



Voluntary Counselling
and Testing (VCT) for
HIV in Malawi:
Public Perspectives and
Recent VCT Experiences



**Voluntary Counselling and Testing (VCT)
for HIV in Malawi:
Public Perspectives and Recent VCT Experiences**

P. Stanley Yoder
ORC Macro
Calverton, Maryland

Priscilla Matinga
Independent Consultant
Blantyre, Malawi

June 2004

This report presents findings from a qualitative research study conducted in Malawi in 2002–2003 as part of the MEASURE *DHS+* project. The Malawi National Statistical Office (NSO) organized and directed this activity, in collaboration with the National AIDS Commission (NAC), with technical assistance from ORC Macro. Funding was provided by the U.S. Agency for International Development (USAID) and the UK Department for International Development (DFID).

Additional information about the MEASURE *DHS+* project can be obtained from MEASURE *DHS+*, ORC Macro, 11785 Beltsville Drive, Calverton, MD 20705 (telephone: 301-572-0200; fax: 301-572-0999; email: reports@orcmacro.com; website: www.measuredhs.com).

This publication was made possible through support provided by the U.S. Agency for International Development under the terms of Contract No. HRN-C-00-97-00019-00. The opinions expressed herein are those of the authors and do not necessarily reflect the views of the U.S. Agency for International Development.

Suggested citation:

Yoder, P. Stanley, and Priscilla Matinga. 2004. *Voluntary Counselling and Testing (VCT) for HIV in Malawi: Public Perspectives and Recent VCT Experiences*. Calverton, Maryland, USA: ORC Macro.

TABLE OF CONTENTS

Acknowledgments.....	v
Executive Summary	vii
Chapter 1	Introduction..... 1
1.1	Objectives 1
1.2	Study Implementation..... 2
Chapter 2	Background..... 3
2.1	Prevalence of HIV in Malawi 3
2.2	HIV Testing in Malawi 4
2.3	VCT in Neighbouring Countries..... 6
Chapter 3	Study Design..... 9
3.1	Specific Research Questions..... 9
3.2	Assumptions..... 10
Chapter 4	Methodology..... 11
4.1	Data Collection Methods 11
4.2	Training..... 11
4.3	Choice of Field Sites..... 12
4.4	Sampling 12
4.5	Data Collection 13
4.6	Data Processing and Analysis..... 14
Chapter 5	Interest in HIV Testing among the General Public..... 15
5.1	Knowledge of AIDS 15
5.2	Signs of AIDS..... 17
5.3	Talking about HIV Testing and Counselling 18
5.4	Reasons for Getting Tested..... 19
5.5	Readiness for an HIV Test..... 21
Chapter 6	Experiences of VCT Clients 25
6.1	Sample of Clients 25
6.2	Seeking an HIV Test..... 25
6.3	Reasons for Seeking an HIV Test..... 26
6.4	Clients' Experience at a VCT Centre..... 31

Chapter 7	The Work of Voluntary Counselling and Testing Counsellors.....	35
7.1	Background and Training	35
7.2	The Counselling Process.....	36
7.3	Pretest Counselling	39
7.4	The Testing Process	40
7.5	Post-Test Counselling	40
7.6	Challenges of Counselling	43
Chapter 8	Conclusion	45
References.....		49
Appendix A	Questioning Guide for the General Public.....	51
Appendix B	Questioning Guide for Voluntary Counselling and Testing Clients	55
Appendix C	Questioning Guide for Counsellors	59

ACKNOWLEDGMENTS

The authors would like to thank the National Statistical Office (NSO) in Zomba and, in particular, Jameson Ndawala, for his able direction of all logistical aspects of the study from the very beginning on through to the presentation of results in Lilongwe in 2003. NSO, through Ndawala and Ladislas Mpando, arranged for the training of interviewers, participated in much of the training, guided the study teams from one site to another, set up the system for transcription and translation in the NSO regional office in Blantyre, and assisted with some of the transcription and typing.

The authors would also like to thank all of the members of the research team, who worked so diligently to collect and process the information collected through interviewing, transcribing, translating, and typing several hundred interviews. We are grateful to the members of the public and to all of the voluntary counselling and testing clients, who generously spent time talking to the study team. We want to especially thank Rebecca Henry for her writing assistance with Chapter 7 and for her editorial suggestions. The director and staff of the Malawi AIDS Counselling and Resource Organisation (MACRO) deserve special thanks for their generous assistance in facilitating our interviews and observations at two of their facilities.

