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SOCIAL DYNAMICS OF VCT AND DISCLOSURE IN UGANDA

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Social Dynamics of VCT and Disclosure in Uganda

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Cover photo: UPHOLD

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AIC	AIDS Information Centre
ART	Antiretroviral Therapy
ARV	Antiretrovirals
CDC	Centers for Disease Control and Prevention
CSO	Civil Society Organisations
HIV	Human Immunodeficiency Virus
JSI	John Snow Inc.
MOH	Ministry of Health
PMTCT	Prevention of Mother-to-Child Transmission
KHC	Kamuli Health Centre
TASO	The AIDS Support Organisation
UHSBS	Uganda HIV/AIDS Sero-Behavioural Survey
UNPCT	Uganda National Policy on Counselling and Testing
UPHOLD	Uganda Programme for Human and Holistic Development
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing

EXECUTIVE SUMMARY

This study, conducted in two districts in Uganda, sought to examine the process whereby individuals seek HIV testing, how they are counselled, and the patterns of disclosure of test results to family and friends. The research focused on the experience of respondents—all clients at VCT sites—to understand their concerns about testing, counselling and disclosure. The overall purpose of the study was to provide information useful to the Uganda Programme for Human and Holistic Development (UPHOLD) for designing interventions to make HIV/AIDS prevention programmes more effective. The study was conducted by UPHOLD with technical assistance from Macro International and was financed through a contract between John Snow Inc. (JSI) and Macro International.

HIV prevention programmes promote HIV testing and counselling so that individuals learn their sero-status and can change their behaviour to protect themselves against HIV infection. Disclosure to others is essential in order to garner support for reducing the risk of HIV infection and for accessing social and medical services. Although most programmes focus on individual behaviour and ways to change it, this study used a different strategy. By focusing on the social context of the experiences of VCT clients, the research shows how social interactions affected both the process of coming for an HIV test and the process of disclosing test results to others. With this approach it was possible to identify the kinds of counselling and social support most needed by VCT clients to share their test results with others and access social and medical services.

Methods

This study relied primarily on open-ended and unstructured interviews with individuals who had been tested for HIV. Interviewers used a topic guide that listed relevant topics arranged in a particular order. This approach provided interviewers with the flexibility to move from one topic to another as guided by respondents, but also allowed respondents to discuss issues relevant to them. The topic guides were developed during the training and were printed in two local languages: Lusoga and Runyankole. Respondents were interviewed in two VCT sites in Kamuli district (eastern Uganda) and two VCT sites in Mbarara district (western Uganda).

In order to learn about both the process of disclosure as well as getting tested, respondents were interviewed twice: first, just after they had been tested, when the interviewer and the respondents discussed their overall social situation and the process of coming for testing and their contact with a counsellor; and a second time at least one month later, when respondents discussed the process of disclosing test results to family and friends. Counsellors at the VCT sites referred clients to the interviewers after they completed their post-test counselling session. The data collection process also included informal observations at VCT facilities and discussions with counsellors about the study objectives and the flow of clients through the system.

The overall sample included 105 respondents: 54 from Kamuli district and 51 from Mbarara district; 48 men and 57 women. A total of 73 of the respondents tested positive, and the status of one respondent remained unknown. Only 44 of the respondents were married at the time

of the interview. Interviews were tape-recorded with permission of respondents, then transcribed in the local language and then translated into English. All the texts were typed in Microsoft Word.

Circumstances of Getting Tested

Conversations about HIV testing focused on the individual circumstances that prompted respondents to get an HIV test and their discussion with others about getting tested. The factors that most affected coming for a test were marital status, household composition, the memory of recent sexual experiences, and current health status. The sample included 24 married men, 20 married women, 31widowed, 10 divorced or separated, and 20 who had never been married. One-fourth of the married men told their spouse they were getting tested, although none of these men came with a spouse. One-half of the married women came without the knowledge of their husband, and five came accompanied by their husbands. The study did not seek to sample husband-and-wife couples, but one such couple was interviewed. Most of the widows told a close relative they were getting tested. The 13 young men who had never been married, but who had girlfriends, came without telling their girlfriends.

The circumstances that led most married men to come for a test were that they had been sick for some time and thought it might be HIV, or they were worried they had contracted HIV from past sexual relations. The circumstances of married or widowed women were similar in that many came because they had been sick for a long time, but others came because they had lost a husband to AIDS and thus thought they might be infected. A small number of men and women who were ill mentioned that they hoped to get drug treatment if they tested positive. The younger respondents who had never been married came not because they were ill, but out of concern that they may have contracted HIV through recent sexual activity. The young men with girlfriends came by themselves, but said they would later come again with their girlfriend. In general, those who were not sick came for testing without telling anyone else.

Counselling

Nearly all the respondents interviewed received both pre- and post-test counselling at the VCT sites. Once prospective clients were registered, the counsellors obtained consent and then discussed general information on HIV/AIDS and the procedure for drawing blood. When clients were numerous, pre-test counselling was administered in a group setting. In most cases counsellors had a very limited time to devote to each client, for they had so many patients to see. Thus the pre- and post-test counselling was usually brief. However, most respondents reported that they received good counselling after the test.

Respondents were asked what they thought of the counselling they had received, and about any advice they had been given. Most respondents praised the counsellors for their caring advice, advice that included a reassurance that they were not alone in being HIV positive, that they should seek medical care when they become ill, that they should avoid multiple sexual relationships, and that they should eat well. Very few mentioned that they were advised to use condoms, or that they were given a referral to a support organization. Very little was said about revealing test results to others, although some respondents reported that the counsellors said that “it is your secret.”

The advice given to individual clients made it clear whether they were HIV positive or HIV negative, for the messages given were standardized: one series for the positives, another for the negatives. The study did not find evidence that the counsellors tailored their advice to the individual social and health situations. Thus while some clients may have received advice they found useful, others did not.

The descriptions of the circumstances that brought respondents to get tested showed just how varied were the social situations of respondents. Clients who were obviously sick needed medical care, they may have needed ARVs, they needed someone to care for them, and they needed referrals to support groups. Married VCT clients needed counselling about how to avoid HIV infection, including methods of contraception and/or child spacing. Women with children, whether married, divorced, or widowed, were extremely worried about how they were going to continue providing for their children if they became sick, and what would happen to these children when they pass away. Judging from the experiences of these respondents, the VCT counsellors do not seek to tailor their advice to individual client. Counselling did not take account of the social status, socio-economic conditions and the responsibilities confronting clients in daily life. Furthermore, there is no systematic follow up by counsellors. Although the counselling was somehow comforting, this was tentative since most of the clients were left alone to handle their ”new identity.” Hence most clients, some of whom became more distressed after knowing their status, expressed a need for ongoing support and advice after the test.

Disclosure

Previous studies of disclosure have focused on disclosure to sexual partners or on the ways that disclosure occurred: direct or indirect, voluntary or involuntary, or not at all. The focus is generally on direct and voluntary disclosure of test results. The concerns of respondents in our study suggest a somewhat more complex picture in which clients think of three groups of people: a few to whom they can reveal their test results, a few to whom they want to avoid disclosing, and some whom they believe may know the results although there has been no discussion. People in the latter group learned the results indirectly or thought a person was HIV positive because of their visible illness or their use of social or medical services.

Learning they were HIV positive presented a real dilemma for most respondents: in addition to the immediate health concerns, people worried about being blamed for bad behaviour or being laughed at because HIV/AIDS is still stigmatized.. A total of ten respondents reported that they shared their results with no one, not even their closest friends and relatives. Two married men told no one at all, and two single men also told no one who knew them. Among women, two married women told no one, two divorcees told no one, and two widows had told no one at the time of our interview.

Despite the individual concerns about revealing their sero-status to others, most respondents did reveal their status to one or several persons, either family members or friends. Voluntary disclosure was always selective. A number of respondents explained that they revealed their test results to a person “because they can keep a secret.” Others said they disclosed to a relative because that person would take care of them if they became sick. Because of the short period of time between testing and the second interview, and the fact that individuals disclose to others over time, the data on disclosure show only direct disclosure that occurred rather quickly.

Married persons who test for HIV carry a particular burden for disclosure since it is assumed that they have regular sexual relations, and thus put their partners at risk for HIV infection . Both men and women experienced difficulties in discussing their HIV status with a spouse. Not surprisingly, those who tested positive had more difficulty disclosing than those testing negative, for two main reasons. First, there was the question of responsibility for bringing the disease into the family. In many cases the spouse who first disclosed that he or she was HIV positive would be blamed for bringing HIV into the home. Both men and women were aware of this problem. Second, married clients were concerned about how to handle the aftermath of disclosure, since they expected their partners would react negatively. Women feared being abandoned by their husbands, while men thought their wives would break down after the bad news. Many expressed uncertainty about how to handle their situation. Despite the sensitivity of the subject, the very sick clients inevitably needed care and support, and hence they had to disclose.

The married respondents interviewed about disclosure included 18 women and 22 men. Nine of the women and 14 of the men revealed their test results to their spouse. However, for both men and women, some who revealed nothing to their spouse did disclose to a friend or relative.

The response of married men who tested positive varied according to their health status. Those who were very sick had no choice but to disclose to their wives whose care and support they needed. On the other hand, HIV-positive men who were not severely sick did not tell their wives about the results. Some of the male respondents alleged that women have weak hearts and could not tolerate hearing news of a husband who tested positive. Many of the married women said they did not know if their husband had ever been tested. Those who told their husband had come with their husband or were quite ill themselves, while those who did not tell were in good health or their husband lived far away.

Conclusion

This study provides detailed information on the experiences of VCT clients in getting tested, in being counselled, and in revealing their test results. The findings show how social relations influence going for VCT and subsequently disclosing test results. These study findings raise questions about the assumptions that have guided the promotion of VCT and follow-up care and support and suggest a series of shifts in overall strategy, notably the following:

- The dominant image of VCT clients as individuals who need to change their behaviour to avoid HIV infection, and who will definitely benefit from just learning their sero-status and being counselled, should be reconsidered. This image should be replaced by one that sees VCT clients as people operating within a network of social relations that has affected their coming for a test and will affect their disclosure of test results. Such a shift in image implies that counsellors would spend more time to understand the circumstances that brought clients in for testing and would offer advice to fit the individual's situation.

- Little evidence was found of a preventive impact of VCT as currently practised. The accounts of respondents of their testing and counselling experiences made very little mention of condoms, of protecting one's sexual partner, or telling others of their results. For this group, the VCT experience did not seem to add information that could help them protect themselves or others from HIV infection. Married men and married women who were found HIV positive expected to continue having sex as before.

- The process of voluntary counselling and testing should not be considered as an end in itself. Rather, it should be considered as a first and essential phase toward changes in social and sexual activity to reduce the risk of HIV transmission. Many of the respondents in this study were afraid they would no longer have contact with persons who might advise them after leaving the testing facility, and they worried about where they would find help. The extension of concern for VCT clients to the period after they leave the facility requires careful and considerate referrals for future contacts with service organisations capable of advising individuals as they wrestle with illness and with their concerns about disclosure to others.

- Disclosure is not a simple matter of VCT clients telling one or two persons that they tested positive or negative for HIV. Rather, the persons told must also accept the news as true, and may need help dealing with the implications. A small number of respondents, both positive and negative, had trouble convincing others of their sero-status. This situation is true of those who are negative but still chronically ill, and of those who are positive and afraid to tell others. Hence, VCT clients may need further assistance to disclose their sero-status convincingly. Ideally, the promotion of disclosure may require further assistance to negotiate mutual acknowledgment between the persons tested and those around them.

Recommendations

- Expand the training of counsellors to include more consideration of the social situation of VCT clients, and the tailoring of advice to fit the needs of clients within their family unit. By considering the situation of clients—marital status, health status, living situation—counsellors will be able to provide more useful advice about how to avoid HIV infection and how to access social and medical services available.

- Develop a referral system so that all VCT clients can contact an institution for medical and/or social support. Above all, make clients understand that leaving the VCT facility is not their last chance to discuss their needs with someone with resources to assist them.

- Establish on-going links with community-based support services for those who have been tested. Since disclosure is a process that occurs over time involving negotiation of social relations in light of HIV test results, VCT clients need someone to advise them on how to discuss their situation with family and friends around them.

- Investigate the possible use of Civil Society Organisations (CSO) grants to provide some of the services recommended here. This should be done through systematic coordination between the CSOs and the VCT facilities. Providing grants to facilitate the process of disclosure and the negotiation of social relations with family and friends of VCT clients is a promising approach to assisting VCT clients.

