently sought an HIV test not because they were in poor health, but because they just wanted to know their HIV serostatus. As shown later in this chapter, such people were influenced to be tested by many other reasons.

The data presented in Table 5.1 show that the respondents can be divided into two distinct groups. The first group is people who sought an HIV test because they were in poor health, and the second group is people who decided to take an HIV test for other reasons. Because the circumstances under which the two groups were compelled to be tested for HIV are different, the two groups are discussed separately.

### 5.2.1 Poor Health as a Reason for HIV Testing

After HIV enters the body, the immune function is reduced and the body is less able to fight infections and cancers. The infected people may then develop symptoms such as swollen lymph nodes, fever, fatigue, and weight loss. These early symptoms may vary in severity, as this gentleman from Iringa indicated:

*I began to feel ill in 2000. Each time I was ill I felt pneumonia, headache or fever. At the hospital they kept telling me that I had chronic malaria. But in 2004 they said I was suffering from TB. In 2006 they examined me and told me I was HIV positive.*

Many respondents who stated that they got tested because of poor health mentioned different types of symptoms of chronic illness that compelled them to take an HIV test. The three main symptoms that were mentioned by respondents living with AIDS were fever (33 percent), TB (26 percent), and abdominal pain (13 percent). The same symptoms ranked high for both men and women among PLWHAs. Among people who had just taken an HIV test and who tested positive for HIV, the three main symptoms mentioned were fever (35 percent), chest pain (16 percent), and coughing (16 percent). Other symptoms mentioned by both PLWHAs and recently tested VCT clients were mumps, headache, herpes zoster, STIs, TB, swollen legs, and rashes. For these respondents, it was clearly their diarrhoea circumstances of poor health over a period of time that brought them in for an HIV test.

The conversations below between the researchers and the respondents illustrate cases of this kind.

#### *Case 1*

**Researcher:** *Why did you decide to take an HIV test?*

**Respondent:** *I have been sick for a long time and have been going to the hospital but I never felt better. For example, I would leave the hospital today, and then the following day I develop something else like headache or stomach ache. Another day I would feel that my feet were aching. I became tired and wanted to know what I was suffering from.*

**Researcher:** *Why did you decide to get tested for AIDS and not for any other disease?*

**Respondent:** *I got tested for malaria but they would say I have no malaria. But I still felt sick. I would be having high fever, but still the doctors would say you are not suffering from anything. Every time I went to the hospital the answer was the same. Since I was feeling very sick, I really wanted to know what I was suffering from. That is why I decided to take an HIV test.*

#### *Case 2*

**Researcher:** *Can you please kindly tell me when you first discovered that you were HIV positive?*

**Respondent:** *It was this year.*

**Researcher:** *Which month?*

**Respondent:** *It was in February.*

**Researcher:** *Where did you take your HIV test?*

**Respondent:** *I went to the Iringa Regional Hospital.*

**Researcher:** *What made you take an HIV test?*

**Respondent:** *I often suffered from high fever, and last October I was admitted at the hospital and got treatment for malaria... after being discharged, I still noted that I was tired all the time. I went back to the hospital and the doctor noted that I was coughing.*

**Researcher:** *What did the doctor tell you?*

**Respondent:** *He advised me to take an HIV test.*

**Researcher:** *So the doctor is the one who advised you to get tested?*

**Respondent:** *Yes, the doctor advised me to get tested after he saw that I had tuberculosis.*

Another respondent narrated her poor health as a motivating factor for seeking an HIV test in the following way:

### *Case 3*

**Researcher:** *What made you take an HIV test?*

**Respondent:** *The idea of testing my health was not from somebody else but I decided on my own because my husband died from a mysterious disease. He first suffered from tuberculosis, then became very weak and finally died... I went on with my normal life although something at the back of my mind kept on telling me that it might be AIDS that killed my husband. After waiting for a long time, I too started feeling bad and suffered from high fever. Sometimes I had malaria and in other times severe diarrhoea. I then decided that it was important for me to test my health.*

**Researcher:** *Whom did you decide to tell that you are going to get tested, because you told me that your husband died?*

**Respondent:** *I told my friend—a girl friend whose husband also died. We usually like discussing things among ourselves because the circumstances under which our husbands died were the same. After advising each other we decided to take an HIV test. My friend went first and tested positive. I then decided to test, too, and the results were positive.*

**Researcher:** *Is there anybody else who was not HIV positive whom you involved?*

**Respondent:** *I did not involve anybody else before testing except my girl friend.*

**Researcher:** *Why did you decide to do that?*

**Respondent:** *I was afraid that they would stigmatize me because people stigmatize those who have this disease. Having this disease is a strange thing... a good example is my mother who started spreading rumours even before I got tested.*

**Researcher:** *Your own biological mother?*

**Respondent:** *Yes, she went around the streets telling people that they should look at me and see how I have lost weight. She assured them that it is because of the disease that is why I am withering away. Due to this, I decided to avoid all my relatives and friends.*

Although poor health brought many of the respondents in for an HIV test, it is not clear whether they wanted only to learn their serostatus and get explanations for their chronic illnesses, or if they also expected medical treatment, or both. Before the introduction of free ARVs in 2005 to Tanzania, one issue that was emphasized in HIV/AIDS campaigns was that AIDS had no treatment or cure. Therefore, for many people, seeking an HIV test was regarded as an act of requesting a death warrant if the results turned out to be positive. As a result, only a very few courageous people ventured to be tested, especially those who had suffered for a while from an illness. It was a way for them to confirm if they were infected with HIV or not, as we have seen above. However, with the introduction of free ARVs in 2005, a number of people who had chronic diseases started to opt for HIV testing to confirm if they had been infected with HIV; and if they had, they wanted to see whether they could be put on medication that could prolong their lives. One respondent echoed this view in the following way:

*When I realized that I was suffering from fever very frequently, and my health condition was deteriorating more and more, I decided to seek an HIV test so that if I am HIV positive, I can start taking ARVs and be able, therefore, to prolong my life.*

This group of respondents has shown that their situation of experiencing poor health and very frequent illnesses, such as recurring fevers or illnesses that never responded to treatment raised more questions than answers concerning their health situation. Therefore, their decision to take an HIV test is most likely motivated by the fact that they want to know the kind of illnesses they have, and whether such illnesses are AIDS related. Second, with the availability of ARVs it is very likely that they also want to take an HIV test so that if their illnesses are AIDS related, they can access care and treatment to prolong their lives.

### 5.2.2 Respondents' Other Reasons for HIV Testing

The second reason that was given by some respondents on why they got tested was to know their HIV status. Table 5.1 above indicates that for both people living with HIV/AIDS and those who had just taken an HIV test, more women than men mentioned this reason. In examining the context of this reason, it becomes clear that what respondents meant by this answer was that their spouse or sexual partners were either seriously ill or had passed away with symptoms suggesting HIV infection. As one gentleman and a lady explained it:

*At first, I had one wife, and when she died she bore a child, I married a second one... the second one was constantly ill, suffering from diarrhoea. In the end I began to wonder... why was she ill frequently? It became necessary that we both go to the hospital for further examination, and when we did, we were both found to be HIV positive.*

*I made up my mind to go for an examination because my husband had died under circumstances that were suspicious. He had first suffered from TB, and after that he became very thin and died. I went on living, in good health, but there was always the feeling in my mind that there could be trouble of some kind. Eventually I decided to go for an HIV test.*

The respondents who got tested because of other reasons ranged from those who had multiple sexual partners and suspected their spouses or sexual partners were promiscuous, to those who had been injured and suspected unsafe blood transfusion. Some had spouses or sexual partners who had tested positive for HIV, or were advised by their doctor to get tested. For these people, although most of them were in good health, they felt compelled to take an HIV test because of concerns about what had happened or was happening to their sexual partners. Below are excerpts of conversations that show that the reasons for taking an HIV test varied widely.

One respondent replied in the following way when she was asked by the researcher about why she decided to take an HIV test:

*In short, it is that I had a lover who had many sex partners. I always felt worried and thought that I might in the long run end up being infected with this disease HIV/AIDS. I then decided to take the test...*

Another respondent did not make her own decision to seek an HIV test but rather was advised by her husband, who had already taken an HIV test, and was found to be positive. This respondent explained to us the circumstances under which she went for an HIV test as follows:

*My husband came back and told me, 'I have taken an HIV test, I have tested positive.' He said, 'You should also go and take an HIV test.'*

Another important issue that we learn of from these findings is that the circumstances under which people decide to take an HIV test may sometimes influence

the way they react when they receive their test results. Some people might be shocked if the results are positive but others may not. To understand this, we asked them how they reacted when their counsellors told them that the results of their HIV test were positive. About 46 percent of those who had just tested indicated that they were shocked or frightened or denied their results, and only 5 percent indicated the results were normal to them, that they had expected such results and were therefore not shocked. The following four cases illustrate this point:

A 45-year-old woman was separated from her husband for one year because he was misbehaving (practicing extramarital sex affairs). This woman went to be tested because she was frequently sick. When asked how she felt when she received her results she said.

*To be sincere I felt so bad since I did not expect that it would have been that way.*

A 29-year-old woman confessed that she had had multiple sex partners and was practicing unprotected sex, yet she was shocked with the results, which were positive, and had this to say:

*I was very much shocked and worried about the whole issue.*

A 33-year-old married woman, when asked how she felt when she received the results, said:

*I was frightened by the news.*

A 46-year-old man went to get tested because of his unstable health condition and the influence of peer pressure. He responded in the following way when asked how he felt when he received his positive results:

*It was a really hard time for me because I believed I could not have that disease.*

The informants above were shocked, worried, frightened, and had a hard time when they were informed that they were HIV positive. They felt that way not only because they were not prepared for such results but also because of the meaning attached to being HIV positive and the way the society perceives HIV/AIDS. Their society perceives HIV/AIDS as a shameful disease and those who are HIV positive suffer discrimination and are isolated. In a way, according to some respondents, the society's negative attitude towards AIDS and people who are HIV positive makes some people fear HIV testing; as one informant says:

*Most people are afraid of testing... because they don't want to learn that they are positive... because AIDS is a shameful disease.*

She, however, went to get tested as a result of her poor health, and her husband was also very sick. Yet she was shocked by the results. When she was asked what the society says about HIV/AIDS, she answered:

*Let us be careful, we should not be involved in unprotected sex, AIDS is bad.*

Most of the respondents who indicated that they were not shocked after learning that their results were positive tended to be those ones who, even before testing, for various reasons, had already suspected that the chances were higher for their results to be positive. Below are some of the reasons showing why they felt this way. For example, a 38-year-old married woman whose spouse was promiscuous had this to say:

*When my health started changing and I started feeling bad, I began to think that it must be AIDS... I had that feeling, and therefore I came here to get tested just to confirm it.*

A 30-year-old single woman who had been well had this to say when her results were communicated to her:

*I felt peaceful because I had already been prepared for that.*

Another female respondent narrated the following circumstances as being behind her decision to take an HIV test:

*I made up my mind to take an HIV test because my husband had died under circumstances that were suspicious. He had first suffered from TB, and after that he became very thin and died. I went on living, in good health, but there was always the feeling in my mind that there could be trouble of some kind. Eventually I decided to go for an HIV test.*

These accounts indicate that testing for them was motivated by a specific situation that the respondents were experiencing. The circumstances within their own household or relationships made them anxious about their own serostatus and afraid that they may have contracted HIV. In this case the decision to be tested was a means to confirm their HIV status whether it was negative or positive. Such circumstances can be summarized as individuals who fear they may have contracted the HIV virus from their spouse or sexual partner because that person showed signs of HIV infection.