This research was funded by the United States Agency for International Development (USAID) through field support from the USAID Malawi Mission and the Department for International Development (DFID) of the United Kingdom. The opinions expressed are those of the authors and do not necessarily reflect the views of USAID or DFID.

EXECUTIVE SUMMARY

This report was written to provide useful information for assessing public interest in HIV testing and counselling and for organising the expansion of voluntary counselling and testing (VCT) services in Malawi. The report is based on a study that examined public interest in HIV testing and the experiences of clients of VCT facilities in the Central and Southern regions of Malawi. The study was organised and directed by the National Statistical Office (NSO) in Zomba with technical assistance from Macro International Inc., an Opinion Research Corporation company (ORC Macro), in collaboration with the National AIDS Commission (NAC). NSO participated in the finalising of the study design and in the training of fieldworkers, directed the data collections and data processing, and presented the results of the study in Lilongwe.

Objectives

The first task of the study was to generate information about public knowledge and experience with HIV counselling and testing. Gaining an understanding of what the public has heard about HIV/AIDS and HIV testing and counselling, as well as the ways that individuals describe their readiness to seek an HIV test or explain how and why they have no interest in HIV testing, was considered essential for assessing interest in voluntarily getting tested for HIV in a facility.

The second task was to document the experience of clients of VCT services currently available in Malawi: the study examined how individuals were welcomed into a testing facility, how they gave blood for a test, and how they were given advice about their own situation and ways to avoid the risk of HIV infection. Special attention was given to the circumstances that brought individuals into a testing facility and to the specific advice they were given by counsellors. It was assumed that client comments about their experience in getting tested and counselled would provide an indication of the aspects of the testing and counselling process that were most important in making VCT services appealing to clients.

The third task of the study was to understand the work of VCT counsellors, particularly those who were full-time professionals rather than volunteers. Of particular interest were their background and previous employment, the training in counselling they received, their interactions with clients, and the advice they provided to those who tested positive and negative. Attention was also given to their level of job satisfaction as counsellors and their own evaluation of the training they had received.

Implementation

The study began with two weeks of training for fieldworkers (interviewers) and transcribers who were trained in principles of qualitative research and in techniques of open-ended interviewing. This group then developed the research instruments (questioning guides) in Chichewa and pretested the instruments in Blantyre.

The study interviewed three different groups of people: 1) adults in the general public; 2) clients who came to a VCT centre for an HIV test; and 3) the counsellors who work in those centres. Information about knowledge of HIV, AIDS, and HIV testing and counselling was collected through individual interviews with adults in rural and urban areas of Blantyre (Southern region) and Lilongwe (Central region). The study team interviewed clients at VCT centres about the circumstances that had brought them to a testing facility and their experience with testing and counselling at these centres. Counsellors working at VCT centres were interviewed about their prior employment, their training for counselling, their interaction with clients, their job satisfaction, and the advice they give to clients. The interviewers took notes from observations of the welcoming and client flow at testing facilities. The interviews were conducted in Chichewa and tape-recorded with permission granted by those interviewed.

Over a period of three months, the fieldworkers interviewed 211 men and women in the general public about their knowledge of HIV, AIDS, and HIV testing, and 245 clients of VCT centres that offered rapid HIV tests and counselling. The team also interviewed the 27 counsellors working at these VCT centres. The recorded interviews were transcribed in Chichewa, then translated into English, and typed in English.

Findings

VCT for HIV has been available in freestanding facilities in Malawi for about five years, with steadily increasing numbers of clients. The number of clients seen in the three Malawi AIDS Counselling and Resource Organisation (MACRO) facilities exceeded 50,000 from October 2002 through September 2003. Among the MACRO clients ($N = 51,178$) of that reporting period, 14.5 percent tested positive for HIV. This result means that during those 12 months, about 1 percent of adults thought to be HIV positive in Malawi (760,000) were tested and counselled. Several privately funded hospitals also provide counselling and testing for HIV, along with other services, and many hospitals offer HIV testing with or without counselling.