CHAPTER 1
INTRODUCTION

1.1 Purpose and Framework of Study

This study examined how individuals in Uganda obtained an HIV test and counselling, how they considered the process of revealing their HIV test results to others, and the patterns of disclosure that emerged from different cases, (that is whether or not the individual disclosed his or her HIV status, to whom, in what manner, and after how long). The individuals in question were clients of voluntary counselling and testing (VCT) facilities who were contacted at those facilities and again later in their homes by field workers who discussed the experiences of clients with HIV testing and the sharing of test results. The overall purpose of the study was to better understand the factors that facilitate getting an HIV test and disclosing test results to others, so that HIV/AIDS prevention programs can better promote HIV testing and the disclosure of HIV test results, and provide social and medical support that fits the needs of individuals.

Most HIV prevention programs encourage individuals and couples to get tested for HIV for several reasons. First and foremost, many HIV/AIDS specialists argue that each person should learn their sero-status as well as that of their sexual partner(s) so they can take measures to protect themselves against HIV infection. Second, it is critical that those who have been infected with HIV learn that they are HIV positive so they can avoid infecting others and can get necessary social and medical support. Third, it is assumed that the counselling process before and after an HIV test can provide vital advice for avoiding HIV infection, whether a person tests negative or positive for HIV. And fourth, if large numbers of people get tested for HIV, this may reduce the stigma of getting tested and of having HIV.

The disclosure of HIV test results is considered critical to HIV prevention for many reasons. First, whatever the result, disclosure to others allows a person to garner social support for any preventive actions they may want to undertake. Individuals who learn they are HIV negative may change their behaviour in order to protect themselves against HIV infection. Second, especially for those who test HIV positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Thus the counselling sessions at VCT sites emphasize the importance of discussing test results with a spouse or regular partner, and suggest that people come for testing and counselling as couples. And finally, without disclosure, a person cannot easily access social or medical services that may be available. While disclosure of test results does not guarantee access to social or medical services, since they may or may not be available, without disclosure, the door to services may remain closed. An intervention that can increase disclosure is likely to increase the use of services. Thus this study focused on the social context of the clients and their experience discussing HIV test results with others.

This study assumed that the nature of social relations of respondents—evaluated through an examination of household composition and friendship network, daily activities and a discussion of their social ties and obligations—affects their willingness to discuss going for an HIV test and revealing the results. Since discussion about getting an HIV test or about the test result is a social event, we expect that the nature of the social ties of individuals will affect their ability to discuss test results with others. The methodological challenge in evaluating this assumption lies in the way evidence about social relations is collected and the way this evidence is assessed. Thus the study examined the social context of respondents interviewed and looked for the kinds of social relations that increased the probability of taking an HIV test as well as the probability of disclosing the test results.

The findings presented in this report focus on the three aspects of the research already mentioned: the process of getting an HIV test; the social context of sharing HIV test results; and the need for and form of social support for VCT clients after testing and counselling. Although the research took place in a Ugandan context and the recommendations of the conclusion are aimed specifically at the UPHOLD project activities and programs, the methodology used and the findings can be applied more generally to HIV/AIDS prevention programs.

1.2 Institutional Framework of Study

This study was conducted by the UPHOLD (Uganda Programme for Human and Holistic Development) project with technical assistance for all aspects from Macro International. Funding for technical assistance came from UPHOLD, a 5-year bilateral programme funded by the United States Agency for International Development (USAID) under Strategic Objective 8 (SO8).

The UPHOLD project works in three integrated social sectors: Education, Health, and HIV/AIDS. In education, UPHOLD provides assistance largely in primary education. In health, the focus is on child and adolescent health, along with reproductive health. The HIV/AIDS programme aims to strengthen VCT and PMTCT services, working for the prevention of sexually transmitted infections and providing support at the family and community level for those infected with HIV. The UPHOLD project has a mandate to increase the use of social and medical services in the 34 districts in which it operates by improving the quality of services and increasing the availability of and access to services. With regard to HIV/AIDS, the project provides assistance in Uganda in three ways: by giving grants to districts, by giving grants to civil society organizations (CSOs), and by providing technical assistance and IEC materials at the central level. The grants to districts and to CSOs are given in response to requests for assistance in organizing and providing social services in one part of a district.

Through UPHOLD, USAID contributes to current efforts to expand service delivery and to promote positive practices for HIV prevention. Since its inception, UPHOLD has provided financial and technical assistance to the AIDS Information Centre (AIC), the leading VCT service provider in Uganda. In order to better inform and refine communications, (both the types of media and materials used, as well as the content of communications for districts, CSOs and central activities) UPHOLD needs information on the process of getting an HIV test and on the process of sharing test results with others. The findings will enable UPHOLD to promote realistic, feasible practices through a deeper understanding of what clients need and what specific practices people can implement.

1.3 The UPHOLD Approach

UPHOLD seeks to increase the use of services through a social transformation approach that addresses the underlying issues of communication and gender-based violence. Although HIV research is abundant in Uganda, research that provides concrete, practical solutions that are based on local contexts and that have been tested in everyday life is urgently needed. In particular, the issue of disclosure of HIV test results deserves attention so that information can guide the expansion of services, preventive practices and care for people living with HIV/AIDS.

The Ministry of Health (MOH) and donor specialists find social and medical service use to be low in Uganda, and UPHOLD considers that this relatively low use stems from both a lack of service-distribution points in some parts of the country and the enduring stigma surrounding anything related to HIV and AIDS. Many individuals simply do not want anyone to know they have been tested for HIV. Stigma may discourage the sharing of test results with others, but it also keeps some women from using PMTCT services or other care and support services.

In recognition of the mandate to increase the use of services, this study examined the social context and experiences of individuals who voluntarily took an HIV test and who may have told others of their test results. The study sought to determine whether or not VCT clients discussed getting an HIV test with anyone else, and to whom, if anyone, clients revealed their test results in the weeks following an HIV test. The study findings are to be used in planning further support by UPHOLD for HIV prevention and social support for those with HIV in many districts of Uganda.

CHAPTER 2
BACKGROUND

2.1 Prevalence of HIV in Uganda

Specialists in HIV/AIDS around the world agree on the critical importance of obtaining accurate estimates for HIV prevalence at national and sub-national levels. An assessment of HIV prevalence is needed for estimating the demand for medical services as well as anticipating changes in morbidity and mortality. Until the past few years, HIV prevalence rates in Asian and African countries have most often been based on data from sentinel surveillance sites that collect blood from women seeking antenatal care. That has been the case for Uganda until recently. In late 2004, the Ministry of Health (MOH) in Uganda, supported by the US government, conducted a national survey with a questionnaire that included questions on demographic issues, sexual practices and HIV/AIDS. In this survey, known as the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS), more than 21,000 adults 15-59 years of age in 417 clusters around the country were interviewed. The MOH, with technical assistance from the Centers for Disease Control and Prevention (CDC) and Macro International, collected blood samples to test for HIV, syphilis, herpes simplex and hepatitis B (Ministry of Health and ORC Macro 2006).

The national UHSBS provided population-based estimates of HIV prevalence for the first time in Uganda. The survey found an overall HIV prevalence of 6.4% among adults 15-49 years of age, with differences by sex and by urban-rural residence. Prevalence was 5.0% among males and 7.5% among females overall. HIV prevalence was 6.5% for rural women and 12.8% for urban women, while the corresponding figures for men were 4.7% and 6.7% respectively. Although slightly higher, these estimates are similar to the routine information found in sentinel surveillance sites over the past two years. However, these figures show a marked decrease in national prevalence from a high figure of about 15% in 1990.

Since 2002 Macro has provided technical assistance to countries for demographic and health surveys that have included HIV testing. In each country where such population-based HIV test results are available, the HIV prevalence found was lower than the estimates obtained from sentinel surveillance site data. Most experts agree that population-based data provide a more accurate reading of HIV infection rates than other methods (Boerma et al. 2003; Fabiani et al. 2003). Procedures for conducting surveys that include HIV testing have now been standardized within Macro.

2.2 Interest in VCT

As discussed earlier, specialists in HIV/AIDS research recommend that VCT services be dramatically expanded so that more individuals learn their HIV status and gain access to social and medical services as needed. A number of scholars are convinced that VCT is an effective intervention for preventing HIV transmission (Coates et al 1998; Horizons 2001). The Voluntary HIV-1 Counseling and Testing Efficacy Study Group directed a study of the efficacy of VCT in reducing unprotected sexual intercourse a few years ago in Nairobi, Dar es Salaam, and urban Trinidad, with mixed results (Coates et al. 2000). Data from VCT centers in the United States show that VCT can lead to changes in behaviour. On the other hand, the extensive study in Rakai, Uganda that followed a cohort of more than 11,000 men and women over an extensive period did not find evidence that counselling led to a reduction of risk for HIV infection (Nyblade 1998).

There is also on-going debate among HIV/AIDS specialists about the level of demand for VCT in African countries and the type of services clients prefer. The evidence from Sub-Saharan African on the effectiveness of VCT in reducing risky actions overall remains unclear. A few years ago the Horizons project conducted research in Kenyan and Ugandan HIV testing facilities on the experience of young people being tested. In both countries they found a wide range of configurations of testing and counselling offered (Horizons 2001). Researchers found that youth wanted to be tested without anyone else knowing about it and were concerned that the test results remain confidential.

Efforts to prevent the transmission of HIV in most countries have long been hampered by a lack of good data about HIV prevalence as well as by poor access to HIV testing facilities, public reluctance to get tested for HIV, and the limited availability of antiretroviral therapy (ART) for those with HIV. The government of Uganda, assisted by numerous donors, has been creating voluntary counselling and testing centers (VCT) around the country over the past 15 years, and has promoted HIV testing as a means of HIV prevention and access to care.

The subject of HIV/AIDS has been highly stigmatized in all countries where HIV infection has been found and AIDS has appeared, and this stigma may keep people from getting tested. For example, in a study on the process of providing HIV test results at home, respondents often said that they preferred being tested and receiving results at home because they did not want others to see them going for an HIV test (Yoder et al. 2006). In some social contexts, this stigma applies to mere discussion of the subject; in others the subject can be discussed openly, but getting an HIV test is something that is hidden from others. In still other contexts, individuals are willing or able to discuss their HIV test results with a close family member or a friend.

2.3 Access to VCT Services

With regard to counselling and testing for HIV overall, service usage in Uganda remains low. The UHSBS of 2004 found that 15% of women reported that they had had an HIV test at least once, while the percentage of men was 12%. The survey indicated that 43% of the women who had taken an HIV test did so as part of antenatal services. During the 1990s, most individuals who obtained an HIV test and the related counselling in Uganda visited one of the testing facilities set up by the AIDS Information Centre (AIC). By 2002 AIC was operating some 70 sites, but most of them were outreach posts in some 34 districts. By the mid-1990s, AIC had established regional centers in five cities and added three more in 2004. The AIC branches and outreach posts use rapid test kits and charge a fee for their service, while counselling and testing for HIV at district hospitals is free. Nearly 75% of funding for AIC activities comes from USAID contributions channeled through UPHOLD.

Currently, AIC provides services in 163 sites around the country. In an evaluation report covering the first eight years of AIC activities, the authors mention several key lessons learned from their experience to date (Alwano-Edyegu and Marum 1999). One lesson is that VCT should be offered as part of a comprehensive HIV prevention programme, not as a single service operation. Therefore, in contexts where no supportive services exist, it may not be appropriate to offer VCT. A second lesson is that anonymity is very important to clients of VCT services. In this case, anonymity means not only that no name is attached to test results, but also, that a person can use VCT services without being recognized. This lesson echoes the concerns expressed by young people in Kenya and Uganda in the Family Health International studies (Horizons 2001).

The AIC summary report of 2004 activities noted that a total of 219,520 clients were seen during the year: 26% in the eight regional offices (Kampala, Jinja, Mbarara, Mbale, Arua, Soroti, Kabale, Lira); 67% in district health facilities supported by AIC; the rest (7%) in outreach posts and home visits. Among these clients, 18% tested positive for HIV—21% of females and 14% of males. The AIC clients, being self-selected, showed a much higher sero-prevalence than the estimated national average. By the end of 2005, AIC centers operated in at least 48 out of 56 districts in Uganda.