The study also interviewed counsellors and individuals working in MOHSW who had a wider perspective on how and why people come for HIV tests. Most of the counsellors and health care providers that we talked to in both Dar es Salaam and Iringa and also people from the MOHSW believed that many come for HIV testing in the hope of getting medical treatment for HIV. One official from the MOHSW had this to say:

*Since the advent of ARVs, the number of people who volunteer to take an HIV test has increased tremendously. There is no doubt that ARVs have brought a sense of hope for future life. When ARVs were not there, most*

*people associated HIV infection with death. Hence they did not want to be tested because that would end up assuring them that they were going to die soon.*

A counsellor from one of the VCT centres in Dar es Salaam and an Imam (Moslem religious leader) from Iringa appear to hold similar views:

*Many people have been coming to our VCT facility requesting to be tested during the last few years. Besides requesting an HIV test, they have also been asking if they would be put on treatment if they were found to be positive. I have no doubt that the availability of the life-prolonging drugs is what encourages people to get to know their HIV serostatus.*

*I hear that the number of people who want to know if they are infected with HIV or not keeps on increasing day after day. I think it is because of the availability of ARVs. These drugs are there and they are like a saviour.*

Information derived from interviews with some counsellors show that besides the circumstances that bring people to take an HIV test that we have outlined above, some people decided to take an HIV test because they were either planning to get married or were entering into new romantic relationships. A brief conversation between a researcher and a counsellor confirms this.

*Researcher: I would like to know the kind of people who come to your testing facility. From your experience, what are the reasons that make people come for HIV screening?*

*Counsellor: We screen only those people who are 16 years old and above. We do not test those who are below sixteen years. If someone has been brought by relatives we still ask the person if he or she was willing to take an HIV test. It is a must for every person to be willing to take an HIV test. We never test people by force and we do not tell them to pay for testing services. All our services are free and most people come to get tested because they want to know their health status. Some come because they might have practiced sex without using a condom. Some get tested because they have had more than one lover. Some might have been suffering from a long time. Others get tested because they are about to get married. We test many different people and these people come to us with different reasons that compel them to get tested.*

### **5.3 Social Relations and HIV Testing**

Although our findings show that some people made the decision to take an HIV test individually without consulting others, others discussed the decision to take an HIV test with people who might have had an interest in their taking an HIV test. For example, about 26 percent of those who had just taken an HIV test (Dar es Salaam and Iringa respondents combined) reported they discussed it with their spouse, 14 percent with their mother, 23 percent with their sister, and 14 percent with their brother. Although men were more likely to discuss it with their brother than their mother, women were more likely to discuss taking an HIV test with their mother as well as their sister. On the other hand, a higher proportion of men than women discussed the decision with their spouse: 32 percent versus 23 percent. Most respondents also reported discussing the kind of health problems they were experiencing with their relatives and friends. Some even told us that they discussed their specific situations with their friends or relatives, situations such as the death of a spouse or sexual partner from a mysterious illness. It is through these discussions that relatives or friends provided a variety of advice, including the importance of knowing their serostatus. According to some respondents, particularly women, some of the people with whom they had discussed their health problems had apparently advised them to take an HIV test, and also accompanied them to a VCT facility. Some respondents felt comfortable discussing their interest of taking an HIV test with people who they thought shared a similar situation or fate.

Finally, it is important to consider the situation of individuals who get tested routinely, cases where a health care provider has initiated the idea of testing (i.e. provider initiated), diagnostic HIV testing, and mandatory testing. In routine testing, HIV testing is offered as a part of the clinical evaluation of all patients in settings where HIV is prevalent. In this situation, those who agree to take an HIV test might not have the chance to discuss it with their relatives or friends. As indicated in Chapter Four, Temeke Hospital in Dar es Salaam is the only hospital we visited where routine testing particularly for TB patients is taking place. At this health facility only five respondents were interviewed. This type of HIV testing, more than others, links the infected patients with preventive care measures. The advantages of HIV routine testing are that it might eventually destigmatize the HIV testing process because many people do not perceive themselves to be at risk or do not disclose risks, and it facilitates the acceptance of HIV testing by offering it to everyone.

### **5.4 Benefits of VCT**

This study also solicited comments on respondents' experiences with VCT services in their respective areas. The large majority of respondents were satisfied with the VCT services received, and only a few indicated they were not satisfied. Those not satisfied with VCT claimed that VCT services either needed some improvement, the procedures were difficult to follow, or health workers were not caring towards the clients. Because counselling and testing are processes that take place together, we shall discuss in greater length the respondents' experience of counselling and testing in the next chapter.

## 5.5 Problems and Challenges of HIV Testing

Although HIV testing through VCT is becoming increasingly available in Tanzania, many people are still reluctant to be tested, for they fear discrimination. As two ladies said:

*My mother started to inform other people that I was HIV positive even before I was tested. She even told my children that their father who recently died was HIV positive and that they should look somewhere else when I die.*

These findings are similar to findings that have been reported by other studies that have shown that individuals avoid getting tested for fear of inappropriate HIV screening without consent and counselling, fear of learning that one is HIV positive, fear of a partner's reaction, belief that one is unlikely to be exposed to HIV, and many others (Fako, 2006; Campbell and Bernhardt, 2003; Burns et al., 2004; Isezuo and Onayemi, 2004; Peltzer et al., 2004; Gage and Ali, 2005). Because fear of rejection or stigma is a common reason for avoiding testing, linking testing with ongoing care and support services, as well as HIV education and awareness in the community, can reduce stigma and may contribute to wider acceptance of VCT.

As far as challenges are concerned, there is a need to increase accessibility to VCT, expand the buildings for VCT to promote privacy and maintain confidentiality, increase awareness, and monitor the quality of counselling. Confidentiality and privacy are the main fundamentals of counselling. Therefore, confidentiality must be strictly observed as far as possible within the counselling setting, which may include co-counsellors or assistants. The counselling should also be done in private. This calls for expanding the buildings for VCT to promote privacy and maintain confidentiality. We shall discuss more issues that relate to challenges and problems of VCT in the next chapter.

## 5.6 Conclusion

In this chapter we have shown that there are many circumstances that compel people to take an HIV test. By looking at the circumstances and reasons that made them take an HIV test, we noted that these respondents fall into two distinct groups: those who got tested because they were experiencing poor health, and those who got tested because of other reasons. For those whose health condition was poor, respondents were seeking explanations for their chronic illnesses and a hope of antiretroviral drugs that could prolong their lives. Those who appeared healthy were motivated by their worries about a family situation like death of a sexual partner, chronic illness of a sexual partner, or concern of infidelity of a spouse or sexual partner. We have also argued that although there are respondents who made decisions to get tested individually, many respondents stated that they discussed the idea of testing with family members, relatives, neighbours, or friends, and that they weighed many factors before deciding to get tested. What this means is that HIV testing is not a technical process isolated from social factors, but it is above all a social process. The process starts by an individual making the decision to be tested or discussing his or her health problems or worries with other people, then he or she accesses testing services, undergoes counselling, takes the test, and waits for the results.



## **6. COUNSELLING AND HIV TESTING**

### **6.1 Introduction**

HIV counselling should ideally be a confidential dialogue between a client and a counsellor to enable the client to cope with stress and make informed decisions related to HIV infection and disclosure. The provision of HIV/AIDS-related counselling services in Tanzania started in 1988, only five years after the first three AIDS cases were identified. HIV counselling usually includes two counselling sessions: a pre- and a posttest session. Although some VCT centres offer group and/or couple counselling, most counselling sessions are individual. All respondents confirmed that they had attended both pre- and posttest counselling sessions.

Pretest counselling sessions are intended to ensure that any decision to take the test is fully informed and based on an understanding of the personal, medical, legal, and social implications of a positive result. Pretest counselling prepares the client for the test and posttest counselling is supposed to prepare the client to receive and cope with the test results. According to Tanzania's MOHSW, because AIDS and HIV infection are associated with profound psychosocial impact to the individual, family, and community, both pre- and post-test counselling are supposed to be done by a trained counsellor.

### **6.2 The Process of Counselling and Testing**

Because most of the first interviews with the respondents who had just taken an HIV test took place either at the counselling and testing facility or in another private place near the VCT facility, we had an opportunity to see the layout and design of the VCT facilities to accommodate the processes of counselling and testing. The counselling procedures that we noticed were three types: individual counselling, counselling for couples, and occasionally group counselling. Group counselling was done only during the pretest phase of counselling. We were told by counsellors that sometimes they were forced to conduct group counselling because the clients were too many for their staff to manage. For sexual partners who came to the facility (boyfriend and girlfriend or married couples), the counsellors normally asked them whether they were real sexual partners and whether they would like to be counselled together or separately. They also asked them if they wanted to receive their test results together or separately.

#### *6.2.1 How Counselling and Testing Took Place in the Study Sites*

When clients arrive at the VCT centre, they go directly to reception where they are directed to a counsellor. In practice each counsellor occupies one room that has a door that can be closed. Pretest counselling seeks to encourage people to be tested as well as make them aware that there are two possible results, positive and negative. If the client agrees to be tested, the counsellor completes the consent forms and takes the client to the laboratory where blood is drawn for testing. If the procedure of testing uses rapid testing kits, clients are usually brought back to the reception where they wait a while for the

results. All respondents that participated in this study had taken rapid tests and therefore went through this process.

When the results are ready, the counsellor who counselled the client comes back to reception and invites the client back again to the counselling room. The client is then asked if he/she is ready to receive the results. The counsellors told us that for those who tested negative they usually advised them what to do in order to remain sero-negative. They also talked with them about the window period and advised them to return to the facility three months later to confirm the results.

For those who test positive the procedure to follow varies from one VCT centre to another depending on whether that VCT centre offers care and treatment services. For those VCT centres like PASADA that offer care and treatment services, the client who has tested positive is then referred to a trained nurse counsellor who examines the client's health. The client then is given an appointment to see a medical doctor who asks that a number of tests be conducted, including a CD4 count. If the client's CD4 count is below 200, he/she has to take other tests and is advised to attend the adherence counselling to prepare for taking medication. Those clients who have a CD4 count above 200 are advised to eat well and maintain a healthy lifestyle. For those VCT centres like Angaza that do not offer care and treatment services, the counsellor fills out a referral form to a CTC. The client can then choose the CTC that is convenient.

### **6.3 Counsellors' and Religious Leaders' Views on Counselling**

To understand how counselling is done in practice in Tanzania, our research assistants discussed counselling with a variety of counsellors who work in VCT centres and CTCs in Dar es Salaam and Iringa. The four counsellors in Dar es Salaam and the three in Iringa were chosen by the field supervisors.