The Malawi Ministry of Health and Population and donors plan to rapidly expand voluntary testing facilities in Malawi as soon as technically feasible. It is unclear to what extent the expansion of testing for HIV will also include professional counselling. In order to attract the maximum number of clients, those responsible for designing the services should consider the likely response of the population to increased opportunities to be tested, the services that are most attractive to clients, ways the population can best be encouraged to come for HIV testing and counselling, and how the clients who come for an HIV test are alike or different from those who do not seek such a test.

Knowledge of HIV transmission

The way that respondents interviewed in the general public understood how HIV is transmitted or how people contract AIDS is very close to the biomedical view and thus does not present a problem for AIDS prevention programmes. Some individuals make a distinction between having HIV as a virus (*kachiroambo ka edzi*) and having AIDS, while others do not. Practically everyone interviewed said the same thing about transmission: HIV or AIDS is transmitted through sexual intercourse and the sharing of razor blades, toothbrushes, and needles.

Knowledge of service availability

Most people interviewed in urban areas had heard about the possibility of testing at one of the MACRO facilities, the freestanding VCT service centres in Blantyre and Lilongwe. The media is being used effectively to advertise the availability of services in urban areas. Rural residents had heard of local sites for HIV testing from friends and family.

Readiness for an HIV test

Interviews with the public in the Central and Southern regions suggest that most individuals in the neighbourhoods visited are not quite ready to be tested. When they were first asked whether they would be tested sometime, most said “yes,” but further discussion revealed that they were not thinking of getting tested in the near future. Respondents said that they might be tested at some point in their lives, but they were not yet ready. The main reasons cited or suggested for not being ready included the following: they are not at risk; they do not want to be seen going to a VCT centre, for that would be recognizing that they may have HIV; and they are truly afraid they have HIV and are very worried about what that would mean for their lives. The fear of being told they are HIV positive clearly keeps people from being tested.

However, only a small minority said that they did not ever want to be tested. The small number opposed to getting tested provides some hope that people might be persuaded to come for testing with the right kind of encouragement.

Conditions of HIV testing

The interviews with the public and with VCT clients clearly demonstrated that they want VCT services that are free, that provide rapid results, that ensure privacy and anonymity, and that include time with a counsellor to ask questions and be advised about how to protect themselves from HIV infection. Many VCT clients told interviewers that they had heard that HIV tests are free and provide rapid results. Some VCT clients said they had come for testing at a facility far from home so they would not be recognised by anyone. The elements of VCT services that should be emphasized as the Ministry of Health and Population expands VCT services throughout the country are as follows: free tests; same-day results; anonymous records; private counselling; and counsellors who ask and answer questions. These conditions can be easily satisfied in centres that provide free services, use rapid test kits, guarantee anonymity, and hire professional counsellors.

Reasons for seeking an HIV test

Clients who came to VCT centres were asked what brought them into the VCT centre. The reasons they gave fall into five categories, presented in the order of the frequency they were mentioned:

- Fear of having been exposed to HIV by one's own actions
- Fear of having been exposed to HIV by the actions of one's spouse or partner(s)
- Feeling sick
- Family events (e.g., marriage, pregnancy, reunion, new partner)
- Job circumstances (e.g., new job, scholarship, application requirement).

Most clients who came for an HIV test differed in two ways from those who did not come: 1) either they or their spouse had several sex partners recently, and 2) they thought they had been exposed to the HIV virus. Both factors needed to be present: multiple partners and high anxiety about having been exposed to HIV. Most men who came for a test were worried about HIV infection because of their own actions, while most women were afraid they were at risk for HIV because of the actions of their spouse. A small proportion of clients came because they were planning a family event: a marriage, a possible pregnancy, or a new sexual partner.

Importance of counselling

VCT clients appreciated the fact that the service was free, that they received the results in an hour or two, and that counsellors invited them to ask questions. Many clients said they were grateful for the information they had been given about the difference between the HIV virus and AIDS, about how HIV is and is not transmitted, and the significance of the window period. These were issues that puzzled many clients. The conversations with clients about their contact with counsellors underlined the importance of the counselling process as both an occasion for health education and for discussing ways to reduce the risk of HIV infection. Some came expecting to hear instructions about how to avoid HIV infection, while others expected information about how to live longer with the virus. A few complained that their contact with counsellors was simply too short. The comments of clients about the counselling process showed that they consider that aspect of HIV testing to be important.