The other major non-government organization that supplements VCT is The AIDS Support Organization or TASO. For many years TASO has provided care and support services for those who tested positive for HIV. TASO now offers VCT services in dozens of sites around the country and provides support services, but only to family members of TASO clients. In its early years, the AIC offered mostly HIV testing with little or no social support, while TASO offered mostly social support to those with HIV. By 2005 both organizations offered HIV testing and social support. Also, scattered throughout the country are private medical facilities that offer HIV testing, counselling, and even antiretroviral therapy.

Finally, many private and government services now offer VCT throughout Uganda, so the options for getting tested are no longer dominated by the facilities of the AIC and TASO. The MOH monitors most of these services with the aim of providing similar HIV/AIDS-related services to most of the Ugandan population. Currently more than 420 facilities throughout the country provide VCT (UNGASS-Uganda Country Report 2005).

The recent availability of antiretroviral therapy (ART) in Uganda may well increase the use of VCT services, since some people who fear they are HIV positive may get tested hoping they will gain access to ART. Dozens of health care facilities now provide ART to qualifying patients. Some are public, some private; some are free, others require fees. In June 2004, the MOH initiated the provision of free ART in some facilities, and had succeeded in getting up to 50,000 individuals on ART by mid 2006.

The availability of VCT and ART services affects the findings of this study since easy access to VCT would encourage individuals to come for HIV testing, and the promise of free ART should facilitate disclosure of HIV test results as part of the process of beginning ART.

2.4 Disclosure of HIV Test Results

2.4.1 Importance of Disclosure

Increasing public use of voluntary counselling and testing services has been a key objective in the prevention of HIV transmission in many countries. It is believed that knowledge of one's own HIV sero-status, combined with effective counselling, can facilitate individual behaviour changes that reduce risk of HIV infection and protect sexual partners as well. In countries in east and southern Africa, hundreds of health care facilities—as well as many stand-alone facilities—offer voluntary counselling and testing services with rapid HIV testing.

The disclosure of HIV test results is critical to HIV prevention as well as for maintaining good health and continuing social relations. In terms of HIV prevention, 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. Individuals who keep HIV testing and test results to themselves are on their own for whatever they decide to do in order to protect themselves against HIV infection. For those who test positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Without such disclosure, VCT cannot play much of a role in preventing HIV transmission.

Additionally, without disclosure, a person cannot access some of the social or medical services that may be available for maintaining health and continuing social relations. While disclosure of test results does not guarantee access to social or medical services, since they may or may not be available, without disclosure, access to services is more difficult. Counselling services have traditionally focused on disclosure to sexual partners in order to reduce HIV transmission. Much less attention has been paid to assisting individuals in disclosing to others in order to continue their lives normally.

2.4.2 Measuring Disclosure

The process of disclosure has been found to be quite complex to describe, to measure, and to 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 sero-status.

A recent audit of 46 peer-reviewed studies on HIV disclosure revealed that 30 had focused on the US and Europe, often on 'high-risk groups,' and 10 were devoted to populations in Africa (Varga et al. 2005). 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 (cf. Kilewo et al. 2001).

A recent study by Linda Niccolai and colleagues has suggested a strategy to measure disclosure to one's sexual partners that can be used with a survey questionnaire (Niccolai et al.

2006). Survey respondents are asked if they have 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, while others did not disclose at all. The authors propose this method for large samples in order to measure variables associated with these three types of disclosure.

Disclosure studies have found that pregnant women tested in a PMTCT center are much less likely to disclose their sero-status to the sexual partners than are women who use a VCT facility. Discussing evidence from their study in Dar es Salaam, Suzanne Maman and colleagues explain that women who use VCT facilities have likely thought about getting tested for quite some time, have often discussed going for a test with their partner, and have perceived themselves as at high risk for HIV infection (Maman et al 2003). On the other hand, pregnant women who are offered an HIV test in PMTCT centers 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 quite different matter for these pregnant women than for women who voluntarily went for an HIV test.

Varga and colleagues report on several patterns of disclosure to a sexual partner in their summary of disclosure studies among African women (Varga et al 2005). Some reports have found that sexual partners are the most likely target for revealing sero-status. Rates of disclosure to sexual partners vary from 20% to about 80%, which may indicate wide variation in the samples and methods of measurement. For reasons easy to understand, disclosure rates appear higher among HIV-negative than HIV-positive individuals.

Although researchers most often focus on voluntary disclosure and on seeking ways to persuade individuals to discuss their sero-status with others, involuntary disclosure also often occurs. Women who have just given birth may reveal their HIV status by how they breast-feed 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 reveal a person's HIV status.

2.4.3 Situating Disclosure

Disclosure is a social process that occurs in time with certain people and not others. As Cusick and Rhodes have pointed out, "Disclosure is therefore best envisioned as a social process which is 'situated' within particular social relationships and contexts" (Cusick and Rhodes 1999). After learning HIV test results, individuals may consider to whom they want to reveal their status as well as people they do not want to know the results. The process of disclosure 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.

Since the process of disclosing one's sero-status—directly or indirectly—occurs over time, discussions of disclosure must include the time that has elapsed since testing. The time elapsed is important, particularly for those who test positive, because they should 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 illness or use of social or medical services. Antelman et al. conducted a study of disclosure among pregnant women in Dar es Salaam from 1995 to 2000 to discover when and to whom HIV sero-status was revealed over time. They found a clear and regular increase in the numbers of women who revealed to their sexual partner and to a female relative over a period of four years (Antelman et al. 2001).

The dominant image of disclosure used in this study considers respondents within their own social relations and expects the revelation of a person's sero-status to affect those relations. That is, the respondents' social situation must be described—family relations, marital status, close friendships—in order to understand which social relations are involved in revealing or concealing one's sero-status. This approach provides a social context for examining the process of disclosure: how individuals reveal their HIV status to some persons and not to others, how they take action to conceal their HIV status from some, and how they share their status with others for support and recognition.

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 as well as the perceived health of a person also has an impact on how the news is received. Since in Uganda chronic illness or the loss of a spouse to an illness that appears AIDS-related so often suggests HIV infection, the individuals who are affected may be commonly considered sero-positive no matter what they say (Yoder et al. 2006). 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.

Longitudinal studies are the most effective method for examining disclosure, provided they allow respondents to relate 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, 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 their revelation of their HIV status to those around them.

CHAPTER 3
OBJECTIVES AND RESEARCH QUESTIONS

3.1 Study Objectives

The specific objectives of the study were to:

- Understand the process of testing for HIV and being counselled
- Understand the concerns of clients about disclosure of their sero-status
- Identify the patterns of disclosure within a social context
- Make recommendations for interventions that fit with client concerns.

3.2 Focus of Study

This study examined how individuals obtained an HIV test and were counseled, how they considered the process of revealing their own HIV test results to others, and the pattern of disclosure (whether or not, to whom, how, after how long) evident among individuals who had recently been tested. Recognizing that these actions were part of a process of social interaction in which individuals participated, the research sought to understand how the social context of these actions facilitated or discouraged obtaining an HIV test and disclosing test results to others. The study sought to discover how individuals discussed getting an HIV test with others—family, friends, neighbors—and then shared their test results or kept them to themselves. It was assumed that the pattern of communication with others on these two issues would suggest ways that social support after testing could be implemented.

The research assumes that the nature of social relations affects the willingness to discuss going for an HIV test and revealing the results. Since the discussion of getting an HIV test and disclosing test results themselves are social events, the nature of the social ties of individuals will affect their ability to discuss test results with others. The methodological challenge in evaluating this assumption lies in the way evidence about social relations is collected and the ways evidence is assessed.

In emphasizing social interaction rather than "individual behaviour," the study sought to situate each respondent at the centre of a network of social relations through which he or she establishes and maintains an identity and accomplishes certain tasks. The importance given to accomplishing tasks is drawn in part from the analyses of social interaction by David Silverman, a renowned specialist in qualitative research (Silverman 1993). We expect that this focus on the social process of getting things done will suggest appropriate ways to intervene with the kind of support that responds to individual needs. By contrast, an emphasis on individual behaviour would stress the importance of personal characteristics in explaining the process of getting tested and disclosing results and would provide fewer insights into the need for social support.

A second assumption underlying the study objectives is that a sufficient number of individuals could be found who had, in fact, discussed their HIV test results with others in order for patterns to emerge and a relationship to be found between social relations and disclosure.

3.3 Research Questions

The main research questions guiding this study were the following:

- What kinds of social relations facilitate a discussion with someone else about getting an HIV test and revealing the result to others?
- What kinds of social and/or medical support do VCT clients need after getting tested?

Whether or not a person talks to someone else about getting an HIV test before going for the test is a significant part of the process of revealing individual concerns about HIV status, so that aspect was included in our study. With regard to disclosure, the study sought to establish not only whether or not the HIV test result was revealed to someone, but also to whom, how it was done, how long after the test, and the response of the person(s) to the news of the test results. We wanted to understand how individuals thought about disclosing to their spouse if they were married, or to family members or other people. Some individuals may disclose only to a specialist such as a doctor or a pastor or other advisor whom they can trust not to talk to anyone about what was revealed. For those who did not reveal their test results, it is most important to understand the consequences of disclosure that individuals feared and the concerns that have kept them silent.

One of the most important aspects of disclosure is the consequences that a person may anticipate in revealing their HIV test results to another person. For married persons, disclosure to a spouse is, of course, the most critical since knowledge of the sero-status of one's partner is the first step in the prevention of HIV transmission. One reason to disclose test results may be to gain support in avoiding HIV infection in general. Another reason may be to avoid passing the virus to a sexual partner. Still another reason some clients disclose their test result might be to enlist a person's assistance in caring for them when they become ill.

There are also consequences to consider if a person does not disclose to anyone. In such cases, the study sought to understand the fears that kept them silent about their test results. Therefore, the way individuals talked about whether to disclose or not was critical to our comprehension of the consequences of disclosure.

A number of specific research questions were formulated during the design phase and adjusted during field worker training to guide the conversations held with VCT clients. Among the most important questions were the following:

- What is the form of the social relations that individuals maintain?
- Which family members and friends do persons interact with most often?
- How do individuals come to use VCT services?
- With whom (if anyone) do they discuss the plan to take an HIV test?
- What happens in their pre- and post-test counselling sessions?
- How do people decide to reveal their HIV test results to others?
- What discussions of their results have persons had since getting tested?
- What are VCT clients' notions of the consequences of disclosure?

- What is the response of others who learn a person's test results?
- What issues keep a person from revealing HIV test results?

These research questions and associated assumptions were examined and revised during the training for field workers. Since the individual assumptions of field workers collecting data through guided conversations affect how they actually guide the conversations, the training sought to give field workers in-depth understanding of the research strategy and of our expectations from respondents. The research team that developed the study proposal made several assumptions that guided the selection of research questions, the sampling, and the structure of data collection. Several of these assumptions are presented below.

3.4 Study Assumptions

- Many individuals come for an HIV test out of a sense of fear or guilt that stems from their own actions, from an idea that they have put themselves at risk of HIV infection.
- Many other individuals come for an HIV test because they suffer from symptoms of illness that suggest HIV infection.
- Individuals who are HIV negative are more likely to discuss their test results with others than those who are found to be HIV positive.
- Married people are more likely to disclose test results than unmarried persons.
- Women are more likely to disclose HIV test results than men.

These assumptions were made because of the evidence found in the general literature on HIV/AIDS and knowledge of HIV/AIDS in Ugandan society. We also formulated an hypothesis that affected the study design, a proposition we were less sure of than our assumptions. We hypothesized that those who had discussed obtaining an HIV test would also disclose their test results, most often to those same individuals.

CHAPTER 4
METHODS AND DATA

4.1 Data Collection Overview

This study relied primarily on open-ended and loosely structured interviews with individuals who had been tested for HIV in order to listen to their descriptions of their social activities and their stories of how they had gotten tested for HIV, and what they did about revealing their HIV test results to their families and friends. Following a topic guide in the form of an outline, interviewers had the flexibility to encourage respondents to discuss issues in any order they wished and to follow up questions as needed. In order to learn about both the process of getting tested and individual actions around disclosure, it was necessary to interview most individuals twice: once just after they had been tested, when respondents discussed the process of coming for testing and their contact with a counsellor, and a second time at least one month later, when the process of disclosure of test results to family and friends was discussed. In a few cases respondents were found who had come to test for HIV for a second or even a third time. Those individuals were interviewed only once, since it was not possible to discuss both their most recent testing experience and their approach to the disclosure of test results from an earlier test.