These counsellors reported that people have many reasons or circumstances that compel them to seek HIV testing. They reported that they met with clients who wanted to know their serostatus because they were sick and wanted to know the cause of their sickness. Others were referred to them by their health care providers (doctors). Some wanted to be tested because they wanted to get married and their religion required that they take an HIV test before the wedding could take place. Others decided to get tested because their sexual partners had died from a mysterious sickness, and they now wanted to be tested because they were entering into new sexual relations.

Because people come for HIV testing in a wide variety of circumstances, counselling should be based on the varied needs of the client. However, that does not always happen. Those who were in poor health condition and those who had lost their spouse because of mysterious sicknesses should certainly be counselled in a different way than those who were healthy and were merely curious or concerned about their HIV serostatus.

The views cited below are those of a counsellor from Iringa and seem to represent the views of most counsellors that participated in this study:

*Many clients come to us with many reasons of wanting to know their HIV serostatus. Some come because they are very sick and their bodies are showing openly symptoms of full blown AIDS patients. Others come because they have lost an intimate romantic partner from a mysterious disease. Others are here because they are planning for marriage or are entering into new sexual relationships. Since the needs/reasons for our clients vary, we always use different counselling approaches.*

One counsellor asserted that the counselling process was usually a major challenge. Most of the counsellors said that pretest counselling was less cumbersome than posttest counselling. The latter was particularly problematic in a situation where the results were positive. One counsellor from Dar es Salaam had this to say:

*Since most of the people come to the VCT facility of their own will, pre-test counselling that aims at informing them of the advantages of testing and the implication of the test results is actually an easy process. What is usually a difficult task is when the results are out and they are positive. Most clients become shocked, some cry and you can sense fear, and sometimes denial in their minds. We are required to deal with their psychosocial emotions and to help them live positively with the results. We are supposed to convince them that being HIV positive does not necessarily mean death. And this is not easy because most of the people equate HIV and AIDS with death. Another daunting task is convincing those who test positive to disclose the test results to significant others. While few agree, and some deny, others simply remain silent and promise us that they will think about it. We can understand that, due to the fear of stigma, people who test positive find it difficult to disclose their positive results; those who opt to disclose do so only to a few people whom they trust.*

In our informal discussions with individuals knowledgeable about VCT, we discovered that some individuals who discover they are HIV positive contact a religious leader for advice or comfort. Therefore, we interviewed five religious leaders in Dar es Salaam and in Iringa to understand why some people sought their services and what kinds of advice or counsel these leaders provided.

The religious leaders we spoke with confirmed that people do come to them to disclose their HIV-positive status and most are individuals who are in poor health. According to the religious leaders, some of them have repented from their “sins” and have become strong believers of religious teachings. The religious leaders provide spiritual counselling that helps the clients to understand that God has not rejected them and is with them, and will be with them even in case of death. While post-test counselling from VCT helps the clients to accept the results and live with them, spiritual counselling helps them to believe that, even when they die, they have nothing to fear. The kind of counselling that the clients get from their pastors, priests, or Imams helps them to accept their destiny. A Lutheran pastor in Iringa had this to say:

*We have had many people disclose their positive HIV status to us and request us to pray for them. Some even go to the extent of telling us their past behaviour that might have made them get infected with HIV. Some mention how they sinned before God and therefore come to us to confess or repent and request to join the church again. We usually pray for them and assure them that God is with them now and forever.*

The pastor above told us that, in addition to counselling individuals who come to them of their own free will for counsel, the church also counsels partners who want to get married, ensuring that the couple gets an HIV test before they get married. A study by Lugalla et al. (2004) on social, cultural, and sexual behavioural determinants of the observed decline in HIV infection trends in the Kagera region of Tanzania also noted that before officiating a marriage ceremony, some Catholic and Protestant churches in Kagera were increasingly demanding certificates that confirmed that the couples had been tested and that each individual was HIV negative.

#### **6.4 Respondents' Experiences with Pretest Counselling**

All respondents in this study said they had received pretest counselling. The majority had attended individual client counselling sessions; very few claimed to have participated in group counselling sessions. The respondents said they had been counselled on a range of issues that included: client's consent to take an HIV test, the manner in which the testing (drawing of blood) was going to be carried out, how confidentiality of their test results was going to be maintained, basic knowledge about HIV/AIDS and its modes of transmission, and risk behaviours that facilitate HIV infection. Below is a brief description of respondents' experiences on a variety of pretest counselling issues.

##### *6.4.1 Informed Consent and Confidentiality*

Most of the respondents said that they were asked by the counsellors for consent before being tested. Besides being asked for consent, they were also asked the reasons for taking an HIV test and the implications of positive or negative test results. A 39-year-old female respondent had this to say:

*On the day I went to take an HIV test, the counsellor asked me a variety of questions, including whether I was willing and ready to be tested and to get the outcome of the test. I told the counsellor that I was. The counsellor asked me to confirm that this was my own decision and that no one had forced me to take an HIV test. I again responded to the counsellor that it was my own decision and that I had pondered about this decision for a while, fasted for two days in order to build up courage to receive whatever the results may be.*

Respondents' views indicate that counsellors did their job seriously and tried their best to follow the ethical procedures that are required before testing people for HIV. The findings show that even in situations where some clients were accompanied by their relative to a VCT centre and the relatives spoke on behalf of the client, the counsellors

usually insisted on getting the testing consent from the client himself/herself. The case of a 40-year-old woman who was accompanied to a VCT centre by her sister and brother-in-law serves as an example. After reaching the VCT centre, the relatives asked a counsellor to test the woman in question. The following shows how the conversation began.

**Counsellor:** *Your relatives want you to have an HIV test. Do you agree?*

**Client:** *Yes, I do.*

**Counsellor:** *Although your relatives are around and are aware of your decision to have an HIV test, our ethics of counselling require that I counsel you alone and that I will share the results of the test with you alone. However, you can share the results with your relatives if you wish to do so. But I, as a counsellor, cannot disclose the results to another person. All that you and I discuss will be confidential.*

As this conversation shows, the counsellor was concerned with not only informed consent, but also with confidentiality. The counsellor explained to the client that although she was escorted by relatives and that the relatives asked on her behalf for counselling and testing, the counselling process was going to be confidential and the relatives would not be allowed to participate. The counsellor also informed the client that the information about the result of her test would be released to no one else except to her.

#### 6.4.2 *Information on HIV/AIDS, HIV Transmission, and Risk Behaviour*

Although almost all respondents already knew about HIV/AIDS and how it is transmitted before they visited the HIV testing facility, as shown in Chapter Five, the respondents told us that their counsellors explained again to them what HIV was, how it was transmitted, the distinction between HIV and AIDS, and the kind of risky behaviours that facilitated HIV transmission. Some clients acknowledged the fact that they learned new information about HIV during these counselling sessions. A quote from one 40-year-old respondent illustrates this:

*Before visiting the VCT centre, I knew very little about HIV/AIDS and HIV transmission. Now I know a lot, I am going to disseminate the knowledge that I gained from these counselling sessions to both my relatives and friends.*

#### 6.4.3 *Assessment of Possibilities of Exposure to HIV Infection*

Respondents also said that the counsellors asked them questions to ascertain whether they had been involved in risky behaviour that might have exposed them to HIV infection. According to both counsellors and respondents, such a discussion prepared the clients/respondents for the outcome of their test results. For example, for those who might have been involved in risky behaviours, a discussion aimed at assessing the possibilities of exposure to HIV infection prepared the clients for the worst results. The

conversation below between an 18-year-old female client and a counsellor demonstrates how some of those discussions aimed at ascertaining how exposure to HIV infection took place.

**Counsellor:** *Do you have a lover?*

**Client:** *No.*

**Counsellor:** *Have you never had one?*

**Client:** *Yes.*

**Counsellor:** *You mean you have never been involved in an intimate (sexual) relationship with a man?*

**Client:** *I have, but that was a long time ago.*

**Counsellor:** *Was this intimate/sexual relationship safe? Please explain?*

**Client:** *Yes, it was safe.*

**Counsellor:** *In what way was it safe? Please explain.*

**Client:** *It was protected sex. We used condoms.*

## **6.5 Respondents' Experience with Post-Test Counselling**

All of the respondents in this study received counselling when they received their test results. They reported that they had been counselled on their worries and concerns, how to cope and live with HIV, and the possibilities of sharing their test results with others. The respondents numbered 35 women and 22 men.

### *6.5.1 Worries and Concerns*

To understand how people reacted after getting their test results, we asked our research subjects how they felt when the counsellors disclosed the positive test results to them. Nearly half of the interviews (N = 27) did not include any information about the response of individuals to the news that they were HIV positive. Three people said they felt “normal” or OK, and five people said the results were not true. The rest were quite unhappy, saying they felt bad, frightened, or shocked.

When asked by the researcher why she felt normal after getting results that she had HIV, a 30-year-old female respondent said:

*I felt just normal. I had been sick for quite some time and from the signs/symptoms that were throughout my body, I knew that I must be infected with HIV already.*

There is no doubt that such a person decided to take an HIV test only to confirm that her sickness was HIV/AIDS related. Another 25-year-old female respondent who became frightened after learning that she had been infected with HIV explained her ordeal as follows:

*First of all I did not believe when the counsellor told me that my results were positive. I became very fearful and so worried. I knew I was going to die soon. Most people have been saying that once infected, the chances for one to survive are small and that most people die early. As a result, I feared that I was going to die soon.*

The above experience is also shared by a 40-year-old female respondent:

*I really felt shocked and very disturbed when the counsellor disclosed the HIV-positive results to me. I thought about my family. I thought seriously that taking into consideration that my husband died a while ago, and now I am HIV positive, who will take care of my family/children when I die. Whom do I leave my family with?*

For those who showed their sense of denial, their feelings are represented by a 37-year-old man in the following way:

*When I learned that I was HIV positive, I simply did not believe what the counsellor was telling me. I thought my relatives might have bewitched me. It is not easy for me to get this infection. This cannot be true.*

#### 6.5.2 Implication of Test Results and Future Health

A 38-year-old married man living with AIDS had this to say as far as the question of future health is concerned:

*The counsellor advised me to live with great care. I was told to abstain or avoid unsafe sex. When abstinence is not possible, I was advised to use condoms. I was told that since I was infected with HIV, now I had to abandon certain activities, and follow A, B, C regime. I then asked my counsellor what A, B, C meant? I was told A meant total abstinence from sex, to which I responded that I was already abstaining. B stood for being faithful (sticking to one sexual partner), which means avoiding multiple partners, and C meant if I could not manage to handle the first two then I was supposed to apply the C which meant using condoms. The counsellor also advised me to eat good nutritious food. He suggested that for my health condition I was supposed to have six meals a day.*

### 6.5.3 Coping with HIV/AIDS and Availability of Care and Support

Respondents suggested that the HIV/AIDS counsellors helped them to handle their emotions, fear of death, and social stigma. A variety of respondents stated that most of their counsellors consoled and gave them a sense of hope in life by telling them several times that being HIV positive today did not necessarily mean death. According to them, their counsellors told them that, with the availability of ARVs, HIV-positive individuals tend to live a normal life. Such counselling is reflected by the conversation cited below between a researcher and a respondent:

**Researcher:** *After being told that you were positive, what kind of advice did you get from your counsellor?*

**Respondent:** *The counsellor told me not to worry. I was told that the condition I was in did not necessarily mean that I was going to die immediately. The counsellor insisted that I needed to follow the instructions of living with HIV. She assured me that if I did so, I could live for a very long time.*

Another 32-year-old female respondent explained how her counsellor assisted her in coping and living with HIV/AIDS:

**Researcher:** *Please, can you tell me the kind of counselling you received after having known that you were infected with HIV?*

**Respondent:** *The counselling I received helped me a lot.*

**Researcher:** *What were you told?*

**Respondent:** *I was told that testing positive was a normal thing nowadays and that there was no need for me to fear or get worried. The counsellor advised me that I was not the only one who was HIV positive. The counsellor said there were also many others who were in the same situation. He said there were rich and poor people who are infected. There are white as well as black and employees as well as rural farmers.*

**Researcher:** *What about how you should live?*

**Respondent:** *I was told to live with hope, and that is what I am doing. I was also told about the food I should eat, and also that when I wanted to be with my husband, we must use the condom.*

Besides psychosocial counselling, the counsellors also provided information for their clients about the services available to people who are living with HIV. For example,

some respondents told us that those who tested in places like Angaza, where HIV/AIDS care and treatment services are not offered, were referred by their counsellors to nearby HIV/AIDS CTCs. Those who tested in Angaza centres and WAMATA in Dar es Salaam were advised to go to Mwananyamala, Ilala, Temeke, or Muhimbili hospitals where ARV therapies were being offered. Those testing in Angaza centres in Iringa were being referred to the HIV/AIDS CTC that was located at the Iringa Regional Hospital. One respondent noted that:

*After testing positive, my counsellor advised me to go also to the care and treatment clinic for the CD4 test so that it can be determined if I should be put on medication (ARVs). I followed the advice, and when I went there it was found that my CD4 had dropped so badly that I had only 64 left.*

#### 6.5.4 Disclosure of Test Results

Another issue that the respondents said was often mentioned in their posttest counselling sessions was disclosure of test results. Some counsellors explained to their clients the advantages of disclosure and urged them to disclose to people who were very important to them. However, counsellors also emphasized the fact that their test results were confidential, meant for them only. The stress placed on confidentiality confused many clients, for clients thought they should not show their results to others, but should keep results to themselves.

## 6.6 Roles and Benefits of Counselling

The analysis of the accounts by respondents of counselling sessions shows that most of them found these sessions to be very helpful. Another benefit of counselling was the preparation of clients to accept their results and to live constructively with them. This gave the clients psychological relief and hope for the future. Learning that being infected was not the end of life, and that they had the chance to live a normal life, gave the clients a new perspective on life. Explaining the benefits of VCT, a 35-year-old man from Iringa had the following to say during the conversation he had with one of our researchers.

*Counselling helped me lot. There are so many things that I learned. I was told not to worry. I was given advice on what I ought to do when I get sick. They also advised me to stop drinking alcohol and to quit smoking-which I did and I now feel better. I really congratulate the work carried out by VCT centres. I think they need to offer these services daily instead of their current routine of only offering the services only three days a week. This will reduce the queue since there are so many people who want to be tested. I also think that it is important that the nurses and doctors that work needs to be a little bit faster in offering their services.*

A 38-year-old man from Iringa indicated to our researcher that one of the benefits of counselling and HIV testing was that it facilitated prevention. He explained his views in the following way:

*The counsellor told me that different people have different types of HIV viruses and therefore even couples who are both HIV positive are advised to practice safe sex. If they continue to practice unsafe sex, the chances are higher for them to acquire new infections. Therefore, he advised me to practice safer sex, such as by using the “Salama” condom in order to prevent new infection.*

The overall findings show that 88 percent of respondents who had just taken an HIV test indicated that they were satisfied with VCT. About 90 percent of respondents who were living with AIDS indicated that they were satisfied with services offered by VCT centres and benefited from the counselling they received. This situation may be explained by the fact that those living with AIDS had received counselling a long time before, and were therefore now able to see and appreciate the changes that were taking place, as had been predicted by the counsellors. In contrast, these changes were not yet perceptible to those people who had just been tested. Although the data show that 45 percent of those living with HIV/AIDS had accepted their positive serostatus and 43 percent were living normally, figures for the other group—i.e. those recently tested—were only 15 percent and 17 percent, respectively, an indication that those who had just taken an HIV test were still contemplating the outcome of their HIV test and were having a difficult time believing that they are positive. Those who were satisfied with the services offered by VCT centres stated that counselling sessions helped them to accept their positive results, adopt safer sexual practices, and live normally with HIV/AIDS.

The respondents who were interviewed for the second time were asked questions about their sexual life. Such questions included whether they participated in sexual relations, and if so, whether these sexual relations were safe or not. They were also asked whether they had multiple sexual partners or if they had reduced the numbers. The people living with HIV/AIDS indicated that they were being supported and not stigmatized by their relatives and others. Likewise, 47 percent of people recently tested stated that they were also supported and not stigmatized by their relatives and others. Only 3.5 percent of people living with AIDS and 2 percent of people recently tested stated they have experienced stigma.

One-quarter of the people recently tested indicated they have stopped having sex. These were mainly widows and widowers. Another 14 percent indicated they have either reduced sex partners or were practicing safe sex.

Most of the people living with HIV/AIDS stated that the counsellors are the ones who advised or referred them to clinics that provide care and treatment services for people with HIV. To them, one of the most important benefits of testing and getting counselled was the improved access to antiretroviral therapy. The findings of this study show that of the 57 PLWHAs, 39 (68 percent) were using ARVs and other medications that treated opportunistic infections related to HIV/AIDS. Discussions with those not on ARVs indicated that they were in good health or their CD4 count was in the range that does not require them to be put on ARVs.

To understand the effects of ARVs on health status, we asked our respondents living with HIV/AIDS to describe their health status when they began taking the drugs and how it has evolved over time. Their responses show that half of the individuals who took ARVs noted a dramatic improvement in their health after one year, and others said their health had also improved.

Overall, it is clear that most respondents were satisfied with VCT services. Counsellors treated them in a friendly way and gave them useful information, especially information about a good diet, safer sex, smoking and alcohol, and psychosocial counselling. Knowing one's HIV serostatus was an important benefit mentioned by many. One respondent maintained that the counselling helped him to know the importance of HIV testing and how to motivate and encourage other people to volunteer to test.

One interesting question is: Why did almost all respondents have very positive attitudes towards counsellors and in general towards the services offered by VCT centres and CTCs? This may be attributable to the fact that the majority of our respondents belonged to a special group in the following sense. They were in poor health and the situation of having chronic illnesses compelled them to take an HIV test. Sometimes people who are in very poor health (sick) are at the mercy of their health care providers and therefore are vulnerable and are likely to appreciate every service offered precisely because of the fear that any critical attitude towards their health care providers is likely to lead to poor services and neglect, a situation that can make matters of their health more worse. To what extent this is true is a subject of further research.

## **6.7 Problems and Challenges of Counselling and Testing**

Besides the fact that the respondents mentioned a lot of positive things about the services offered by VCT centres, these testing facilities also experience a variety of problems and challenges. For example, although many respondents were happy with individual counselling, those few who participated in group counselling indicated that they were not happy with it. According to them, group counselling neither paid attention to individual problems and circumstances, nor did it maintain confidentiality.

Another challenge associated with counselling and testing was the lack of easy access to referral services that could provide other necessary tests that were required for one to be put on ARV therapy. Respondents thought that these tests should be made more accessible so that someone does not need to wait for a long time. Below is a response from a 40-year-old female respondent from Iringa who was asked to express her opinion about the services offered by VCT centres.

*To be honest, I think, they should try to improve the services. You know, there are some people who were tested a long time ago but have not received the other required services up to now. After getting the test result other final tests may include the CD4 count tests. If you ask them the reasons for not performing the test, the health care providers can tell you that the machine for testing the CD4 count is out of order. This can be so for three to four months. It is important that the services are improved.*

*Many people are increasingly willing to take an HIV test because they want to access medicine, but such delays tend to discourage people and others lose hope. I have also noted that some health care providers tend to use harsh and foul language. I suggest that they should be friendly to patients.*

Another 40-year-old male from Iringa said the following expressed his concern about the VCT and CTC services:

*Sometimes you may visit the clinic when the date of your appointment collides with the day for children's clinic. In some cases the service providers become so unfriendly and harsh and they usually decline to help you. Most patients become so embarrassed with this situation.*

Another challenge confronting people in connection with counselling and testing is the distance they have to travel to access the service. Most of our respondents visited the VCT centre after having experienced frequent illnesses and their health condition had already started to deteriorate. They indicated that some of them lived in the rural areas and were forced to travel to urban areas to access such services. For people who were poor, this was indeed a barrier for accessing both VCT and CTC services.

Another major challenge that confronts Tanzania's VCT process is the ongoing problem of the situation of stigmatized stand-alone VCT facilities. For example, the Angaza centres are stand-alone centres. Although the CTC services are attached to most hospitals, such services are accommodated in special buildings that are easily labelled as buildings for people with HIV/AIDS. For example the CTC at Iringa Regional Hospital has been built and is hidden behind the outpatient wing of the regional hospital. Information derived from health care providers as well as some respondents indicated that most people labelled that building as "Nyumba ya Kliniki ya Watu Wenye Ukimwi," meaning "the building that houses the clinic of people who have HIV/AIDS." In a country like Tanzania where stigma against HIV/AIDS is still high, isolating VCT services from other health services tends to stigmatize these services and this can function as a barrier for people wanting to opt for HIV tests but do not want other people to know.

## **6.8 Conclusion**

This chapter has described the structure of the counselling process as experienced by our respondents, and the content of what they were told during the pretest and posttest counselling sessions. Respondents reported on their contacts with counsellors in very positive terms, often saying how useful they found the advice offered. A certain number also sought advice from religious leaders to support them. Although the majority of respondents' attitudes towards the process of counselling and testing was positive, and there were clear benefits to both counselling and testing, the findings showed that some people were critical of the services provided at various VCT centres. The findings also showed that there are many problems and challenges associated with the experience of VCT processes in Tanzania that need to be addressed to bring about improvement in the services offered by VCT facilities.

## **7. DISCLOSURE AND SOCIAL RELATIONS IN TANZANIA**

### **7.1 Introduction**

It is increasingly recognized that VCT can play a critical role in the prevention of HIV/AIDS. However, this can only become an effective strategy if those who take an HIV test disclose the outcome of their test results to others. Although getting people to take an HIV test is one thing, and an important step in its own right, disclosing the outcome of the test results to significant others, and sexual partners in particular, is another thing. Without disclosure, these significant others will not be able to know whether their friends, relatives, or sexual partners are infected with HIV or not. To sexual partners, the lack of knowledge of the serostatus of the sexual partner puts them at risk of contracting HIV themselves.