Possibilities of referral

The policy of NAC and MACRO encourages counsellors to refer VCT clients to social and medical support services, whether they test positive or negative. In 2003, there were still very few such services available in the country, except for several private facilities with outside funding. The

counsellors interviewed talked about the referrals to medical services that they provided routinely to clients. However, the clients interviewed did not report being referred to any support groups of any kind, social or medical. It is unknown what importance counsellors actually gave to that aspect of the service.

Counselling in VCT services now has several objectives: to provide an opportunity for health education, to provide information for reducing the risk of HIV infection, and to refer clients to support services. Conversations with clients indicated that they were grateful for the HIV and AIDS information they were given and that they learned from the experience of counselling. Clients also recognized they were given instructions about how to reduce risky actions. They were not, however, often referred to support services. That aspect of counselling clearly deserves more attention.

The future of VCT in Malawi

The form that VCT services take in Malawi depends to a great extent on the decisions by the Ministry of Health and Population and NAC about several issues:

- 1) How should VCT services be marketed?
- 2) How will individual permission to test for HIV be obtained?
- 3) What importance will be given to the role of counselling?

While this study found that respondents had heard about VCT services on the radio, suggesting that radio is an effective channel, what should the messages be? Should promotion mainly emphasize that people should come for testing if they believe they have been exposed to HIV infection? Or should promotion materials focus largely on being tested for planning for the future? What is the current strategy of the Ministry of Health and Population and NAC to promote HIV testing, and how clearly has it been articulated?

An examination of the radio messages broadcast in the past year or two would show the relative importance given to various messages about the reasons for coming for an HIV test. The relatively small numbers of clients among those interviewed who came for an HIV test to plan for the future suggest that more emphasis should be placed on encouraging individuals to come for testing for that reason.

A consideration of different ways of obtaining permission to test for HIV becomes an issue in antenatal clinics, where program directors seem to have two options for women: to “opt in” or to “opt out.” The first option (opt in) means that women will be asked whether they agree to have their blood tested for HIV, or not. Only those who say “yes” will be tested. The second option (opt out) implies that blood will be taken and tested unless a mother specifically asks that no HIV test be conducted. But similar ethical dilemmas may arise in other circumstances where individuals are present for a particular service or activity that includes the drawing of blood, such as testing for syphilis in a clinic for sexually transmitted infections.

The relative importance of counselling in the testing process has been the subject of debate in government and donor circles for some time. Some might be tempted to expand HIV testing rapidly without counselling in order to increase access to services to all of the population, because maintaining and expanding the role of counselling in the testing process take time and resources to train and supervise counsellors. Yet the counselling process is central to better inform the population about the risk of HIV infection and ways to protect against it, as well as to provide an entry point for social and medical services. Some of the counsellors interviewed said that they do not have sufficient time with clients and that they need more support. The role of counsellors in VCT services should not be compromised as services expand.

CHAPTER 1

INTRODUCTION

This study of the National Statistical Office (NSO) of Malawi examined public interest in HIV testing and the experiences of clients of voluntary counselling and testing (VCT) facilities. Although the initial objective of the study was the formulation of a questionnaire in Chichewa and English that could be used in a survey to measure public interest in HIV testing and counselling, it quickly became clear that the data collected could be useful to the Malawi Ministry of Health and Population, to donors, or to anyone else involved in the expansion of VCT facilities in Malawi. This report was thus written to make these data available to interested parties within and outside Malawi.

The background section (Chapter 2) describes the context of HIV/AIDS in Malawi and current options for VCT in Malawi and in neighbouring countries to provide a wider context for the study results. The study design chapter (Chapter 3) presents the research questions that guided the data collection and the underlying assumptions of the research. Chapter 4 discusses the study's methodology, including data collection and sampling. Chapter 5 through 7 present the findings and report on conversations held with three types of respondents: the general public, on their interest in HIV testing; VCT clients, who experienced HIV testing and counselling; and VCT counsellors who provided services. The conclusion (Chapter 8) provides an overview of the implications of the findings.