The data collection process also included informal observations at VCT facilities and discussions with counsellors about study objectives and the flow of clients through the system. Study interviewers worked with counsellors to set up a system that could identify VCT clients who might consent to an interview.

4.2 Institutional Collaboration

The research team decided it would be most appropriate to work with VCT facilities established by the AIDS Information Centre (AIC), since the AIC pioneered VCT services in Uganda and the UPHOLD project has provided assistance to the AIC since UPHOLD began its operations. The AIC team of counsellors in Kampala was briefed on the study before it began, and an AIC representative attended the field worker training. The UPHOLD regional coordinators from the two study districts also attended the training and worked closely with AIC counsellors at the testing sites in the field. An AIC representative also participated in some aspects of the data analysis.

4.3 Sampling

The research team had several concerns in choosing the sample. First, how many different sites and languages could be included in this small study? Second, how many cases would be needed, at a minimum, and how many cases could reasonably be processed in the time allocated? Third, how would the individuals actually be chosen and according to what criteria?

Because of time restraints, the study was conducted in only two linguistic areas. The team decided to work in one site in an eastern district and one in a western district. The data collection was conducted in Kamuli district where the main language is Lusoga and in Mbarara district where the main language is Runyankole.

Although researchers always welcome more cases, in considering the demands of data processing as well as the need for more variation, a target number of 100 respondents was initially proposed, with about equal numbers of men and women. It was thought that 100 cases would provide a sufficient range of experience to identify patterns among the cases. Since much of the analysis focuses on individual experience, the target number was likely to provide a productive range of experience with HIV testing and disclosure.

The identification of specific respondents to participate in interviews presented a real challenge since individuals had to be identified and then asked if they would be willing to talk to the field workers. At the testing sites the research team enlisted the assistance of counsellors who introduced VCT clients to the field workers. Counsellors were told that interviewers wanted about equal numbers of men and women, and that the majority of respondents should be HIV positive. The counsellors, who knew the types of clients we were seeking and had just spoken with the clients, passed them on to the field workers. It is not possible to determine to what extent the clients interviewed were truly representative of the client pool at the facilities where fieldwork was conducted. However, the variation in the family and social situations of respondents suggest that a wide range of experience was captured with this approach.

The actual sample retained for analysis included 105 individuals: 54 from Kamuli district and 51 from Mbarara district. The sample, classified by sex and by district, can be seen in the table below.

Table 1 Respondents by sex and by district

District	Women	Men
Kamuli	30	24
Mbarara	27	24
Total	57	48

Forty-four respondents were married at the time of the study, 20 had never married, and the remaining 41 were widowed, divorced or separated.

4.4 Training and Instrument Development

Research that relies on open-ended and unstructured conversations around specific themes requires field workers who understand both the study objectives and the specific research questions of interest. Field workers must also have the communication and inter-personal skills to be able to get individuals to talk easily about their own experiences. It is also necessary to discover the knowledge and general perspective of the trainees on the topics of interest, in this case HIV/AIDS, HIV testing, disclosing one’s own HIV test results, and clients' own history of getting tested for HIV.

The training operation was directed by P. Stanley Yoder of Macro assisted by Xavier Nsabagasani of UPHOLD. The training focused on principles and usefulness of qualitative research, the approach and research questions of this study, the knowledge and experience of interviewers regarding HIV and AIDS, interviewing techniques, and the development of topic guides to follow in conversations with respondents. The principles of research emphasized included: the importance of examining social interaction; the discovery of local terms and concepts; and techniques to assist respondents in describing which elements were most relevant to them. Field workers discussed the ways that specific research questions were related to the overall study objectives. Interviewing techniques included introductions, establishing a personal connection, maintaining a totally non-judgmental approach at all times, using periodic repetition of what was just said as a prelude to another question, and listening carefully at all times.

Topic guides were developed during the training through intensive discussion of the overall objectives of the study and the specific research questions. Rather than a list of specific questions to ask, a two-page outline was designed that covered all the issues of interest to the study. Topics were arranged in a particular order: general items, personal items, family items, and then more specific subjects related to the respondents' experience with HIV. Some subjects were included because they acted as a possible bridge to other topics. For this approach to function effectively, the interviewers needed to follow the lead of the respondents, who might shift the order of discussion topics or introduce relevant elements not included in the topic guide. If the respondents did not change the discussion order, this would be taken as an indication that they were not at ease with the conversation and were waiting passively for prompting.

Two teams of three persons each were formed during the training: one team whose members spoke Lusoga for Kamuli district, and the other whose members spoke Runyankole for Mbarara district. The research questions and likely subjects for topic guides were discussed in general in English, and then each of the two teams worked on their own topic outline with comments in the local language. It is critical to be able to work in local languages in the process of instrument development so that the concepts used in the topics are locally relevant and easily grasped in the local language. Once the topic guides were written in the two languages, the teams engaged in simulated interviews to get some sense of what might happen in the field. Corrections to the topic guides were made as fieldwork advanced with the simulations. Further small revisions were made after the pre-test in Kampala. The English version of the topic guides used in the field can be found in Appendix A.

4.5 Fieldwork

The data collection in Kamuli and Mbarara districts was directed by Xavier Nsabagasani of UPHOLD. The field work was divided into two phases: a shorter pilot phase and a longer main phase because it was important to give respondents an opportunity to indicate what elements were relevant to them. During the pilot phase the teams were asked to conduct about 50 interviews with VCT clients at each site.

The main contacts with respondents in both districts occurred in facilities that offer VCT services right after clients had been counselled and had learned their HIV test results. In Kamuli district the pilot phase included interviews with clients at two stationary facilities (Kamuli Health

Centre, or Mulago, and Kamuli Mission Hospital, or Rubaga) and several mobile teams or VCT outposts. The main phase of data collection was limited to the stationary facilities where all those receiving an HIV test came specifically to get tested. Some respondents seen in the pilot phase were visited in their homes during the main phase so they could discuss the process of disclosure since having been tested.

The fieldwork process was similar in Mbarara district where the team operated at the AIC branch in Mbarara, located in a residential area known as Lugazi. In all the sites the counselors were very helpful in introducing clients to the interviewing team.

In both districts the study looked for VCT clients who had chosen to get an HIV test (rather than ones who were simply asked to come as part of a mobile VCT activity) and for individuals willing to talk to the field workers a month or more later for a second interview. During the pilot phase a small number of individuals were interviewed who had just been tested by a mobile unit that went from village to village asking people to get tested. Since they were simply responding to a request from a mobile team, such individuals had less to say about their decision to get tested. Almost universally, respondents welcomed the visit by a field worker to their homes a few weeks after the first visit; many of them talked about being too isolated socially.

Most respondents readily agreed to be tape-recorded. For those few who refused, the interviewers took careful notes of the conversation and reported back to the group. The interviews lasted from 30-60 minutes each, depending on the respondent's desire to talk. Xavier Nsabagasani monitored the progress of both study teams through periodic visits and regular phone calls to follow the evolution of the fieldwork. P. Stanley Yoder followed the progress of data collection throughout the fieldwork via e-mail as well as conversations with Nsabagasani in person and by telephone.

4.6 Data Processing

With few exceptions, the interviews were all tape-recorded in a setting where the respondent and the field worker met in a private space. The research assistants all transcribed their own interviews in Lusoga or Runyankole into a hand-written text. The research assistants were taught to transcribe everything that was said, both questions and answers, and to write down word for word what they heard without summarizing anything. These texts were then translated into English and typed in Word for easy access. This process of first transcribing text, then translating the texts into English, and finally typing the tests into a computer in English was quite time-consuming, but it was the only reliable way of making the comments and conversation of respondents available to others for analysis. About four months was devoted to this process. The typed interviews—each 10-15 pages of text—were printed out and bound for easy reading in the UPHOLD office.

4.7 Data Analysis

The analytic process for qualitative studies of texts and narratives is a cumulative process. The procedure used by the research team relied on the following activities:

1) Consideration of each case as a unit, looking first for the connections that respondents themselves made between various elements discussed, followed by the research team looking for connections they could establish between elements. Such connections often take the form of an explanation of an action or a specific reason given for an event. In this part of the analysis the social relations described by each individual were examined to check for possible associations with a particular type of social relation and the ability to disclose test results. Part of this exercise was the construction of narratives about getting tested and discussing results with others.

2) Classification of cases into categories by standard demographic variables such as sex, marital status, and age. Other criteria more linked to the local context were also used: having been counselled or not, HIV status, health status, whether they discussed going for a test with someone or not, and whether they disclosed their test results to anyone. In this exercise we looked for patterns in the actions taken by individuals. It was found, for instance, that a higher proportion of women than men discussed their test results with another person.

3) Study of the language used to describe relationships, events, conversations with a counsellor, and their own reflections on disclosure. The narratives were examined for content and specific themes. This exercise provided the locally relevant concepts that were necessary for understanding the perspective of individuals on their own experience. Many cases were found of individuals who spoke of feeling isolated and unsure where to turn for assistance.

4) Preparation of "profiles" of each respondent's experience with respect to family situation, social contacts, HIV testing, sero-status, and disclosure of test results. These profiles were one-page summaries of key points from the information collected from each respondent, and were typed out to facilitate obtaining an overview of each respondent's individual situation.

CHAPTER 5
SOCIAL AND ECONOMIC SITUATION OF RESPONDENTS

5.1 Socioeconomic Characteristics

The VCT clients who came for HIV testing and were interviewed by field workers were self-selected, and they shared certain characteristics. Most were peasant farmers and small-scale traders, and thus had limited financial resources. Except for those who were terminally ill, these were busy people who worked long hours to support themselves and their families. They were engaged in mainly manual activities such as farming, small-scale trade, bicycle repairing, building and transportation (boda-boda or motor scooter taxi drivers). Most of these activities require physical strength and hence good health. A few of the respondents were civil servants or students.

5.2 Marital Status

Table 2 shows the distribution of respondents by sex and by marital status. As noted earlier, candidates for the interviews were identified by counsellors who were asked to select about equal numbers of men and women and more HIV positive than HIV negative respondents. Thus the interviewees were those whom the counsellors recommended to us during the initial data collection period. Only a few individuals refused the request for an interview.

Table 2 Respondents by sex and marital status

	Marital status				
Sex	Single	Married	Widowed	Separated or divorced	Total
Male	13	24	5	2	44
Female	7	20	26	8	61
Total	20	44	31	10	105

The table displays systematic differences by gender among those who came for testing, particularly in the numbers who had lost their spouse and who were single. The large number of widows—43% of the women—suggests that women are coming for an HIV test after their partners died of conditions they thought might have been AIDS. When the numbers of divorced and separated women are added to the number of widows (26), we find that 56% of the women interviewed had been married earlier but were no longer. That figure contrasts sharply with the percentage of men who had been married but were no longer married (7 of 44, or 16%).

Some of the widows remained living at their husbands' homes taking care of their children, utilizing the resources their husbands left behind. Those whose husbands died without leaving much property relied on their relatives for support and care. Some widows still had the strength to look after themselves or had children old enough to look after them. Their challenge was learning how they could maintain good health and keep caring for their children. Others were simply too sick to do anything but rest.

Some widows who had divorced before their husbands died took refuge at their parents' home or that of close relatives such as their aunts. These were mainly younger women who needed support for their children as well as for maintaining their own health. Because they were often bedridden, these widows were completely dependent on outside support for food, shelter and medication.

There were also a few men who were widowers and had been almost certain that they were HIV positive before testing. Some of these men lived with their children in their home.

5.3 Sero-status of Respondents

The field workers never asked respondents for their test results since these were to be kept confidential. However, in the course of the conversation, it nearly always became obvious whether the client had tested positive or negative because of the way the counselling experience was described or because the individuals simply said they were positive or negative. It was common for sero-positive respondents to report: "They found me sick;" "I have the disease;" or "They found I had died long ago." On the other hand, those who were HIV negative often made remarks such as "They found me alive;" "They found my blood clean;" or "They found me free."

The prevalence of HIV was high among the 105 respondents, with 73 testing positive and 31 negative. The sero-status status of one individual remained unknown. Our discussion of coming for a test and disclosing results focuses more on the 70% of the respondents who were found HIV positive than on those who tested HIV negative.