Most of our respondents considered disclosure as an important action that followed voluntary counselling and testing for HIV. The findings indicate that the respondents disclosed their HIV status selectively and voluntarily. The major circumstances that led them to take an HIV test were: frequent illness, observed experience from a partner (in case of illness or/and death), a family situation, and advice from another party. Our findings strongly suggest that motivation for disclosure varied according to the type of relationships in which the individual was involved. For example, mutual obligation seemed to be an underlying factor in disclosing to a family member and/or partner. Although some respondents discussed taking an HIV test with their close relatives, and others made those decisions without involving anyone, when it came time to disclose, social relations played a very important role in determining who was told and not told about the outcome of the test results.

### **7.2 Collecting Data on Disclosure**

Collecting data on disclosure and eventually measuring and evaluating it is a complex process. According to Nsabagasani and Yoder (2006), disclosure may be voluntary or involuntary, direct or indirect, full or not full at all. Most studies of disclosure have examined disclosure that is voluntary and direct, that is, situations in which an individual voluntarily tells someone else directly of his or her serostatus. "Delayed disclosure" is when disclosure was done after having sexual relations. Finally, there are those who do not disclose at all (Nsabagasani and Yoder, 2006).

This study focused on the patterns of voluntary and direct disclosure. The following main research questions guided this study: What are the factors and circumstances that compelled people to take an HIV test? How do people disclose or not disclose the results of their HIV test to significant others over time? Were the factors involved in that process mainly individual characteristics that push an individual towards disclosure, or were they primarily aspects of the social relations maintained by individuals?

The study also examined not only whether or not the HIV test result was shown to someone, but to whom, how it was done, how long after the HIV test it was shown, and the response of the person or persons to whom individuals disclosed the news of the test results. The study also collected information about the type of individuals to whom the respondents did not wish to disclose their test results. For those who did not show their test results at all, the study tried to understand the consequences of disclosure that individuals feared or expected. The study wanted to understand why such people opted to remain silent.

As described earlier, the study used two different strategies to collect data on disclosure. For respondents who had been living with HIV infection for months or more (PLWHA), we conducted a single interview. For respondents who had been tested only recently for HIV, we conducted one interview on the day of testing and a second interview four to eight weeks after testing so they would have a little time to disclose test results to others.

### **7.3 Why People Fear Disclosing**

Disclosing HIV test results is not an easy process. It is a complex and personal matter that usually entails communication about a potentially life threatening, stigmatized, and sexually transmissible disease. The circumstances involved and the explanations given vary widely across different peoples, cultures, age groups, marital statuses, and types of relationships, as well as social situations and contexts. The issues of stigma and confidentiality play a particular role for young, single people in their decision to disclose or not to disclose. For instance, a 20-year-old woman from Iringa explained her reasons for disclosing her test results to her cousin but not the rest of her family in the following way:

#### *Case 1*

**Researcher:** *Since you got your HIV test results, you said you have not told anybody apart from your cousin, neither your aunt nor uncle?*

**Respondent:** *I have not told them.*

**Researcher:** *Can you please tell me why?*

**Respondent:** *They know that I am suffering from TB but they do not know that I have HIV, but there is a day, I will tell them.*

**Researcher:** *You said that you have received and accepted the test results as God's will and you now regard HIV as any other disease. Why don't you want to disclose to your mother and/or your father? Just tell me what is on your mind.*

*Respondent: People differ.*

**Researcher: What is the difference?**

*Respondent: You can disclose to the mother, father, and aunt but they will tell other people about it. I don't want that to happen. But I know my cousin will not tell anyone else, she is the one who knows my secrets and she keeps them. She even knows where I get my TB drugs from.*

Another respondent, a 40-year-old man living with HIV, explained the dilemma he faced at work in the following manner:

*Due to the circumstances I am living with, I can't tell anybody. I am working in a hotel, and I fear I might lose my job. If I lose my job, how am I going to survive? Where will I live with my children? Therefore I have not disclosed my condition to anybody other than doctors and you.*

The process of disclosing one's results varies from one person to the next, depending sometimes on psychosocial circumstances. Some disclose the same day they learn of their results, but others wait for a period of time. The majority of the respondents in this study disclosed their results to close relatives such as parents, their spouse, siblings, aunts, and uncles. Some respondents did not want to disclose to other people such as neighbours or friends and some relatives because they did not trust them and were concerned about keeping the news of their HIV status private. They feared that these people might spread the news to others. They were afraid that if the news of their HIV status became widespread, they would face discrimination. When asked why he did not want to disclose his test results to other people, one respondent said:

*I don't want anyone who is not my relative to know my status. There will be no confidentiality. The advantage of telling close relatives only is that... if they understand you they will help you.*

In considering the comments of the respondents in general, it is clear that the levels of stigma and discrimination against people who test HIV positive or have AIDS still remain high in Tanzania. Hence, many people fear disclosure: some because they have witnessed or heard about adverse outcomes to disclosures, others because they worry that people who are not their relatives will hear about their situation.

#### **7.4 How People Disclose: Disclosure and Social Relations**

Disclosure of HIV status has been linked to acceptance of the HIV-positive diagnosis. Holt et al. (1998) argues that disclosure is usually not initially possible because the person is still grappling with the initial impact of their sero-positive status. They have to come to terms with the diagnosis first. Therefore, in most cases, some time will elapse from the time one is tested to the time when one shares the outcome of the test results

with other people. Several studies have shown that people who are sick are more likely to disclose their HIV status than people who are asymptomatic (Meursing, 1999).

A reading of the interviews indicated that the social context of individuals and the nature of their social relations often facilitated their getting tested for HIV. Respondents discussed the decision to take a test as well as to disclose their HIV test result to some people and not to others for various reasons. The strength of social ties to family, friends, and acquaintances influenced disclosure patterns. In addition, the kinds of marital ties (single, married, separated, or divorced) and sexual partnerships (monogamous, multiple, concurrent) that individuals maintain greatly affected the disclosure process.

Generally, the study found that people discuss HIV tests and show the results to people with whom they are very close and with whom they share a high level of trust. These are mainly blood relatives, such as parents (especially a mother), a brother, sister, uncle, or aunt, and sometimes close friends.

For some respondents, it was not easy to accept the results of their test; they consequently felt the need to be retested. In such situations, disclosure will be delayed. For example, a 35-year-old man from Iringa explained his dilemma in the following way.

#### *Case 2*

**Researcher:** *Ok, I would like now to know whether you told other people after receiving your test results.*

**Respondent:** *No, to be honest, I have not told anybody yet.*

**Researcher:** *You have not told anybody?*

**Respondent:** *Yes.*

**Researcher:** *I remember you told me that you are married.*

**Respondent:** *Yes.*

**Researcher:** *You mean, you have not told even your wife?*

**Respondent:** *I have not told her, maybe after getting a second test.*

**Researcher:** *Why is it difficult?*

**Respondent:** *I am convincing her.*

**Researcher:** *Mmm, convincing...?*

**Respondent:** *I want her to go and get tested, so that I can also get tested for the second time.*

**Researcher:** *Do you have other reasons which hinder you from disclosing?*

**Respondent:** *You know sometimes the test instruments can reveal false results. I can spread the information that I am infected when actually I am not... like now I am starting to feel well. Maybe the test result was wrong. I will tell my family only after being tested for the second time. People may start spreading information that I am positive when I am not. Why should I put myself into such situation? After all, why should I tell them? I will tell my family after getting the results of the second test.*

The findings indicate that there is a close relationship between people with whom the respondents discussed taking an HIV test and the people to whom they disclosed their test results. Therefore, we briefly consider what respondents said about having talked to others about getting tested for HIV.

About one-quarter (26 percent) of the respondents who had just taken an HIV test had discussed their decision to test with their spouses before getting tested. Overall, there was little difference between men and women in this regard. However, a higher proportion of men (32 percent) talked with their wife about getting tested than women did with their husband (23 percent). Some respondents discussed the testing decision with a sister or brother. In this group, more women than men (29 percent vs. 14 percent) discussed the test with their sisters, and more men (27 percent) than women (6 percent) confided in a brother that they planned to get tested for HIV. Female respondents were also more likely to discuss with their mothers their intent to take an HIV test than male respondents (20 percent vs. 5 percent). Thus, gender directly affects who talks to whom about sensitive issues pertaining to HIV/AIDS.

When these data are compared with the data on the kinds of people to whom respondents disclose their results, a similar pattern emerges. If we consider all respondents together without taking into account the passage of time, we find that many respondents disclosed their results to their spouses (42 percent). Men were more likely to do so than women (55 percent vs. 34 percent). One of every ten respondents disclosed to their mothers (12 percent), about 18 percent to their sisters, and about 19 percent to their brothers. Although there was no significant difference between men and women in terms of disclosing to their sisters, more men tended to disclose to their brothers than women did to their brothers. Our analysis shows that most people tend to disclose their test results to people whom they had involved in the earlier discussions of whether to take an HIV test or not. Very close members of the family were the most likely to be involved in both of these decisions: getting tested and sharing test results. ‘Close members of the family’ refers to individuals like mother, father, brother, and sister.

These findings obtained from respondents interviewed some four to eight weeks after testing are similar to the responses from people living with HIV/AIDS. In this latter group, more men (57 percent) disclosed to their spouses than did women (22 percent).

About a third of the respondents disclosed to their mothers, but there was a slight difference by sex: 37 percent of women spoke to their mother, and 30 percent of men did so. These findings show that there is a gender dimension in the pattern of disclosure for the longer as well as the shorter term. More than half of the female respondents (56 percent) disclosed their test results to their sisters and only 11 percent to their brothers. On the other hand, about 33 percent of the male respondents disclosed their results to their brothers. Only 24 percent of the male respondents disclosed their results to their sisters. Overall, about 32 percent of the respondents disclosed their results to their children. Female respondents were more likely to disclose to their children than male respondents (44 percent vs. 21 percent) suggesting that mothers in Tanzania were more likely to be closer to their children than fathers. This assumption is likely to be true because women in Tanzania tend to be more prominent in the domestic sphere of life (household) and men are more so in the public sphere of life.

Our findings show that most respondents disclosed their results to one of these three blood relatives: a mother, sister, or brother. Apart from blood relatives, married couples were inclined to discuss their results with their spouses, brothers, and sisters-in-law, followed by uncles, aunts, and friends. Very few single people with sex partners disclosed their results to these partners. Generally, respondents did not find it easy to discuss and disclose their results to fathers. This finding may reflect the fact that in Tanzanian society, children find it easier to discuss personal issues that concern their health with their mothers than with their fathers. It also reflects the traditional position and role of women in Tanzanian society where women act as the caregivers in a situation of health as well as in a situation of sickness. In this case, most people know that once they become bed-ridden due to sickness, it will always be mothers, aunts, sisters, or any other female relative that will assume the responsibility of taking care of them. The response below from a 46-year-old married man illustrates individuals' motives and expectations of disclosing their results to specific persons:

*I told my wife the same day that I got my test results because she supports and nurses me. Not telling her would have hurt her, but I told my brother after two days. He was surprised and asked where I got the disease from.*

Another married, 30-year-old woman from Iringa responded by saying:

*I told my mother and my sister the same day of getting my test results. My young sister who is also positive accompanied me to the hospital where I had to take a test. I told them because they are the ones who care for me. You know, I have to eat well. I don't like my neighbours to know that I am positive, they will just point fingers at me and won't give me any help.*

As we have already mentioned, expectations such as possible social support tend to influence the process of disclosure. Most of the respondents confirmed that obtaining care was a major motivating factor in disclosing their results. For instance, a 47-year-old man living with HIV/AIDS from Iringa explained this factor in the following way:

*...eeh since I became sick, I had to go back home and stay with my parents because I could not go on living alone in a rented house.*

Disclosure of HIV-positive test results can help reduce HIV transmission if a sexual partner is told right after the results have been learned. As mentioned earlier, disclosure is a process that occurs in time, often over a long period of time. Therefore, it may be useful to examine disclosure in terms of time elapsed since testing positive. Given its complexity, we anticipated finding differences in how and when and where disclosure occurred.