1.1 Objectives

The original mandate of this study was to collect information about what the general public knew about HIV testing and counselling and to document the experience of VCT clients who came to facilities for an HIV test. Client experiences in VCT facilities became part of the study because it was assumed that the experience of VCT clients in getting tested would affect general knowledge and opinions about the process of testing and counselling as clients told others about their experience in getting tested and receiving counselling. The study chose to interview counsellors as well, to obtain their perspective on the testing and counselling process.

The first task of the study was to generate information about public knowledge and experience with HIV counselling and testing. Gaining an understanding of what the public has heard about HIV/AIDS and HIV testing and counselling, as well as the ways in which individuals describe their readiness to seek an HIV test or explain how and why they have no interest in HIV testing, was considered essential for assessing interest in getting tested for HIV voluntarily in a facility.

The second task was to document the experience of clients of VCT services currently available as individuals were welcomed into a testing facility, as they gave blood for a test, and as they were given advice about their own situation and ways to avoid the risk of HIV infection. Special attention was given to the circumstances that brought them into a testing facility as well as to the specific advice they were given by counsellors. It was expected that client comments about their experience in getting tested and receiving counselling would provide some indication of what aspects of the testing and counselling process were most important in making VCT services appealing to clients.

The third task of the study was to understand the work of VCT counsellors, particularly those who were full-time professionals rather than volunteers. Of particular interest was their background and previous employment, the training in counselling they received, their interactions with clients, and the advice they provided to those who tested positive and negative. Attention was also given to their level of job satisfaction as counsellors and their own evaluation of the training they had received.

1.2 Study Implementation

This study was organized and directed by NSO in Zomba, with technical assistance from Macro International Inc., an Opinion Research Corporation company (ORC Macro) in collaboration with the National AIDS Commission. NSO participated in the finalizing of the study design and in the training of fieldworkers, directed the data collections and data processing, and presented the results of the study in Lilongwe. The NSO officers who directed the study were Jameson Ndawala, assistant commissioner, and Ladislav Mpando, chief statistical officer. Data processing took place in the regional office of NSO in Blantyre. NSO hired an experienced consultant from Blantyre, Priscilla Matinga, to direct the fieldwork and the data processing for NSO. ORC Macro was represented by P. Stanley Yoder, senior qualitative research specialist for Measure DHS. The research was financed jointly by the United States Agency for International Development and the Department for International Development (United Kingdom).

CHAPTER 2 BACKGROUND

The overall picture of voluntary counselling and testing (VCT) for HIV in Malawi can best be understood in the context of current knowledge about HIV prevalence, government policy toward HIV prevention, care and treatment of those with HIV infection, government and private efforts to combat HIV transmission, and options for VCT services. Comparison with VCT programs in neighbouring countries can provide ideas for possible approaches to expand VCT strategies. This chapter briefly provides some of that context.

2.1 Prevalence of HIV in Malawi

The first hospital cases of AIDS in Malawi were diagnosed in 1985 (Cheesbrough, 1986), but they were preceded by an increased incidence of Kaposi's sarcoma. According to John Lloyd Lwanda, the 2 percent prevalence rate of HIV discovered among antenatal patients at Queen Elizabeth Hospital in 1985 suggests that HIV may have arrived in Malawi around 1977 (Lwanda, 2004). Prevalence rates among antenatal patients at that hospital subsequently increased rapidly, reaching 8 percent in 1987 and 19 percent in 1989 (Taha et al., 1998).

In the late 1980s, AIDS specialists in Malawi debated what Chichewa terms they should use for AIDS and for the HIV virus. They eventually settled on *Edzi* for AIDS, an onomatopoeic "Chewaizing" of AIDS (Lwanda, 2004). The HIV virus became *kachiroambo ka Edzi*, since *kachiroambo* means a tiny creature, or microbe. Although the media have been using these terms now for years—*Edzi* and *kachiroambo ka Edzi*—many of the persons interviewed did not distinguish between the HIV virus and AIDS. Rather than saying "*kachiroambo ka edzi*," or the AIDS virus, they would say simply "*Edzi*." In speaking in Chichewa, and most likely in English as well, individuals use "the AIDS virus" and "AIDS" interchangeably.