5.4 Social Contexts and Situations

The conversations with respondents always began with a discussion of their family and marital situation, their work, the family members and friends they saw most often and confided in, and the associations they participated in. Most respondents have a wide network of social and economic relations with whom they share concerns, including health problems. Many of the interactions were linked to social support groups such as *"Nigina"*[1] in the case of Kamuli and *"Bika oyeguze"*[2] in the case of Mbarara. Others included self-support financial groups, post- test clubs and religious groups. Many of the respondents belonged to and participated actively in these associations. These associations were instrumental in helping the clients deal with their day-to-day needs and the resolution of social and economic problems.

Informal social connections that clients maintained included friends, relatives, business associates, religious friends and neighbours. Within these networks, there were a few people whom our respondents said they trusted and with whom they shared secrets. There was no

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[1] *Nigina* is Luganda word meaning literally "feel good." In such groups, members support each other by contributing for basic necessities.

[2] *Bika oyeguze* literally means "keep and borrow." In this social support group, members pool together money which they can lend to each other.

consistent pattern of how the social network influenced the decision to take an HIV test or to disclose test results. Some of the clients were influenced by their social contacts to go for a test, and later on, they disclosed their test results to the same people. It was often reported by clients that after talking with friends, some of their friends went straight for an HIV test. Others never shared the idea of going for the test with anyone despite having people in whom they confided. Some clients went for testing without telling anyone but later disclosed their results to others. Some respondents disclosed to employers, close relatives and health workers who had been treating them.

5.5 Information about HIV Testing

Respondents reported that they had heard information about VCT from diverse sources. Most of them had heard about VCT from radio programs, church gatherings, friends and/or public gatherings. The radio was indeed a common source of VCT information, as seen in this conversation:

> ***What has prompted you to test for HIV?***
> *Now you see; I usually listen to a radio programme. People who are sick they say that they have spent twenty years with HIV and they are doing their work as usual.*
>
> ***Which programme do you usually listen to?***
> *This programme of TASO I like it very much and their services. There is a programme on Radio West I listen to, and "Akagwe" (Calamity) on Radio Uganda on a programme of parliamentarians. And when it is Sunday I listen to radio Kabale on a programme of youth which is straight talk.*

In Kamuli, a local radio programme called "Mpanga" was mentioned as a common source of information. The AIDS Education Group for Youths (AEGY) uses this medium to share information and create awareness about HIV/AIDS. The group also has a program in secondary schools to train students as peer educators, offers home visits to HIV patients, and provides HIV patients with mosquito nets, blankets, and mattresses. The main radio programme mentioned in Mbarara was Radio West, which provides information about VCT among other things.

People also got information from their friends living with HIV/AIDS who had disclosed their HIV status. Indeed, a few respondents were motivated to be tested by friends who had already tested and were now living with HIV. People living with HIV/AIDS provided others with information on where to go for support in case they tested HIV positive. However, respondents gave the general impression that few people would be willing to talk to others about their HIV status and where to go for support. Some of the respondents were in contact with people in their communities who were HIV positive and were benefiting from a programme supporting HIV positive people. For instance, the respondents in Mbarara acknowledged the contribution of TASO in alleviating the problems of HIV/AIDS victims and noted how their friends had benefited from TASO.

Information was also occasionally obtained from workshops and sensitization efforts by government officials and CSOs who operated locally. In Kamuli, Plan International was mobilising communities to come for VCT and had established a youth centre where VCT services were provided. During this study some of our respondents were recruited from the youth centre site.

5.6 Discussion of Getting an HIV Test

Discussion with others about getting an HIV test is often assumed to be an important first stage in motivating a person to disclose test results. Respondents often mentioned discussions with friends and relatives about their own chronic health problems and other health-related worries. Skin rash, weight loss, syphilis and TB were considered signs of HIV/AIDS. Friends and relatives advised them to go for a test when they noticed such symptoms. Chronic illness that did not respond to treatment was often taken as a sign that a person should get tested and "establish the truth." Establishing the truth had different connotations. Some wanted to rule out the possibility of having the disease. Some were encouraged by friends who had tested positive, were being treated, and seemed to be doing well. In situations where VCT was linked to a health facility, such as Kamuli Mission Hospital (or Rubaga) or Kamuli Health Centre (or Mulago), a few respondents had discussed the possibility of testing with the health personnel. Health providers often cite the health problems of an individual as a means of persuading them to take an HIV test.

Some respondents came alone, while others were escorted by friends and relatives. In Kamuli, the common modes of transport to the testing sites were bicycles and walking. Most of the women were transported by male friends or relatives. Some had shared their thoughts about the problems that brought them to the facility with those who escorted them. Others kept it to themselves, saying nothing to those who assisted them in arriving at the VCT centre. In Mbarara, VCT clients came from near and far. Some were from neighboring Ugandan districts or other countries such as Tanzania and Rwanda.

Overall, the large majority of the respondents had few financial resources, were in poor health, were married or had been married, and were HIV positive. The next chapter discusses the circumstances that brought them in for an HIV test.

CHAPTER 6
THE PROCESS OF GETTING AN HIV TEST

6.1 Circumstances of Getting an HIV Test

Discovering the reasons that lead a person to act in a certain way, in this case to get an HIV test, is always a major methodological challenge. First of all, there are almost always several factors, not just one, behind the action. Second, the person interviewed is often tempted to answer in pat phrases that have been learned through contact with the media and in health education exercises. Third, the individuals themselves may not have a clear sense of the reasons behind getting tested. Often the reasons given in conversations are simply those that come to mind the quickest.

Given all these caveats, this study presents two versions of the individual circumstances that contribute to a person taking action to get tested. First, the process is presented in terms of the reasons respondents gave to explain how and why they came for an HIV test. Second, the individual circumstances—organized by the gender and social situation of respondents—are presented in order to discover overall patterns. The most important individual circumstances examined are marital status and living arrangements.

The reasons provided by respondents were varied and sometimes overlapping, but they can be grouped into five main categories:

1) Symptoms of chronic illness
2) Hope of getting antiretroviral drugs
3) Concern about past sexual activity
4) Interest in gaining access to support services
5) Concern about initiating or continuing a sexual relationship

6.2 Symptoms of Chronic Illness

VCT clients complained of constant sickness that afflicted them, symptoms which frequently served as the trigger to HIV testing. People came for the test most often when the symptoms were apparent to all, or when people knew that their partner had died of AIDS or had showed signs of having AIDS. The health problems most often cited, as already indicated, were problems such as headache, general body pain, genital itching, skin rash and syphilis. General body weakness and loss of weight were also commonly reported. Clients became especially worried when these problems did not respond to treatment. Associated with this for clients—especially women who were widows or who had divorced—was a history of having had sex with someone who had died of AIDS.

For instance, a 27-year-old woman was interviewed who had divorced and was living alone. Her two children were staying with their grandmother. She reported that she would sometimes seek advice and support from her mother. Her main livelihood was working in the garden in the morning hours and selling beer, waragi (local gin) and sodas in the evenings. Her health was fine, but she was worried because her former husband had a wife who had died of AIDS, and the man himself was sick. Apart from selling beer, she also engaged in sex with some of her customers. So she knew she may well have contracted HIV.

Problems of chronic symptoms dominated the discussions regarding the reason for getting tested, as can be seen in the four cases below:

Case 1
Interviewer: ***What prompted you to go for an HIV test?***
Respondent: *I got rash all over my body and I came for treatment, several times. However, I wasn't getting better. There was no improvement. I came for treatment but I was not getting healed. I tested for syphilis and got treatment for it, but still I was not improving, so I decided to take an HIV test.*

Case 2
Interviewer: ***I would like to here about how you decided to take an HIV test the first time***
Respondent: *I used to have constant headaches. I moved to different health centres for treatment but there was no improvement at all, which prompted me to come here for a blood test to find out the cause of illness. The second time, medical people came to our village for a VCT outreach and I tested positive again.*

Case 3
Interviewer: ***I would like to hear about how you decided to take an HIV test that first time.***
Respondent: *I have very painful backache. In fact I had come to get some treatment, chest pain, fever that comes on and off, cough, syphilis. In fact, this syphilis has started on my children. We always get small swellings in our private parts. I took all my children for tests and I was told it was* kabotongo *(syphilis) that is hereditary. In fact even my late husband had this* kabotongo*, I am afraid and worried for the children.*
(With very sad facial expression and voice indicative of pain and deep concern)

Case 4
Interviewer: ***Have you got the services for malaria?***
Respondent: *For me I was suffering from malaria. I went to the hospital they found me with malaria… and they gave me quinine injections. The malaria resisted. I got scared and told my wife that I am going to test for HIV. That's how we came to test.*

There were those who were obviously sick and others who suspected they were. They had shared their problems with some of their relatives and friends who in turn advised them to go for the test, because the signs had started showing. As already alluded to, some of the clients had relatives who were sympathetic and encouraged them to establish their status. Some of these friends and relatives had brought respondents to the testing centres. Some of the relatives promised to support the clients by purchasing ARVs and other medications if they went for the test.

6.3 Hope of Obtaining Antiretroviral Drugs

Family members of persons who were obviously sick encouraged clients to come for testing and promised to support them in the purchase of ARVs. They hoped they would be able to live much longer if they got the drugs. Clients said quite often that they had seen other people in the community who were known to be HIV positive, were on ARVs, and were showing signs of improvement. However, most clients were too poor to afford these drugs by themselves. They needed assistance from the government. For instance, in Kamuli, many respondents came to test because they had heard that the government was providing free ARVs. The speculation that the government had released free drugs to Kamuli Mission hospital increased the number of people who turned up for VCT. Some of the clients had already started on ARVs. Others had spouses already taking ARVs; still others had not started on ARVs, but wanted to start. However, most respondents did not know the required procedures before starting on ARVs. They thought being HIV positive meant they would be able to begin ARVs quickly.

6.4 Concern about Past Sexual Activities

Some respondents sought VCT services because of chronic illness, but some who were apparently healthy tested purely out of concern about past sexual activities. In a few cases, individuals came for a test because they recalled past sexual experiences with a person who later died with conditions similar to AIDS. Younger clients were worried about having had unprotected sex recently. There were even some who had used a condom, but wanted to check just in case the condom had leaked. Often young people wanted to establish their status before getting married.

The responses below from two younger clients (the first female, the second male) illustrate the way individuals talked about their situations.

Respondent 1

Interviewer: ***Knowledge and experience with HIV/AIDS***

Respondent: *At first I had a boyfriend who had promised to marry me but unfortunately he didn't. But during the time when I was still with him, we had unprotected sex since I knew that he was the only one. I had hoped that he was also faithful. After some time I found that he had another girl whom he married. So after that, I decided to take up a test.*

Respondent 2

Interviewer: ***What prompted you to make the decision for an HIV test?***

Respondent: *I have two girls with whom I have been having live sex together, or unprotected sex. One of the girls seems to be having other men, so I am not sure of myself now. I was planning to look for another girl to marry, but I have been worried about my own health now. I need to prepare myself now and then decide what to do.*

Some respondents regretted their past actions, which they regarded as careless behaviour that had put their life at risk. One of the respondents told us how she had abstained from sex for a long before having sex just once, which prompted her to come for a test.

The younger unmarried men and women came for testing to make sure that they were not positive, to be certain they had not contracted HIV through their past sexual relations. If they were to be found positive, they could break off their relationship with a boyfriend or girlfriend. If negative, they felt free to continue with their current relationship. The young men claimed they would then get tested again with their girlfriend.

There were others whose sexual partners had died, and they did not know the cause. For some, it was rumored that their partners had died of AIDS, but they were not convinced. The following respondent, a woman from Mbarara, was encouraged by others to get tested because of her husband's death.

> *You see there have been some rumours ever since my husband died that he could have died of AIDS. These rumors have made me uncomfortable without peace of mind. Though my husband died of malaria… I don't know exactly. He died after a short sickness of malaria but some people at the village say that AIDS of now days changed and kills people very fast without signs. This has been disturbing. I told my sister about it and she encouraged me and mobilized some money for transport to Mbarara, and actually we came together. Sometimes some men come to me wanting to have sex with me, but I usually refuse, because I don't know myself, so I may get problems without knowing.*

6.5 Gaining Access to Support

As already indicated, most respondents came from poor backgrounds; some were widows with little property. They were grappling with problems of school fees, lack of food and clothing for their children and also wanted money to meet the costs of medication for themselves and their children. Some of our respondents said they were aware of some organisations providing support to people living with HIV/AIDS and to orphans whose parents died of AIDS. There were those who tested because they had heard that there were funds available to support those who are HIV positive.