Table 7.1 below provides a summary of the time that people living with HIV/AIDS took before disclosing their HIV test results to their significant others.

Time from HIV testing to first disclosure of results	People living with HIV/AIDS					
	Female		Male		Total	
	Percent	Number	Percent	Number	Percent	Number
1 month	33.3	9	24.3	7	28.1	16
1 - 6 months	22.2	6	13.3	4	17.5	10
6 -12 months	7.4	2	3.3	1	5.3	3
More than 1 year	0.0	0	6.7	2	3.5	2
No disclosure	0.0	0	3.3	1	1.8	1
Not stated	37.0	10	50.0	15	43.9	25
Total	100.0	27	100.0	30	100.0	57

According to Table 7.1, more than one-quarter of the respondents living with HIV/AIDS disclosed their test results to others within a period of less than one month. About 18 percent disclosed between periods of one to six months, 5 percent disclosed between a period of six months to one year, and 4 percent did so after more than one year. Only one out of 32 respondents had not disclosed to anyone after more than one year had passed. The information derived from the interviews shows that 25 of 57 respondents (44 percent) did not provide information on the duration between testing and disclosure.

Overall, only five people out of the 114 respondents failed to disclose their test results to anyone at all: three single females, one divorced male, and one married male. The discussion of disclosure among different social groups below provides a fuller picture of how disclosure occurs.

## 7.5 Disclosure among Different Social Groups

The social group of reference to individuals and the social interactions in which they participate tend to determine how different individuals decide to share the results of their HIV tests with others. The criteria for classifying respondents are marital status and having a sexual partner. The variation of patterns of disclosure is also determined by the type of reaction a person anticipates from others as well as the type of support one expects. Below are some examples of why, how, and when people who differ by marital status and having a sexual partner disclosed their test results.

### 7.5.1 Disclosure among Married Respondents

In African countries confronted with an HIV/AIDS pandemic, cases of sexual transmission of HIV often occur within stable relationships. Therefore, prevention within the couple is of primary importance (Brou et al., 2007). For HIV prevention to occur within stable relationships, it must begin with the testing of both partners, followed by disclosure of test results to one another.

Some married individuals disclosed their HIV test results to their spouses, and some did not. The majority of married men (55 percent) showed the results to their wives, and a minority of women disclosed their results to their husbands (34 percent). Women were much less likely to show the test results to their spouses than were men. Also, women tended to have someone else with whom they shared information about their testing and results. For instance, most women had someone to accompany them when they went to take an HIV test, usually a close female relative such as a sister and/or mother.

Although most of the respondents disclosed to their blood relatives, one widow from Iringa, age 31 years, disclosed first to her brother-in-law. This was unusual, but they were on very good terms, and he had been very supportive of her. However, in reality, it is rare for married women to disclose first to a relative of their husband. Disclosure to a relative of a spouse risks accusations of infidelity and immoral behaviour.

The above scenario suggests that to understand disclosure well in terms of how it takes place, we must not ignore the cultural and social context within which people live and disclosure takes place. We must assess the extent to which the social environment determines or shapes people's lives and by so doing influences the process of disclosure. It is important to recall that those who disclose or do not disclose live not in a vacuum but rather in a social context. Unfortunately, the behavioural and biomedical models tend to neglect this reality. The models pay little attention to social context and structural issues, and as a result, important issues that influence people's lives, such as gender dynamics and power relationships between men and women are either forgotten or considered as not important.

Because of gender inequality in Tanzania, disclosure of HIV test results by a woman to a husband can potentially harm or destroy a relationship. Women have to think hard before disclosing their HIV-positive status to their husbands. Some are beaten or accused of infidelity or of bringing death into the family. Some are simply divorced and sent away. When asked about the reaction of her husband after showing the results to him, a 30-year-old woman from Dar es Salaam confirmed such a situation in the following way:

*My husband was furious and blamed me of infidelity and he planned to call a meeting of relatives to tell them that I had brought a disease in the family.*

Female respondents were often afraid of disclosing their results to their husbands first. These findings appear to be similar to other studies elsewhere in sub-Saharan Africa that have documented women's experiences of disclosure to their partners and reported barriers to disclosure, such as women's fears related to stigmatization, family rejection, breach of confidentiality, or accusations of infidelity (Medley and Carcia-Moreno, 2004). The understandable fears expressed by women stand in marked contrast to the situation of married men, who tended to disclose their test results to their wives first. The major reason they gave for disclosing to their spouse is the support they expected they would receive - especially when the individual's health begins to deteriorate.

One respondent, a 37-year-old married man, elaborated on his motives for disclosing the results of his HIV tests to specific persons by saying:

*I told my wife because she is my first aide. She is able to work and earn money. I told my brother as well, because he wanted to know what disturbs me, and he is very helpful. Moreover, there are some of my friends who know my status and they support us...other relatives know my status although they are not helpful.*

The statement above shows the patterns and reasons for disclosing HIV results to specific persons as opposed to just anyone. In addition to their spouse, men preferred to discuss and disclose their results to a close male relative, especially a brother or uncle, or a friend. One man disclosed even to his ten-cell leader, an important local political figure. If someone reports to a ten-cell leader, unless it is a close friend or relative, the individual is seeking government support (particularly financial), which is distributed by such leaders at the community level. This could come in the form of tax exemptions, school fee waivers, and help for their family to assist orphaned children financially. This is confirmed by the Ward Executive Secretary of Mkimbizi Ward in Iringa Urban when he says:

*Many people with HIV/AIDS are increasingly coming to report to our office and they usually tell us their status although we are not doctors or nurses. Some even bring letters written by their doctors confirming that they are HIV positive. The main reason that compels them to reveal their status to us is because they need either financial support for orphaned children or exemptions from paying school fees or any form of development levy that is required by the local government.*

#### 7.5.2 Disclosure among Widows

The respondents interviewed in this study included four widows. Three of the four had several children to care for; they limited disclosure to one or two people. For instance, three women disclosed to their sisters, and one woman disclosed to a close friend who was also HIV positive. One disclosed to her sister-in-law because the two had a good relationship. Generally, widows disclosed their results to their close relatives and their children (if they were mature enough to understand). Most disclosed as a means to gain support in case they fell sick. They were very concerned about what would happen

to their children in case they died, and they expected their relatives would take care of their children in case they become seriously sick or died.

Information derived from religious and government leaders shows that some widows disclose their HIV-positive status to them because they need care and support. According to them, this is more so with widows who are sick and are taking care of orphans at the same time. In this case, sickness and the need for support for orphans compel these people to share their situation with religious or government leaders. At the same time, these leaders told us that some widows did not like to show their HIV serostatus although most people suspected the cause of death of their partners to be AIDS. They also confirmed that there were some widows who continued to have sexual relations with other people in the community, and that such widows were very unlikely to volunteer to take an HIV test.

### 7.5.3 Disclosure among Young Singles

Of the respondents interviewed, 11 were young and unmarried: three young men and eight young women. The patterns of disclosure among this group differed from those who were married or divorced. Four individuals (two men and two women) disclosed their results to their mothers, two girls disclosed to their boyfriends, and one young man disclosed to his girlfriend. In addition, one woman and one man also disclosed to their friends. One woman disclosed to a church leader in addition to her relatives. One young man did not disclose to his girlfriend because, he said, he feared that she might commit suicide. Three young women did not disclose to anybody at all due to their fear of being discriminated against. One 17-year-old girl disclosed neither to her relatives nor to her boyfriend because she was also uncertain about their reaction. She was more concerned with holding onto their support as long as she could than she was with disclosing her results. Below, she explains her situation:

#### Case 3

**Researcher:** *...Thank you very much my young sister. Now, can you please tell me after receiving your test result to whom have you so far disclosed the test results?*

**Respondent:** *To be honest I have not told anybody. I have not disclosed to anybody because of fear to be chased away from home. I have not even told my boyfriend for fear that he might abandon me while I still need his support.*

**Researcher:** *If until today you have not told even your boyfriend, don't you have a concern that you might infect him?*

**Respondent:** *I will not tell him at all because I depend on him as far as money is concerned. If I tell him, where will I be getting the money? My mother is not well-off financially. The major reason why I do not want to disclose is my fear that I will*

*lose the job as well as be chased away from home. At the same time, my boyfriend will abandon me, and then I will have problems.*

Fear of abandonment, dependency, and loss of social support forced this young lady to avoid disclosure to her relatives and her boyfriend, people whose help she will need in the near future.

Similarly, one man disclosed to his brother and a girlfriend but not to his neighbours or work colleagues for fear of discrimination. Below is a conversation between an interviewer and a 25-year-old petty trader woman from Iringa who lives with her relatives. Her responses indicate the reasons why she did not discuss and/or disclose her test result to others.

#### *Case 4*

**Researcher:** *It is about three weeks or a month now since you last tested for HIV. Have you revealed your results to anybody?*

**Respondent:** *In fact, I haven't told anybody... I am still assessing the situation and the social environment I am living in first; I am not sure how they will respond after disclosing that I am HIV positive.*

**Researcher:** *You have lived here for three years now; do you want to say that you still don't know?*

**Respondent:** *Aah! When you live with people, they can appear to be good, but I am not sure how they are going to react when I tell them that I am HIV positive. I do not know whether they will have a negative attitude or not. Thus, I am not disclosing to anybody. I am not sure whether they will keep it a secret.*

The conversation above indicates the reality that disclosing HIV test results (especially when the results are positive) can result in rejection, discrimination, or even violence. Thus, in some cases, disclosing to some persons can be more of a detriment than a benefit. Due to this unfortunate reality, people usually scan the social environment within which they live before they decide whether or not they should disclose their test results and if so, to whom.

The findings of this study show that unmarried people who had a sexual partner (boyfriend or girlfriend) did not immediately disclose to their partner. Again, the reasons these individuals gave for avoiding disclosure were the same - they feared their partner's reaction. As stated above, a 24-year-old man from Dar es Salaam said that:

*I have not disclosed to my girlfriend because I fear that she might commit suicide.*

One situation in which people actually feel comfortable disclosing their HIV results is when an individual has a friend or relative who is also HIV positive. These people feel at ease when disclosing their test results to these people because they are in the same situation. They share a common fate and experience similar feelings about being HIV positive. They also believe that such people are very unlikely to stigmatize or discriminate against them.