The National AIDS Control Programme (NACP) was founded in 1988 by the Malawian government to lead efforts for health education and the prevention of HIV infection. Before NACP's formation the government had already set up screening mechanisms to ensure a safe blood supply in the two main hospitals in Blantyre and Lilongwe. Similar mechanisms were eventually established for all district and private hospitals. NACP was later replaced by the National AIDS Commission (NAC), an agency that has formulated a national strategic framework of HIV/AIDS prevention and support to guide prevention, care, and treatment.

When the strategic framework was formulated by NAC at the end of 2000, it was recognised that despite government and private efforts to educate the population and care for those with HIV/AIDS, the HIV/AIDS situation in Malawi had not greatly improved in recent years. HIV has spread rapidly among adults (15-49 years old) since the first case of AIDS was officially diagnosed in Malawi in 1985. AIDS has become the leading cause of death among adults 15-49 years old, a group that makes up 44 percent of the total population. In fact, the death rate for adults 15-49 tripled between 1990 and 2003. Mortality from AIDS has reduced life expectancy from an estimated 52 to 42 years.

Malawi now ranks among the countries with the highest national prevalence rates of HIV in the world, but prevalence is not evenly distributed among adults by age or gender. In the age group of 15 to 24, the HIV infection rate of females is twice that of males. Infection with HIV continues to be particularly high among adolescent girls.

Trends over time in HIV prevalence are established with data from sentinel surveillance systems that most often test blood from clients of antenatal clinics. In 1990, NACP began routinely collecting

blood from women attending antenatal clinics for HIV testing in selected sites across the country. The number of sites was increased to 19 in 1994 and has remained the same since then, although the specific location of several sites has been changed. The sites were selected to represent the three main regions of the country as well as urban, semiurban, and rural populations. There are five sites in the northern region and seven in the central and southern regions. Syphilis testing is also conducted in these sites. The number of women tested varies by site, from 193 to 846 (National AIDS Commission, 2001). Annual sentinel surveillance data are available for all years except for 2000 and 2002, when no surveys were conducted.

NAC estimates HIV prevalence in Malawi from antenatal clinic data and the modelling computer software Estimation and Projection Package and Spectrum. In 2003, NAC estimated that the national prevalence of HIV among adults was 14.4 percent, with a range from 12 to 17 percent (National AIDS Commission, 2003). This range of HIV infection has remained constant for the last seven years. Estimates for the rural population and urban areas were 12.4 and 23.0 percent, respectively. The total number of infected adults was 760,000. There are also approximately 70,000 children less than 15 years old with HIV and 60,000 people over the age of 50 who are infected.

HIV infection is not, of course, spread uniformly across the country; there are clear regional differences in HIV prevalence. The country is divided into three regions: Northern, Central, and Southern regions. HIV infection among women attending antenatal clinics in 2003 was lowest in the Central region (15.5 percent) and highest in the Southern region (23.7 percent) with the Northern region in between at 20.0 percent. Until 2003 the Northern region had always shown lower prevalence rates than the other two regions. For reasons still unknown, prevalence in the Central region has decreased from 23 percent in 1999 to 15.5 percent in 2003. Rural rates have always been lower than urban rates, but that difference narrowed in 2003 as rural rates rose to 14.5 percent from 12.1 percent in 1999.

HIV prevalence rates from sentinel surveillance data reached a peak in the mid- to late 1990s and have declined in urban and semiurban areas. At the same time, rates in rural areas have increased. This recent increase suggests that interventions aimed at HIV prevention must address rural as well as urban areas.

2.2 HIV Testing in Malawi

Many organizations, both public and private, have been seeking ways to prevent the spread of HIV in Malawi. Some groups have advocated the establishment of stand-alone centres or hospital divisions that offer HIV testing along with counselling about how to avoid the risk of HIV, but few such centres exist. The Ministry of Health and Population approved the use of rapid test kits for pilot studies in 2000, but it has been slow to allow the expanded use of rapid test kits. However, experiences in a number of African countries have demonstrated that individuals will be far more likely to come for an HIV test if the results are available the same day.

From a public health perspective, VCT offers an entry point for both health education and support, as well as medical care. The use of VCT as a preventive measure has been shown to reduce HIV transmission in certain high-risk groups (Coates et al., 1998). The Voluntary HIV-1 Counselling and Testing Efficacy Study Group has compared the effects of testing and counselling in a three-country study (Coates et al., 2001). Through the Horizons Project and other programs, the United States Agency for International Development (USAID) promotes VCT as a means for reducing risky behaviour. By providing counselling before and after the HIV test, individuals receive information and support for avoiding activities that put them at risk (Horizons, 2001).