6.6 Initiating or Continuing a Sexual Relationship

We would not expect any respondents already married to get an HIV test in order to know their sero-status before beginning a new sexual relationship. However, one married man was interviewed who came to get tested with a girlfriend before they continued sexual relations. Among the women, only one would fit this category: a woman who came with her boyfriend for a test. Four single men who came for testing said they came because they wanted to get married or begin having sexual relations with a girlfriend.

6.7 Overall Patterns among Men

Our respondents included 13 single men and two who were divorced. The two men who were divorced got tested because they were sick, and both were found HIV positive. None of the 13 single men were sick when they came for testing, and only one tested positive for HIV. Five of the single men came because they were worried they might be positive due to their past sexual adventures, and two were worried about other means of transmission. These single men had girlfriends, but none came with a girlfriend for testing, even if they had a steady relationship. A number of single men said they would come again with their partner later, but they first wanted to know their own status.

A 23-year-old single man with a small shop explained his position. Although he claimed he had never had sex, he was worried that he might have inherited HIV from his father who died of AIDS. He wanted to get married and so came for testing, but he did not come with his girlfriend.

> *No, I wanted to first test myself and see, before bringing her to test with me and they tell us how we are.*

Another example comes from a conversation with a 28-year-old university graduate. The man had a girlfriend who lived at a distance but visited him quite often. He had persistent malaria and came because his malaria was not responding to treatment. He thought he might have gotten HIV from an old girlfriend. He heard on the radio that persistent malaria and night sweats might be a sign of HIV infection and came for a test without telling anyone. When asked about his girlfriend, he said:

> *The point was that for me, I wanted to have the HIV test first without her knowledge and see how I am. Now I am going to visit her one of these days.*

The five widowers in the group all came for testing because they had been ill for extended periods of time, and treatment did not seem to help them. Three of the five indicated that their wife had died of AIDS, and another one suggested that was the case. Thus for these men, each one living with children and other relatives, their illness and personal history suggested they could well be HIV positive.

The circumstances of the 24 currently married men differ from those of the single men. Most of these men (19 of 24) came for testing because they had been ill and were worried about HIV infection. Several men talked about having been asked repeatedly to get tested by their wives. At least six men told their wives they were getting an HIV test, including one man who told both of his wives before being tested, but most did not tell their wives they were going for a test. Several were quite worried about being HIV positive because they had several regular sexual partners.

Thus, the married men interviewed were motivated to test for two main reasons: chronic illness over time with symptoms that fit with a diagnosis of HIV infection, often with an inability to work normally, and personal anxiety brought on by having had multiple sexual partners. No information is available about what most of the wives knew or thought about their husband's illness or extra-marital sexual activities; very few men stated that they had discussed their situation or testing with their wives.

6.8 Overall Patterns among Women

Female respondents can be usefully considered as living in four types of circumstances: 1) single women who have never been married and who are likely living with parents; 2) women divorced or separated from their husbands, living with their children and their parents or other relatives; 3) married women usually living with their children and husband; 4) widows living with siblings or other relatives and nearly always with several of their own children.

The circumstances of the seven single women are somewhat dissimilar. One briefly lived with a boyfriend, had a son, but never married. When she got sick, she came for a test and was found positive. Five of the other six women had had boyfriends, became somewhat anxious about HIV infection and came for testing several times; they all tested negative. One young woman heard on the radio that HIV can be transmitted from a parent, and, since her father had died of AIDS, she came for a test.

The eight divorced or separated women interviewed had all been sick for some time, and while six of them were concerned about HIV infection, two were tested for HIV involuntarily as part of getting treatment for herpes or pneumonia. One of these said she had never thought of testing for HIV: "… because I had never even suspected that I could have AIDS." At least three of these eight women had expected they were positive because of their husband's sexual activity. All eight tested sero-positive.

The 20 married women all lived with their children, numbering from two to eight each. Several had a husband working in another town that they would see infrequently. Ten of the women did not tell their husband they were getting tested, five others told their husband, and five came for testing with their husband. Four of the women asked their husband to get an HIV test, but they all refused. Most of these married women clearly were unable to discuss their testing situation with their husbands.

The majority (14) of the married women complained of poor health, but they were not all HIV positive. Several came because their husband was chronically ill or they thought their husband had sex with other women. These respondents reported discussing their situation with family and friends far more often than did the married men. Only one of these woman said she came on her own without telling anyone else.

The largest group of female respondents (56%) was composed of women whose husbands had died. A total of 18 of the 26 widows said their husband had died of AIDS or that they suspected that was the case. Most of the widows were testing for HIV for the first time and had waited one or more years after their husband's death to come for testing. Only one of these widows tested HIV negative. Only two of the widows reported their health was fine. The rest suffered from various symptoms, many suggesting HIV infection. Thus the combination of suspecting their husband had died of AIDS, plus their own poor health which was visible to those around them, brought them in for testing.

6.9 Overall Patterns

Respondents' descriptions of the circumstances that brought them to get tested reveal two critical points. One, there is a tremendous variation among the respondents in their social situations and needs for assistance. Two, there are systematic contrasts by gender in the process of coming for a test. Many married men got tested because they were sick, they needed a diagnosis, and they needed someone to care for them. Most widows got tested in a context in which those who knew them suspected they had HIV because they had lost their husband to AIDS. Married women often lived with a husband whom they suspected of having sex with other women. Single men seemed just worried about themselves; they seemed less concerned about their girlfriends.

CHAPTER 7
THE ROLE OF COUNSELLING

7.1 General Pattern of Counselling

The respondents interviewed all received both pre- and post-test counselling except for a few cases at the hospital and the health center in Kamuli. Once prospective clients were registered, the counsellors obtained consent and then discussed general information on HIV/AIDS and the procedure for drawing blood. Whenever clients were numerous, pre-test counselling was administered in a group setting. In a few instances people were tested without counselling.

The AIC counsellors were largely men and women with many years of experience in counselling and testing. They worked long hours and showed great respect for their clients. The counsellors were supportive of this study and helped in recruiting clients for interviewing. They willingly advised the interviewers on what precautions should be taken when dealing with the clients. Observations at the testing centres indicated that they were often overwhelmed by the numbers of the clients. However, despite the large numbers counsellors were seeing, clients appreciated the service they received. The clients reported that the counsellors treated them with sympathy. Clients were often told to avoid multiple sexual relationships, take regular medication, and eat well. Some counsellors also recommended the use of condoms to respondents.

Since in most cases counsellors had limited time to devote to each client, the pre- and post-test counselling was usually brief. However, most respondents reported that they received good counselling after the test. HIV positive clients were told to be calm about the results and to start living carefully by eating well and treating all opportunistic infections at a health centre or hospital. However, in most cases, clients received the same messages despite the tremendous variation in their individual social and health situations. Thus while some clients may have received advice they found useful, others did not.

7.2 Specific Needs for Counselling

The respondents described varying needs that could have been better addressed with specific attention from a counsellor. As already indicated, some were young single people or widows with young children, while others were married couples. Some were extremely poor and others were severely sick. Most of the respondents expressed the need for further support and advice after receiving their test results. Some became visibly distressed when they learned that they were HIV positive. Table 3 summarizes the varying situations of clients and their related needs.

Table 3 Types of respondents by HIV status and symptoms of illness

Respondent type	Concerns and worries
HIV negative without symptoms (very few)	- Prefer to keep the results to themselves - Worry that if they disclose people would try to infect them - Want to know how to avoid HIV infection
HIV negative with symptoms	- Have difficulty convincing the public that they are negative since they appear sick - Need to effectively treat these symptoms - Want to know how to stay safe, avoid HIV infection
HIV positive with symptoms	- Worry about public opinion - Want the symptoms treated - Want ARVs - Need mediation on how to disclose to their spouse - Need strength to support their families - Want to be able to provide for their family before they become too sick
HIV positive without symptoms (very few)	- Have difficulty disclosing results, particularly to a spouse - Need advice on how to maingain good health

The contrast in the situations of each of the four types of cases shows the need for specific support and information for each type.

During the interviews, respondents expressed their worries in different ways. A man at AIC Mbarara lamented:

> *What is worrying me now are my children. Now that I am not working, it's not easy to get money. One of the children is here at home. She was sent away from school due to lack of school fees. Now I don't know how I am going to handle the situation. I was the sole breadwinner in the home; everything would wait for me. Now it's difficult to explain to the children this kind of sickness I have. I don't know how my daughter will go back to school. I am helpless now.*
>
> *What is disturbing me also is my lack of appetite. Sometimes my wife has to look for some soft food like meat or fish with little money she gets from* matooke (banana mush), *but again we can't sell much because it's our main food. I have many children to feed. Now that I am weak there is no source of income.*
>
> *Life is so challenging now, but I have no option; I have to accept it. If God could only help me to regain some energy and start working again then I would utilize my working responsibly. Though I was told not to do a lot of work for my situation. If I regain some energy I will have to look for money so that I can complete this house of mine. You can see how it is; I don't want to leave my children suffering.*

> *Sometimes I pity my poor wife who has to bear it all. I no longer function like a man in the home. I forgot about sex and I pity my wife. If she gets someone outside who is HIV free, I may not mind since she is negative. The counsellors told us to use condoms, but even then, I cannot manage.*

Although they received counselling and were somehow comforted, the helpful effect was mitigated by the fact that most of the clients were left alone to handle their new identity as HIV positive. Although they appreciated the counselling they received from the testing centers, it was apparent from their narratives that this was not sufficient. They needed further support and advice to negotiate recognition of their new identity back in their communities. Although this aspect is emphasized in the new Uganda National Policy on counselling and testing, it may well be difficult to practice in the current context of VCT services.

In the HIV testing centres visited for this fieldwork, once test results are delivered, there is no follow-up by the testing centers unless the clients decide on their own to return and seek help. Even when clients return later, no system is in place to attend to their needs. This situation is of particular concern considering the weak linkages between the testing centers and the local communities of those who have been tested.

7.3 Examples of Clients' Needs for Assistance

Although their needs varied greatly, respondents were consistent in expressing some need or other. A woman respondent at AIC Mbarara described her dilemma when she went for an HIV test with her husband. The results showed that she was negative while her husband was positive, a discordant couple. Although they received both pre- and post-test counselling, the husband was shocked by the results. According to the wife, the husband went away sad and could neither eat nor sleep for some time. As a result, he started losing weight dramatically, and the woman too became worried. She asked for assistance from a counsellor to help them deal with the situation.

Judging from what VCT clients told us about their counselling experience, the counselling process was unable to take into account the socio-economic conditions and the expected roles and responsibilities that clients needed to fulfill. The counsellors did not address the chronic symptoms of illness that clients brought with them, symptoms that needed treatment. Some respondents who tested HIV positive seemed convinced that they had been handed a death sentence, and that they were going to die immediately. Some of the clients were devastated by the idea of dying without leaving anything behind for their families. A male client tested in Mbarara was married, with 5 children, and lived together with his family. He had a rash all over his body, and he described his situation in these words:

> *You see at first I got something that cut my body, you can see* (He opened the shirt and showed the interviewer the large rash on his body). *You can see how my whole body is finished. They told me that it is syphilis and I went to test and they got it there, but this malaria is so much. It would attack me; I could get treatment, after three weeks it could come back. When I told my wife that I am going to test she accepted. We came, and when we tested, they found I have HIV.*
> **(At this point he looked down in silence for three minutes).**

> *My wife was found HIV free. Things of these days you have to ignore. I don't have anything else to do. You continue praying for me; it's not easy.*

After the interview was completed, the respondent requested the interviewer to continue visiting him. He asked if UPHOLD has a program to care for orphans of HIV/AIDS patients.

It is unclear to what extent counsellors could, in fact, deal with the multiple needs of VCT clients. The time pressure and the standardized messages counsellors are trained to deliver do not promote the kind of empathetic listening that would help clients the most. The greatest fear of clients, besides the fear they may soon die, seemed to be that they would be left alone with no one in whom they could confide after they left the testing facility.

CHAPTER 8
DISCLOSURE OF HIV TEST RESULTS

8.1 Importance of Disclosure

As mentioned in the Background section, HIV/AIDS specialists consider disclosure of HIV sero-status as extremely important to prevent HIV transmission, to garner social support for changes in sexual activity to reduce risks, and to access social and medical services. This perspective applies mainly to voluntary HIV testing and voluntary disclosure to others, particularly to one's sexual partner(s). It is assumed that knowing one's sero-status will facilitate risk reduction, in that those found HIV negative can find support among family or friends to change their behaviour to reduce risk of HIV infection, and that those found HIV positive can tell at least their sexual partner(s) so that together they can engage in "safe sex." In fact, experts agree that it is most important to reveal one's sero-status to a sexual partner immediately after getting an HIV test result.