#### 7.5.4 *Disclosure among the Divorced*

The respondents interviewed included 13 divorced persons: eight women and five men. Four out of the eight women disclosed their results to their sisters, and two of them disclosed to their brothers. Two women disclosed to their daughters. Four out of five men disclosed their results to their sisters, and two of them disclosed to their friends as well. Only one discussed his results with his brother, another man planned to tell his son, and one man disclosed to his mother. As mentioned previously, and as these results show, both women and men prefer disclosing their result to female relatives. This also indicates that women in many families have close and strong social relations and are held accountable for providing support more than their male counterparts. A 29-year-old divorced woman from Iringa had a sexual partner but chose not to share her result with him. Instead she shared her results with her mother and sister. She explained her reasoning in the following manner:

*I told my sister and mother. They understood and promised to help me. I am divorced; otherwise, I could have told my husband... I don't want my neighbours to know because they will start talking to other people. I did not want to inform my sexual partner because he will be angry and might harm me. I know for sure that he will say that I have not been honest in our relationship.*

Another respondent (a 40-year-old divorced man) elaborated on his experience of disclosure in the following way:

*I told my sister first. I disclosed to her because she is a loving sister. I told my young sister as well because she has the same problem... The advantage of disclosing to them is the moral and material support that they give me. They know my problem and I feel more close to them and it is easier for me to communicate with them.*

The two examples above simply confirm the fact that most people in this study preferred to disclose to close relatives like mothers and siblings. They also confirm the earlier argument that good relationships and anticipated social and psychological support are among the prime factors that shape the dynamics of the disclosure process, particularly in terms of how to disclose, when to disclose, and to whom.

## 7.6 Disclosure and HIV Prevention

Respondents in this study confirmed that disclosing a test result to a sexual partner facilitated further discussion about HIV/AIDS and encouraged the individuals' partners to also get tested and seek medical support if needed. Furthermore, disclosure sometimes facilitated discussion of safer sex, such as condom use. For instance, a 46-year-old man from Iringa explained the situation in the following way:

*Case 5*

**Researcher:** *Ok, when you got back your HIV test results and learned that you were infected with HIV, what was your reaction?*

**Respondent:** *I was somehow shocked.*

**Researcher:** *When you thought of disclosing to your family, what came in your mind?*

**Respondent:** *As far as my family is concerned I knew that there will be no problem with the exception of my wife. I was so concerned about her reaction. Then, I thought maybe I should bring her to the counselling and testing facility instead of me telling her at home, I was afraid that she might get confused and be shocked.*

Another 38-year-old man from Iringa had the following to say when explaining the preventive measure he was thinking to take after testing positive and disclosing his results:

*An HIV/AIDS counsellor told me that everyone has a specific type of a virus. When an infected person has sexual contact with someone else this can cause a new infection. Therefore, the counsellor advised that it is not good to have sexual intercourse with an HIV-positive person... She told me that in case I failed to abstain then, I should always use the "Salama" condoms in any sexual relationship.*

Another respondent (a 60-year-old woman) explained how she disclosed her status and also the benefits of disclosing in the following way:

*I disclosed first to my husband, then to my mother, and finally to my young sister. They advised me to seek ARVs. My husband agreed and accepted the situation and he now wants to go and take an HIV test as well. If you tell other people they will help. You should not keep quiet. Relatives are willing to help.*

From conversations with these respondents, we have learned that accessibility to ARVs has influenced people's perception and attitudes towards HIV/AIDS to some extent. Indeed, it is a disease that does not yet have a cure. However, accessibility of

ARVs has brought hope for patients and families. Our conversations left the impression that people now discuss HIV/AIDS and the availability of ARVs more openly than they did 10 years ago.

Most respondents indicated that their sexual practices and relationships changed after taking the test and disclosing their results to their sexual partners. Sixteen respondents said they have stopped practicing sex altogether, and six respondents stated that they practiced safer sex. Three said they no longer had multiple sex partners. Few respondents said that their sexual relations have continued unchanged after learning of and disclosing their results. Further conversations with such people showed that their sexual partners are also positive, and therefore they do not see the rationale of using condoms when both are in the same situation. Two respondents confirmed that they continued to practice unprotected sex. This calls into question the hope of public health specialists who hold that learning one's serostatus can by itself make people practice safe sex and therefore control further HIV transmission. These findings also mean that the counsellors need to continue working hard to help individuals with sexual partners who are also positive to understand the dangers of having unprotected sex.

In addition to the ones mentioned, two respondents decided to encourage their sexual partners and other close relatives and friends to go and take an HIV test so that they may also learn their serostatus. A 40-year-old man from Iringa explained how he was expecting to disclose his results:

*Eeh, I knew that my family will not have a problem knowing that I am positive but I was concerned with the reaction from my wife, I think, I should bring her for counselling and testing here instead of telling her at home, probably she might be confused.*

In the same context, one respondent confirmed that he now speaks more openly about HIV/AIDS than he did before taking the test. Very few respondents declared their status publicly. However, one respondent, a 30-year-old male living with HIV/AIDS, said the following when he was explaining why and how he declared his status to the village and village leaders:

*I told all of my relatives. Even my community at home knows my status because I have already declared myself; I have declared through a newspaper... it has helped me, because when the community knows the situation there are many benefits. For example, my village knows that I live with HIV/AIDS, and has therefore exempted me from paying any financial contributions for development purposes.*

Some individuals have disclosed to those who support them to ensure that the support they will receive will include, for example, nursing care. Married couples disclosed to their spouses more frequently than they disclosed to others, and more often than single people disclosed *their* results to their sexual partners. The majority of these married people took the initiative to practice safe sex, such as using the condom or encouraging their spouses to go for the test as well. The study has also indicated,

however, that disclosure is limited among singles or individuals with multiple partners. There are many reasons why single people refrain from disclosing their status to their partners.

Moreover, most of the HIV-positive respondents were looking forward to securing medical support, especially ARVs, as we have already shown in Chapters five and six. Disclosure may also lead to support facilities as well as initiation of and adherence to HIV treatment and medication. The MOHSW encourages patients, particularly TB patients, to choose someone reliable from their family or community who will help them adhere to their medication and support them through their illness. The idea behind this is that, by relying on a close family member or friend for medical attention, less will be expected of the hospitals which are already overburdened with the responsibilities of providing for and supporting patients' medication and treatment. This means of intervention is only possible when patients disclose their results. Without disclosure, patients can garner no social support and are left to fend for themselves.

This chapter has demonstrated how the process of disclosing HIV/AIDS test results takes place in Tanzania. Nonetheless, the decision to disclose or conceal one's serostatus remains an intensely personal one. The decision whether or not to disclose varies among different people, cultures, age groups, marital statuses, types of relationships, and social and personal situations and contexts. Although there are many challenges involved with disclosing serostatus in Tanzania, disclosure rates are high.



## 8. CONCLUSION AND RECOMMENDATIONS

### 8.1 The Process of Voluntary Counselling and Testing

Interventions in countries with a generalized HIV epidemic have focused on promotion of individual behaviour change and getting people tested for HIV, often in VCT centres. Once people know their HIV status, they may reduce their risky behaviour and thus slow the spread of HIV/AIDS. For this intervention to succeed, however, those who are tested and know their HIV serostatus must disclose their results to others, particularly their sexual partners, so their sexual relations can be safe. This study was designed and implemented with these background principles in mind.

This study interviewed only respondents who had tested positive for HIV. The large majority of persons interviewed, both those recently tested (60 percent) and those living with HIV for some time (68 percent), had been chronically ill when they were tested for HIV the first time. Most of the remaining cases came for testing because their spouse or sexual partner had died of symptoms similar to AIDS, or was also chronically sick. Thus, more than 90 percent of those interviewed were tested because they or their sexual partner were ill or had been ill. Their own situation or that of their sexual partner suggested to them that they might be infected with HIV, and they had come to check on that possibility.

Despite these indications of vulnerability to HIV, many respondents were shocked to hear they were, in fact, infected. Some were shocked at the results, or frightened or fearful, but others seemed to have expected such an outcome and were not surprised. Although these latter responses were few in number, an analysis of their circumstances shows that most of these were widows who had lost a spouse some time ago from a mysterious illness, and now they were also suffering from chronic illnesses. In this case, it was probably easy for them to expect that they would be HIV positive.

The social relations and living situation of respondents varied widely: some were married with children, others were widowed or separated, and others were not married but had sexual partners. Marital status and having a sexual partner or not should affect a person's reaction to being told they were HIV positive. Those who were widows or who did not have regular sexual partners found themselves in a different social situation than those who had spouses or regular sexual partners. The latter may have been contemplating how to communicate their test results to their partners.

These differences in social relations and individual situations are important in considering how services might be improved in VCT facilities. Clients who are married or have regular sexual partners need counselling that is different from the counselling given to those without regular sexual partners. Advice about whether to have children or not, and about the use of contraception, should also be different according to the nature of sexual partnerships.

## **8.2 Respondents' Views of Counselling**

Respondents were asked to comment on the process of counselling and any benefits they received from the process. They generally spoke in very positive terms, saying they learned many things in both pre- and posttest counselling sessions. Those things included the importance of knowing their HIV serostatus, a greater knowledge and understanding about HIV/AIDS and its modes of transmission, the significance of the window period, and the rationale of testing and retesting if the results are negative. The respondents indicated that their counsellor gave them caring advice, assisted them psychologically, and reassured them that they were not alone and that being positive did not mean death. Some counsellors also referred them to care and treatment clinics and encouraged them to adhere to treatment.

Our conversations showed that the counsellors emphasized confidentiality of the results and rarely spoke about showing the test results to others, particularly to sexual partners. None of the respondents said that the counsellors told him/her to disclose test results to others, but they did say that their counsellors encouraged them to bring their partners in for testing. This emphasis on confidentiality but not on disclosure may well stem from the national guidelines for VCT that were prepared by the MOHSW (2005). In these guidelines, more emphasis is put on confidentiality of the results than on disclosure.

Another aspect of counselling that may be linked to the training is that the advice given to all people who have tested positive is the same, regardless of whether or not they are married, single, widowed, sick, or healthy. The social situation and need for assistance of a single woman who is not yet ill compared with a married man with symptoms of AIDS are quite different, and they should be given rather different advice. Counsellors seem to have adopted standardized messages for clients who are positive, and they recite these messages to their clients without taking into consideration their situation. Such counselling by rote does not consider the social context and concerns of the client. Opportunities to provide useful advice to individuals who need assistance to live with HIV are missed.

## **8.3 Social Relations and Patterns of Disclosure**

This study has indicated that reasons for disclosure or nondisclosure tend to be linked to the type of close relationship that individuals have with their significant others to whom they decide to disclose or not to disclose. Benefits include acquired psychosocial support, active coping, and improved wellbeing. Most of the respondents who disclosed their test results did so to their blood relatives. Most respondents disclosed to their female relatives and/or partners such as a wife, mother, sister, sister-in-law, aunt, and cousin before and more frequently than they did to their male relatives such as a father, brother, uncle, nephew, and/or brother-in-law. Most of the married clients, particularly men, disclosed their test results to their spouses. Most single people disclosed the results to their parents and relatives, but not to their sexual partners. Widows disclosed to their close blood relatives as well as their children. This was the case with the divorcées as well, who disclosed their results to blood relatives, children, and friends.