A document of the national AIDS strategy planning unit of 1998 mentioned that people are not aware of the advantages of being tested, they are concerned about confidentiality of the results, and they

are not willing to wait long for results (Coombes, 2001). Very little data on how and why individuals come for HIV testing in Malawi are currently available. In one survey conducted by Umoyo Network (2000), 54 percent of the sample said that illness motivated them to be tested. A better understanding of what brings people for testing would be useful for planning the expansion of testing services and/or VCT centres.

While a number of donors, government ministries, and nongovernmental organisations (NGOs) advocate the establishment of many VCT centres throughout the country, it remains unclear to what extent such centres would be used by the population. To what extent is the adult population interested in getting a test for HIV, or in being counselled in conjunction with receiving the test results? Why would men or women come for testing? Why did those who were tested in the past year seek a test? We know little about how to answer such questions.

The questionnaire used in the 2000 Malawi Demographic and Health Survey (MDHS) asked five questions about HIV testing, including “Have you ever been tested to see if you have the AIDS virus?” and “Would you want to be tested for the AIDS virus?” The survey found that 8.5 percent of women and 15.2 percent of men interviewed reported that they had been tested for HIV, so the rate of testing for men is nearly twice that for women. The difference between men and women is most pronounced for those age 25-29 years old, among which 23.7 percent of men and 10.6 percent of women had been tested. A total of 16.5 percent of women and 11.3 percent of men said that they did not want to be tested. Having been tested at least once correlated closely with higher education, and urban populations were more likely than rural ones to have been tested.

There are currently both public and private centres able to conduct HIV testing, and sometimes counselling, in the country. During the 2000 MDHS, men and women were asked whether they had been tested for AIDS and, for those who responded affirmatively, where they had gone for the test. Fifty-eight percent of women and 49 percent of men said that they had been tested in a public (government) facility. Thirty percent of women and 38 percent of men reported that they had been tested in a private facility. Eight percent of women and 10 percent of men said that they had gone to Malawi AIDS Counselling and Resource Organization (MACRO), a nongovernmental agency supported by the Centers for Disease Control and Prevention (CDC) with a centre in Blantyre and one in Lilongwe that had been operating for several years at the time of the survey. A third MACRO centre offering VCT had also been opened in Mzuzu in November 2000.

The national strategic framework for HIV/AIDS prevention in Malawi includes establishing numerous centres for HIV counselling and testing, the training of qualified counsellors, and a public education campaign to encourage the use of testing services. USAID has allocated funds for at least 11 new VCT centres to be established as soon as possible. NAC and donors seek to expand testing centres that provide counselling before and after the blood test. For example, MACRO receives donor funds through the Umoyo Network to maintain its three testing centres. A few other (private) centres operating with assistance from international NGOs offer systematic counselling along with HIV testing in the country.

MACRO was formed as a national NGO in 1995, but it did not attract large numbers of clients until 2000. The increase is attributed in part to the introduction of whole-blood rapid HIV test kits to its centres in January 2000. Clients can receive their test results in less than one hour. The MACRO annual report for 2000 reported a major increase in the number of clients served, with each centre (Blantyre and Lilongwe) serving more than 1,000 clients per month (Malawi AIDS Counselling and Resource Organisation 2001). The increase in clients was attributed to the ability to conduct rapid tests and to provide same-day test results, as well as a major advertising campaign on the radio. About 75 percent of the clients were male. The MACRO clients who requested an HIV test in 2000 tended to be young. Three-

fourths (76 percent) were 15 to 29 years old. The rates of testing positive for HIV among the 21,483 clients tested in these two VCT centres was 13 percent for males and 33 percent for females. The rate of HIV-positive MACRO clients in 2000 for females age 25-44 years was around 50 percent.