This chapter presents the findings related to the revelation of HIV test results by VCT clients with several main goals in mind: 1) to identify overall patterns of disclosure among certain categories of respondents; 2) to consider the relationship between individual social situations or circumstances and actions of disclosure; 3) to consider the evidence that VCT serves a preventive role among the respondents interviewed. First we describe how the evidence on disclosure was produced and some limitations of the data.

8.2 Collecting Data on Disclosure

Collecting information on how respondents had revealed their test results to others presented a major logistical challenge. Since the process of disclosure occurs over time—and the more time elapsed since an HIV test, the more likely some disclosure will occur—how could field workers identify participants in a VCT facility and then visit them later to find out how they had handled information about their test results? We solved this dilemma by asking permission of respondents seen first at a VCT facility to visit them in their homes four to six weeks later. Although the time period is shorter than ideal, the time allocated to data collection did not allow for a longer period.

At these home visits, field workers usually began the discussion on disclosure by asking: "Did you tell anyone about your test results?" Respondents who said "yes" were asked for details. Those who said "no" were asked if they had disclosed to specific individuals, such as their spouse, a sister, or their girlfriend. Quite often those who said no had, in fact, told one or more people about their results. To avoid asking questions that invite yes/no answers, and thus facilitate providing incomplete or false answers, we suggest beginning with a different set of questions. It would be better to ask:

> "How many people know about your sero-status?"
> "Who are they?
> "How did they find out?"

Of course, it is important to determine as best we can who was told, but information about others who may have heard the news indirectly is also relevant, particularly since some persons have people in mind that they want to keep from learning their test results.

Because the second interview was conducted in a relatively short period of time after the test, and in some cases not everyone who had been told of the test results was mentioned, the data collected on disclosure is a low estimate of what actually occurred. We did succeed, however, in getting respondents to talk at some length about their concerns related to disclosure. We believe that this information is at least as important as obtaining a complete list of individuals who learned about someone's HIV test results. It should also be noted that respondents welcomed this second visit to their homes, for they were very glad to have a chance to discuss their situation with someone else.

Despite the individual concerns about revealing their sero-status to others, most respondents did reveal their status to one or more persons, either family members or friends. At the time of the second interview, a total of two married men and two single men had told no one who knew them. Among women, two married women, two divorcees, and two widows had told no one. Among those who had revealed their status to one or two or three people, most remained concerned that "their secret" not be generally known.

8.3 Concerns about Revealing Test Results

Learning that they were HIV positive presented a real dilemma for most respondents because in addition to the immediate health concerns, people worry about being blamed for bad behaviour or being laughed at because HIV/AIDS is still so stigmatized, Some clients did not share their results with anybody, even their closest friends and relatives. Among those who disclosed, some disclosed immediately and others waited for a while. Others looked for intermediaries to help them disclose. Here is an example of a brief dialogue about disclosure.

Interviewer: ***Did you share the results with anyone?***

Respondent: *Yes, I had to tell my friend, the nurse who advised me to come and test. I shared with her everything I was told at AIC. She also told me that many people have the disease but are on drugs. She encouraged me and guided me on what to eat in order to regain energy so fast. I also told my sister Imelda. She was so sorry, but told me that she knew I am sick. She said that the rash I had was abnormal for an adult person like me. She said that such rashes are for young children but not for adults.*

The circumstances of respondents faced with the knowledge of their sero-status varied tremendously. Some did not want others to know they were sick, since that would ruin their reputation and create trouble for them. One respondent was selling drinks in a bar and sleeping with some of her male customers. Although she had told her mother she was going for a test, she did not tell her or anyone else the results. She argued that if she told her mother she was HIV positive, her mother might die of remorse. She was also worried that if the word spread, she would lose her customers at the bar, including the men with whom she regularly had sex.

Others argued that they did not disclose because the counsellors told them that the results were supposed to be confidential.

Example #1

I made the decision alone without telling anyone. Why should I tell them the results? These are not things to just talk about; we do these things of having sex secretly, even testing for HIV should be a secret. The counsellor also told me that it's my secret."

Example #2

I don't think about telling the results to others because the counsellors told me that it is confidential.

A married man in Kamuli living with his wife and eight children had this to say about telling his sister:

Because she is the one I know who can keep that secret of mine.

He explained why did not tell his wife:

Women have a weakness apart from you (the interviewer). Most of them have a weakness in their heart. She can become wild and she may begin insulting you…

In thinking about the person or persons to whom they would reveal their HIV status, many respondents said they chose X "because they can keep a secret." Many persons mentioned that they were afraid of being talked about in the village, and that people would hear about their sero-status and would begin "to spread rumours." It seems reasonable to believe that the subject of such "rumours" would be how they got HIV. Repeatedly, respondents mentioned the fear of being talked about by others. This kind of fear is a clear manifestation that the clients expected the community at large to be hostile to people who are known to be HIV positive.

In general, many married women were afraid they would be blamed by their husband for having taken a test at all, and that they might be deserted by their husbands if positive. Unlike men, even when critically ill, some women feared telling their husbands because they thought their husbands would blame them for taking the test because they were guilty of misbehaviour. Women in polygamous marriages thought they would also be blamed by their co-wives.

A 34-year-old widow explained her dilemma in this manner:

(If she were to tell someone,)

That person would go spreading the news to the whole village. And I told you, I don't have parents or any close relatives and my husband also passed away. My children are still young, so I can't disclose to anyone.

8.4 Disclosure among Married Respondents

The married respondents interviewed included 20 women and 24 men. Married persons who test for HIV carry a particular responsibility for disclosing since it is assumed that they have regular sexual relations and thus put their partners at risk for HIV infection. Both men and women experienced difficulties in discussing their HIV status with a spouse. Not surprisingly, those who were HIV positive had more difficulty disclosing than those found HIV negative. First, there was the question of responsibility for bringing the disease into the family. In many cases the spouse who first disclosed that he or she was HIV positive would be blamed for bringing HIV into the home. Both men and women were aware of this problem. Second, married clients were concerned about how to handle the aftermath of disclosure, since they expected their partners would react negatively. Women feared being abandoned by their husbands, while men thought their wives would break down after the bad news. Many expressed uncertainty about how to handle their situation. Third, despite the sensitivity of the subject, the very sick clients inevitably needed care and support, and hence they had to reveal their test results.

Table 4 shows the numbers of men and women who disclosed to their spouse. Four of the married respondents interviewed were not interviewed a second time, and thus there is no information on their disclosure.

Table 4 Disclosure to a spouse among married respondents

	Men	Women	Total
Disclosed	14	9	23
Did not disclose	8	9	17
Total	22	18	40

Among the men who disclosed, eight were HIV positive and six were HIV negative. Among those who did not disclose, seven were HIV positive and one was HIV negative. Among the women who disclosed, five were HIV positive and four were HIV negative. Among those who did not disclose to a spouse, eight were HIV positive and one was HIV negative.

The response of married men who tested positive varied according to their health status. Those who were very sick had no choice but to disclose to their wives whose care and support they needed. On the other hand, men who were not severely sick did not tell their wives about the results in order to avoid rumours, blame, and disruption of family relationships. Some of the male respondents alleged, as already indicated, that women have “weak hearts” and could collapse after hearing the news. Some men who did not disclose to their spouses disclosed to others, including parents, siblings, close friends, and other relatives.

Men who were not overtly sick chose not to share test results with their wives to avoid having people spread rumours or being blamed for loose morals. A man who had tested positive said:

> *No, for me I don’t trust women, they spread rumours, even if it is something within the home. Outside she will tell her closest friend and by the way, a woman will not give you proper advice.*

Although a number of men spoke disparagingly of their wives, there were examples of men who spoke well of their wives and who shared the process of testing for HIV with them.

One 30- year-old farmer in good health had two wives who lived in different villages. He told the interviewer he is very close to his wives. He had discussed the process of getting tested for HIV with both of them before going for a test. After he had learned of his HIV-positive results, he told each wife separately, and asked them to get tested as well. One of the women turned out to be HIV positive, the other negative.

The table shows that half of the married women shared their test results with their husbands and half did not. Many of these women said they did not know if their husband had ever been tested. Those who told their husband had either come with him or were quite ill themselves, while those who had not told were in good health or their husband lived far away. Women were not asked about their relationship to their husband, but many had quite critical things to say about them, such as: “He has other women,” or “He does not care for me and my children.” None of the women ever said anything about the implications for continued sexual relations even though they recognized that they were HIV positive.

Two aspects of the situation of these married women must be noted: 1) the tremendous variation in their reasons for getting tested, in their family relations, and in their communication with their husband; 2) the numerous indications that husband and wife communicate so poorly. One woman said she confided in her husband. They had come for HIV testing together, which for her was the second time. Nearly all the others had critical things to say about their husband; a number of them blamed him for their HIV infection. The range of situations and the poor communication between spouses constitutes a great challenge for any intervention seeking to facilitate disclosure between spouses, for it means somehow improving communication in general between the two.

One married woman who tested positive disclosed neither to her husband nor to her two co-wives, saying that because they were Moslems and she was a Protestant, they would blame her for bringing HIV into the household. She chose to disclose only to her mother and brothers. Another who was positive, and also pregnant, chose to tell her mother instead of the husband. Four of the nine married women who told their husbands said they had told no one else.

In situations where women had lost trust in their husbands, they saw no value in sharing their sero-status with their husbands. There was a young woman who chose to disclose to her sister and a nurse friend but never told her husband, because there were no longer on good terms.

> *That drunkard mad man! I tell him what? He does not care for his children and me. He has another wife in town. I have not yet told him. He will see for himself, because I believe what is in my blood is also the same thing he has. He deserted me when I started falling sick and when I got rashes. It’s like he does not want to see me.*

Men’s reactions after receiving the results from their wives were diverse. As already indicated, some declared later that they had tested and already knew their status. This became an opportunity for them to share the results. After their wives disclosed to them, some made no comment, which was unsettling to their wives. A few wives said that this was a sign that the husband already knew he was positive but had not told them.

8.5 Disclosure among Widows

The respondents interviewed included 26 widows, all but one of whom had tested HIV positive. As mentioned earlier, 18 of the 26 thought that their husband had died of AIDS. Nearly all had several children to care for, their own and sometimes those of a relative. It is reasonable to suppose that the family members and friends of most of these widows already suspected they had HIV because of their husbands' deaths and their own chronic illness. Despite that reality, many widows limited their disclosure to one or two people—a relative or friend. On the other hand, some were in desperate need of social and economic assistance, so they were more willing to disclose to anyone able to give support. A few went for help to organizations such as TASO (Mbarara) or Plan International (Kamuli).

There were some widows who still wanted nobody in the proximity to know their status. One widow told no one in the village but chose to disclose to a large Christian gathering very far away from where she lived. "*You know what? It is very hard to understand people in my village. They can't keep a secret.*" Several widows wanted to keep their status a secret because they were having sexual relations with men in the community and did not want to jeopardize those relationships. One of those widows complained that the wives of local men insulted her because they suspected she was sleeping with their husbands.

8.6 Disclosure among Young Single Respondents

The situation of the younger men and women who had never been married was quite different from the rest of the respondents: nearly all tested HIV negative, they were not necessarily in a steady sexual relationship, and those who had a steady relationship did not necessarily consider it permanent. Only seven females and 13 males were in this category. All but one of the 13 men had a current or a recent girlfriend, but only one man told his girlfriend his test results. This finding fits with the situation of single men mentioned earlier: young men who first came by themselves for a test, and if they proved negative, indicated they would return for testing with their girlfriend. They did not want to take the risk of learning their test results together. On the other hand, four of the seven young women spoke of having a boyfriend, and each told him her test results. These numbers are too small to allow for generalization, but there does seem to be a contrast between young men and women in their willingness to discuss HIV tests with a sexual partner.