There were only two cases where respondents disclosed to their religious and political leaders.

Finally, very few (five) of the respondents had not disclosed their test results to any one at all. For these few, it was their fear of being stigmatized and discriminated against that made them keep quiet. After assessing their situation, people decide to disclose or not to disclose, likely little by little. If they decide to disclose, they do it selectively. That is, they usually identify the people whom they think should know about their HIV-positive status and those who do not deserve to know.

Expected social support and the ability to maintain confidentiality also played a key role in influencing someone's decision to disclose. Most respondents disclosed to their family members because of their close and mutual relationship as well as the social support they expected to gain. It must be emphasized that the nuclear as well as the extended family tend to be the backbone of social relationships at the community level in Tanzanian society.

We have also found that there is a gender dimension to the process of disclosure related to both disclosure to spouses and to the identity of the persons in whom to confide. Overall, men were more likely to disclose to their spouses than were women (55 percent vs. 34 percent). In considering only the responses from people living with HIV/AIDS that were interviewed in Iringa, more men (57 percent) disclosed to their spouses than did women (22 percent). Although there was no significant difference between men and women in terms of disclosing to their sisters, more men tended to disclose to their brothers than women did to their brothers. More than half of the female respondents (56 percent) disclosed their test results to their sisters and only 11 percent to their brothers, whereas 24 percent of the male respondents disclosed their results to their sisters. On the other hand, about 33 percent of the male respondents disclosed their results to their brothers.

These differences by sex can be attributed to the gender inequality that exists in Tanzania. Men simply have more social and economic power than women generally. Because men are socially more powerful, they disclose their HIV-positive status to their spouses with less fear of being rejected or fear of violence. On the other hand, women are vulnerable to accusations of infidelity in case they test positive and are blamed for bringing HIV into the family. At the same time, it is the women who shoulder the responsibility of taking care of the sick and providing for all the necessary services they need at home. Therefore, people feel obliged to disclose their HIV-positive status to them because they anticipate support and care from them once they fall ill.

#### **8.4 Challenges to Getting Tested**

Although most respondents were happy with individual counselling, those few who participated in group counselling indicated that group counselling neither paid attention to individual problems and circumstances, nor maintained confidentiality. Second, the respondents as well as the counsellors mentioned the lack of easy access to referral services that could provide other necessary tests required for beginning ART.

Patients now wait for equipment or reagents to be delivered to perform tests necessary to begin taking ARVs.

Another challenge confronting people wanting to test is the distance they have to travel to access the service. Most of our respondents travelled far to a VCT centre. Another major challenge of VCT is that the use of a stand-alone facility may be stigmatized. Although CTC services are attached to most hospitals, we noted that such services are accommodated in special buildings that are easily identifiable by people as buildings for people with HIV/AIDS. In a country like Tanzania where stigma against HIV/AIDS is still high, isolating VCT services from other health services tends to stigmatize these services.

### **8.5 Implications of Study Findings to VCT Services in Tanzania**

The findings of this study help us to understand the nature of social relations that surround and influence not only processes of counselling and testing for HIV/AIDS, but also the process of disclosing HIV test results to others. For example, the findings show that:

- It is important to recognize that individuals live in a social context that influences the way they perceive risks, the way they make decisions about HIV testing, and finally whether to disclose their test results to others or not. Understanding this reality can assist counsellors in considering the individual circumstances of their clients and tailor their advice to fit the needs and problems that clients experience.
- It is important to treat post-test counselling not as the end process of VCT services, but as an introduction to a system of support. This is only possible if ways of maintaining future contacts between VCT service providers and clients are put in place. Although the national guidelines for VCT encourage follow-up counselling after posttest counselling shows HIV test results, this study did not collect findings about whether this takes place in practice.
- Disclosure is not a simple matter of individuals telling one or two persons they are HIV positive or negative. Rather, the person who hears the news must also accept and believe that news and may need help in dealing with the implications. What this means is that most VCT clients need further assistance to negotiate the news of their serostatus.

### **8.6 Recommendations**

The observations and findings from this study suggest the following points of emphasis and policy recommendations:

- The amount of time and money needed to obtain an HIV test constitutes a barrier to VCT services. It is assumed that if VCT services are more accessible, more people will use the services. Therefore, there is a need to facilitate access to VCT services for the public, particularly in rural areas.

- Most respondents who were not married did not disclose their HIV result to their sexual partners. This situation presents a challenge for counsellors to persuade single individuals to share their test results with their partners.
- VCT counsellors need to discuss the importance of disclosure with their clients more often and more directly, for this issue receives little attention now. This is especially important for younger single individuals who are sexually active but do not disclose their status to their sexual partners.
- A referral system needs to be developed so that clients who get their HIV test in facilities that do not offer care and treatment services can access such services for medical and social support. One way to do this would be to expand care and treatment services in stand-alone VCT facilities.
- Links should be created between clients and other community-based support services so that continuous support is available at the local level to assist VCT clients in communicating with their families or friends about their situation. This can work well if there is constant interaction and communication between VCT facilities and organizations that offer social support at the local village level.



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## **APPENDIX A: INTERVIEW SCHEDULES AND GUIDELINES**

### **Conversation Guidelines for Respondents**

#### **Interview #1 Objectives**

This first interview seeks to discover the nature of the respondents' social interactions with family and friends, the health of the respondent and close family members, the use of medical services by the respondent over the past few months, and the circumstances that brought them in for an HIV test. The interview is divided into several sections. The first section begins with a discussion of the composition of the household in which they live and the friends they see often and the person they rely on for advice, then moves to talking about work and leisure time of the respondent, the associations to which they belong, and their involvement in those groups. The last section is devoted to discussing the circumstances that brought the respondent in for an HIV test.

#### **Questioning Guide for Interview #1**

##### **I. Social Context and Social Interactions**

###### **A. People in household and others close to respondent**

1. Household composition  
Names, ages, and relation to respondent
2. People they see most often (friends, neighbours, others)  
The three to four people most important to them

Questions: Tell me about the people who live in your household:

- What is your relationship with each of them?
- Who are the people you see most often?
- What is your connection with them?
- Among these people, which ones do you know best?
- What is your connection to each of them?
- To whom do you go for advice about a problem you might have?
- Examples of a recent problem you went to discuss with someone.

###### **B. Current activities**

1. Working activities away from the house
2. Working activities at the house
3. Rest/relaxation activities

Questions: What kind of work do you often do?  
With whom do you do this?  
What kind of work do you do at the house?  
When you have time, what do you do to rest? With whom do you usually do that?

C. Associations, clubs, and groups you belong to

Questions: Tell me about the groups you belong to (the clubs and other groups)  
How long have you been a member?  
How often do you meet with them?

D. Recent public events attended

1. Family events (weddings, baptism, funerals, birthdays)
2. Other events attended

Questions: Tell me about the public events you attended in the last three months  
What other ceremonies did you attend?

## **II. Respondents' Health and Recent Use of Health Care Services**

A. Health of family members

Any cases of severe or chronic illness

B. Respondent's own health in general

Ways to maintain good health

C. Respondent's health in the past few months

D. Use of medical services in past few months

Questions: Tell me about the health of your family members. Any serious illnesses?  
How is your health in general?  
Have you been taking any medicines in the last three months?  
Tell me about any visits to a local healer in the last three months.  
Tell me about any visits to a health centre in the past three months.

## **III. Knowledge and Experience with HIV/AIDS**

A. Knowledge of HIV transmission routes

B. Knowledge of HIV testing

C. Others they know who have been tested

D. Knowledge and experience with people who had AIDS

Questions: Tell me what people say about HIV and AIDS around here.  
What do you know about getting an HIV test and counselling?  
Tell me about other people you know who have been tested for HIV.  
Tell me about anyone you know personally who had AIDS.

#### **IV. Decision to Take an HIV Test**

- A. Circumstances: family and/or social situation at time of testing
- B. Others involved in decision
- C. Thoughts about how other people decide to take an HIV test

Questions: I would like to hear about your social and family situation just before you took an HIV test.

What was going on in your life?

Did you decide suddenly or had you been thinking about it for awhile?

Did you talk to anyone about getting an HIV test?

Tell me about how other people decide to take an HIV test.

#### **Interview #2 Objectives**

This second interview focuses on the respondent's knowledge of HIV and of AIDS, the process of getting tested for HIV, and their recent experiences in talking to others about their HIV test results or their activities done to conceal their test results. We want to understand how respondents have considered telling others, the benefits and drawbacks, and then what they have actually done about it in the past two months or so. Also of interest is the identity of persons they do not want to know about their results. For each category of person (wanting to tell or told, somewhat ambiguous, not wanting them to know at all), what is of most importance is the social relationship between them and the respondent.

#### **Questioning Guide for Interview #2**

##### **I. Respondents Experience with HIV Testing (Most Recent Experience)**

- A. Experience with most recent HIV test
- B. Overall impression of services
- C. Counselling pre- and post-test
- D. Thoughts about all that now

Questions: Tell me about your experience in going for an HIV test.

You have any comments about the service?

How did the counselling go before giving blood?

How did the counselling go after you got your test results?

Do you have other things to say about going for a test?

##### **II. Discussion of HIV Test Results**

- A. Possible discussion of test results with someone else
- B. Their thoughts about showing the test results
- C. Response of person who learned results
- D. Benefits and drawbacks of showing test results to others

Questions: What thoughts have you had since your test about talking to someone else about the results?

Who were the people you thought about telling your results soon after the test?

Who were the people you did not want to hear about your HIV test results?

How and why were you thinking about telling them (or not)?

What is your relationship to them?

With whom did you discuss your test results?

Why did you decide to tell them about the test results?

How did they react when you told them?

How did you decide not to tell anyone about your test results?

Did you tell your sexual partner? How is that?

### **III. Changes in Their Life Now that They Have Learned They are HIV Positive**

A. Family situation

B. Friends and acquaintances

C. Work relationships

D. Health

E. Sexual activity

## **Conversation Guide for People Living With HIV/AIDS**

### **I. Demographic Information**

This section provides basic demographic data about the individual and should be an informal get-to-know-you introduction. Remember, the tone and context of the interview process matters as much as the “facts” that are discovered.

Please tell me a few things about yourself and your life

Age

Marital status

Family

Living situation

Education

Work experience, past and present

### **II. Getting Tested for HIV**

Circumstances of first HIV test

Subsequent HIV tests

Counseling received

Referrals given

### **III. Health Status**

Health situation before getting tested the first time

Health status now

Effect of health status on working and social life

Taking ARVs

Obtaining drugs; effect on health status

#### IV. Showing HIV Serostatus to Others

Here we want the respondent to talk about the showing of his or her HIV status to anyone at all, as it has occurred or changed over time. This temporal dimension is critical. It is important to ask directly about revelation to a sexual partner(s).

Time period right after being tested

First few months

After one year

Current situation

Drawbacks to disclosing serostatus to sexual partner, to family, to others

Benefits of disclosing serostatus to sexual partner, to family, to others.

#### V. Respondent's Participation in Activities of the PLWHA Association

Becoming a member

Common activities

Actions of association in the community