8.7 VCT as a Preventive Measure

Common public-health wisdom about the purpose and effects of VCT holds that learning one's sero-status is valuable in itself in so far as it increases the options for protecting oneself and sexual partners against HIV infection. However, this did not appear clearly in the respondents' concerns. They had come for testing because they were sick and needed treatment and ARVs, if possible, or because they feared they might be punished by HIV infection for their sexual experiences. While the study did not include questions about recent sexual activity or how their sexual activity had changed after getting tested, respondents who tested positive did not talk about the impact of sero-status on sex. One would have expected some to make reference to protecting partners from HIV infection. Several of the single men who were tested and who did not tell their girlfriends, claimed that if they tested HIV positive, they would drop the relationship without telling the girlfriend what had happened.

No one talked about the need to protect a sexual partner from HIV infection, with two exceptions. One was a married man who tried to convince his wife to use condoms without telling her that he was HIV positive. She refused, saying he should save those things for his other women. The other was a 40-year-old widow who said she had told no one about her sero-status, but who then said:

> *There are people who come to ask me for sex, and I usually tell them that I am sick, but some do not listen. When you are a widow on the road like me here, every man will want to have sex with you. What surprised me is that some man comes and asks me to give him sex. I tell him that I am sick, and he says, I am also sick, so we can combine.*

This woman implied that she usually refused to have sex with these men, but she also said that she did sometimes have sex and without a condom.

In short, judging from what respondents said worried them, there was little awareness of or concern for protecting a sexual partner. Those who tested negative were relieved that they were not going to be punished, and those who were HIV positive were worried about getting treatment for their illnesses. No one, man or woman, said anything about not having sex any more (and few talked about using condoms). While the HIV-positive people had many serious concerns, avoiding HIV transmission to their partners was not one that they mentioned.

The VCT clients interviewed included cases of discordant couples where the women had tested negative while their husbands were positive, yet the wives were unable to negotiate for safer sex with their husbands. The married men who were positive gave no indication that they would stop having sex or use condoms. Women married to an HIV-positive man worried about getting infected but did not expect to be able to avoid sex with their husband. One of the men who was HIV positive disclosed to his wife, but she did not believe him. She thought he was deceiving her so he would have a pretext to separate.

For knowledge of one’s sero-status to be beneficial, the new knowledge must be negotiated, not simply announced. If any prevention objective of VCT is to be achieved, the fact that a person is HIV positive or negative must be comprehended and accepted along with its implications. The process of disclosure should be a process of mutual acknowledgment of the situation. For that to occur, VCT clients need outside assistance in discussing their situation with family and friends.

CHAPTER 9
CONCLUSION AND RECOMMENDATIONS

This research examined the process of coming for an HIV test, of being counselled, and the concerns and actions of VCT clients related to revealing their test results to others. Recognizing that these actions were part of the social interaction in which individuals participated, the research sought to understand how the social context of these actions facilitated or discouraged obtaining an HIV test and disclosing test results to others. The overall objective of the study was to collect data to assist UPHOLD in designing interventions to better promote voluntary counselling and testing, to train and support counsellors, and to consider how to meet the social needs of VCT clients after testing.

9.1 Circumstances of Getting Tested and Counselled

The circumstances that led most married men to come for a test were that they had been sick for some time and thought it might be HIV, or they were worried they had contracted HIV from past sexual relations. The circumstances of married or widowed women were similar in that many came because they had been sick for a long time, but others came because they had lost a husband to AIDS and thus thought they might be infected. The younger respondents who had never been married came not because they were ill, but out of concern that they may have contracted HIV through recent sexual activity. The young men with girlfriends came by themselves, but said they would later come again with their girlfriend.

The descriptions of the circumstances that brought respondents to get tested showed that the social situations of respondents were quite varied, with a clear contrast by gender in what prompted them to get an HIV test. These differences among respondents have implications for counsellors who may or may not ask their clients for information about their individual situation in the pre- or post-test counselling process. Clients who are obviously sick need medical care, they may need ARVs, they need someone to care for them, and they need referrals to support groups. Married VCT clients need counselling about how to avoid HIV infection, including methods of contraception, or child spacing. Those with children were also worried about how they were going to continue providing for their children when they became sick, and what would happen to their children when they pass away.

Respondents were asked what they thought of the counselling they had received and what advice they had been given. Most respondents praised the counsellors for their caring advice, advice that included a reassurance that they are not alone in being HIV positive, that they should seek medical care when they become ill, and that they should eat well. Very few mentioned that they were advised to use condoms, or that they were given a referral to a support organization. Very little was said about revealing test results to others, although some respondents reported that the counsellors said that "it is your secret."

It is unclear to what extent counsellors could take the time necessary to learn about the situation of their clients or to deal with the multiple needs of VCT clients. During the period of data collection, the counsellors observed served many clients in a day and were concerned about not having enough time with each one. Our observations suggest that counsellors rely on standardized messages for most clients and that they are trained to transmit these messages, but not to evaluate the situation of individual clients and advise them accordingly. A reliance on scripted messages for all is one way of saving time, but it may not provide the advice that clients need the most.

The struggle of counsellors to meet the needs of VCT clients raises the question of what we should expect from the testing and counselling process. The common wisdom in meetings and in the literature says that getting tested is an end in itself, a critical step toward HIV prevention. The experiences and concerns of these respondents suggest that perspective is naïve and expects too much of the testing and counselling process. Respondents did not express concern about transmitting HIV to their sexual partners.

Overall, the greatest concern of these VCT clients was that now they would be left alone, that they have no one to discuss their situation with after they left the testing facility. They wanted contacts with service organisations after leaving the VCT facility. For these respondents, a single visit for counselling and testing left too many of their concerns unaddressed. These were troubled individuals who expected blame and criticism from their immediate family and their wider social contacts if it became known that they were HIV positive.

Among the respondents of this study, getting an HIV test was highly stigmatized. Many of the widows who lost their husband to AIDS waited years before getting a test. None of the single men who got tested came with their girlfriend. With one exception, the married men who got tested did not come with their wives. These respondents did not want to be tested at the same time as their sexual partners.

9.2 Disclosure of HIV Test Results

Married persons who test for HIV carry a particular responsibility for disclosing since it is assumed that they have regular sexual relations. Both men and women experienced difficulties in discussing their HIV status with a spouse, fearing they might be blamed for having several sexual partners. Half of the married women (9 of 18) and a little over half of married men (8 of 14) revealed their test results to a spouse.

The response of married men who tested positive varied according to their health status. Those who were very sick had no choice but to disclose to their wives whose care and support they needed. On the other hand, men who were not severely sick did not tell their wives about the results. Some of the male respondents alleged that “women have weak hearts” and could not tolerate hearing news of a husband who tested positive. Some of the men who did not disclose to their spouses disclosed to others, including parents, siblings, close friends, and other relatives.

Many of the married women said they did not know if their husband had ever been tested. Those who disclosed their test results to their husband had come with their husband or were quite ill themselves, while those who did not tell were in good health or their husband lived far away. Women were not asked about their relationship to their husband, but many had quite critical things to say about them. Both married men and women were less likely to disclose if they appeared to be in good health. These respondents did not talk about the problem of transmitting HIV to a spouse.

Our conversations with married respondents revealed that their health status and the nature of their relationship to their spouse were the factors that most influenced whether they shared their HIV test results. The men and women who made critical comments about their spouse, and there were quite a few, did not share their test results. These findings suggest that interventions that promote “couple counselling” should proceed with caution. The concept of “the couple” in public health may not fit well within Ugandan society where the relationship between husband and wife may not be their primary relationship. In addition, the promotion of disclosure among married persons must be able to deal with the social problems that affect the relationship. The need to address social relations also applies to widows and to those never married if they have sexual partners.

The study design assumed that disclosure of HIV status enables individuals to solicit support from relatives, friends and sometimes employers. Respondents who were sick had to reveal their HIV status so they could get help. Some respondents disclosed to others so they could obtain assistance for taking ARVs. Those who were very sick were assured by relatives and friends that if found positive, they would help them secure medication. However, if people were not visibly sick or if they felt they were capable of purchasing the drugs themselves, they often kept the results to themselves.

9.3 Implications for Overall Strategy

This study provides rich information on the experiences of VCT clients in getting tested, counselled, and then revealing their test results. The findings show how social relations influence going for VCT and subsequently disclosing test results. The findings suggest a series of shifts in overall strategy in the promotion of VCT and follow-up care and support, notably the following:

- The dominant image of VCT clients as individuals who need to change their behaviour to avoid HIV infection, and who will definitely benefit from just learning their sero-status and being counselled, should be reconsidered. More appropriate would be an image that considers VCT clients as people operating within a network of social relations that has affected their coming for a test and will affect their disclosure of test results. Such a shift in image would encourage counsellors to spend more time to understand the circumstances of the clients that motivated them to get tested.

- The process of voluntary counselling and testing should not be considered as an end in itself. Rather, it should be considered as a first and essential phase toward changes in social and sexual activity to reduce the risk of HIV transmission. The extension of concern for VCT clients to the period after they leave the facility requires careful and considerate referrals for future contacts with service organisations capable of advising individuals as they wrestle with illness and with their concerns about disclosure to others. So many of the respondents in this study were afraid they would no longer have contact with persons who might advise them. Some of the provisions of the

1995 policy guidelines for HIV counselling and testing (Uganda MOH, 2005) seek to address this issue.

- Disclosure is not a simple matter of individuals telling one or two persons they are HIV positive or negative. Rather, the persons confided in must also believe the news, and they may need help dealing with the implications. A small number of respondents, both positive and negative, had trouble convincing others of their sero-status. This situation is true of those who are negative but still chronically ill, and of those who are positive and afraid to tell others. Hence, VCT clients need further assistance to negotiate the news of their sero-status.

9.4 Programmatic Recommendations

- Expand the training of counsellors to include more consideration of the social situation of VCT clients as well as to tailor counselling to fit the needs of clients within their particular family unit. By considering the situation of clients—marital status, health status, living situation—counsellors will be able to provide more useful advice about how to avoid HIV infection.

- Develop a referral system so that all VCT clients have the opportunity to contact an institutional source for medical or social support. Above all, make clients understand that leaving the VCT facility is not their last chance to discuss their needs with someone with resources to assist them.

- Establish on-going links with community-based support services for those who have been tested. Since disclosure is a process that occurs over time VCT clients need someone to advise them on how to discuss their situation with family and friends around them. Individuals need assistance in discussing their sero-status with those who should know, but also with those who may have found out indirectly. It might be possible to establish links with community-based support services that can offer periodic contacts with those who have been tested.

- Investigate the possible use of CSO grants to provide some of the services recommended here. This should be done through systematic coordination between the CSOs and the VCT facilities. Providing grants to facilitate the process of disclosure and the negotiation of social relations with family and friends of VCT clients is a promising approach to assisting VCT clients.

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APPENDIX A
TOPIC GUIDE FOR INTERVIEWING RESPONDENTS

Questioning Guide for Interviews

Interview objectives

This first interview seeks to discover the nature of the respondents' social interactions with family and friends, the health of the respondents and close family members, and their use of medical services over the past few months. The interview has two parts. The first part will begin with a discussion of the composition of the household in which they live and the friends they see often, then move to talking about the respondents' work and leisure time , and then move to their use of time during the past week, the associations to which they belong and their involvement in those groups, and the individuals they talk to about various topics of importance to them. The second part will focus on the health of close family members and that of the respondent, and the respondent's experience with using health care services in the past few months.

I. Social context and social interactions

A. People in household and others close to respondents
  1. Household composition
    Names, ages, relation to respondent
  2. People they see most often (friends, neighbors, others)
    The 3-4 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. Activities of the last week
   Ask about what they did on each day, beginning with yesterday and working back to get information about the last three days.
   When completed, ask if they forgot anything.

Questions: Tell me what you did yesterday, and with whom?
What about the day before that?
And the day before that?

D. Associations, clubs, groups they 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?

E. 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. Respondent's 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.

Questioning guide for Interview #2

I. 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.

II. Decision to take an HIV test

A. How decision was made
B. Others involved in decision
C. Thoughts about how people decide to take an HIV test

Questions: I would like to hear about how you decided to take an HIV test.
Did you talk to anyone about getting an HIV test?
Tell me about how people decide to take an HIV test.

III. Respondent's experience with HIV testing

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

Questions: Tell me about your experience in going for an HIV test at the AIC.
Do you have any comments abut 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?

IV. Discussion of HIV test results

A. Possible discussion of test results with someone else
B. Their thoughts about revealing the test results
C. Response of person who learned results

Questions: What thoughts have you had since your test about talking to someone else about the results?
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?
Are you happy or sad that you told them?
How did you decide not to tell anyone about your test results?