The MACRO annual report for October 2002 to October 2003 shows that the number of clients has continued to increase (Malawi AIDS Counselling and Resource Organisation 2003). During this reporting period, the three MACRO facilities served 51,178 clients: 18,841 in Blantyre, 17,840 in Lilongwe, and 14,497 in Mzuzu. These figures included 1,060 couples who came for testing and counselling. Clients at these VCT facilities tend to be younger; 62 percent of MACRO clients for this period were 15 to 29 years old. The report also shows that the male/female ratio was closer to 2/1 than 3/1, as had been reported for the year 2000. The gender gap in clients has closed somewhat. However, women had consistently higher rates of HIV-positive results in all age groups. While this may reflect somewhat higher prevalence rates for women, it may also indicate that women come for testing in circumstances that are different from those of men. A higher percentage of women than men reported that they came for a test because they felt ill.

The MACRO experience to date has shown that the numbers of VCT clients can be increased rapidly in stand-alone facilities in Malawi. Interviews with VCT clients in MACRO facilities in Blantyre and Lilongwe showed that the expectation of free and rapid test results was part of the reason for their coming for a test.

2.3 VCT in Neighbouring Countries

A number of reports and published articles about VCT in neighbouring countries (Kenya, Tanzania, Uganda, and Zambia) show that VCT services in these countries has been more rapidly developed than such services in Malawi. In Uganda, the AIDS Information Centre (AIC) was founded in 1990 to provide not only voluntary counselling and testing, but also medical services for sexually transmitted infections (STIs) and social support services to clients. A Joint United Nations programme on HIV/AIDS (UNAIDS) case study reported that more than 370,000 clients had been served by AIC in four sites by 1999 (Joint United Nations programme on HIV/AIDS, 1999). In Tanzania, the African Medical and Research Foundation (AMREF), with support from USAID and other donors, has set up a network of 19 VCT sites throughout the country.

The Horizons Project recently conducted research in Kenya and Uganda on the experience of young people being tested in the facilities offering HIV tests. In both countries, researchers found a wide range of configurations of testing and counselling offered. Some facilities provide only testing and no counselling. Other facilities provide only counselling, but they send clients to another venue for testing (Horizons, 2001). Clinics that offer antenatal or STI services in Kenya and Uganda may test for HIV without the client's knowledge, with results unlinked to individuals.

The studies conducted in Kenya and Uganda by Horizons indicated that youth were concerned about two aspects of the testing process: that the interaction be confidential at the facility and that they could come for testing and leave again without being seen or recognised by anyone else. Youth in Nairobi said people go for testing only if they do not feel well, that is, if they suspect their health is failing. In a country such as Malawi, with an urban population that may be 25 percent HIV positive, one would also expect a certain number to want to be tested because they fear they have HIV.

The Voluntary HIV-1 Counselling and Testing Efficacy Study Group conducted a study of the efficacy of VCT in reducing unprotected intercourse in sites in three countries: Nairobi, Kenya; Dar es Salaam, Tanzania; and Port of Spain, Trinidad (Coates et al., 2000 Sweat, M. et al., 2000). More than three thousand (3120) individuals and 586 couples were randomly assigned to receive VCT or a health education talk. Those who were assigned to VCT were tested for HIV and received individual

counselling. Those assigned to health education watched a 15-minute video and participated in a discussion about HIV transmission and condom use. The study showed a marked decrease in rates of unprotected sex for both men and women participating. The decrease in unprotected sex for men was 35 percent for the VCT group and 13 percent for the health education group; results for women were 39 percent and 17 percent, respectively.

A study of VCT in Zambia offers some insights into how and why people participate in testing for HIV (Fylkesnes et al., 1999). A random sample of households was selected in one urban neighbourhood of Lusaka and in several rural neighbourhoods around Kapiri Mposhi, some 150 kilometres to the north. Adults in these households were invited to take an HIV test. From the total sample of 4,812 individuals interviewed, 37 percent expressed a willingness to be tested. They were given instructions about when and where to go for the test. Of this group (37 percent of 4,812 = 1780), only 9.4 percent ($N = 167$) actually came for a test, and less than half of this number returned for counselling and the test results. Urban men used this opportunity more than did urban women, but the proportion of the rural population who came to be tested was higher than that of urban residents. The researchers suggest that individuals seemed to prefer a context for testing in which the health care personnel did not know them and where privacy was assured.

CHAPTER 3 STUDY DESIGN

This study among the general public and voluntary counselling and testing (VCT) clients in Malawi was designed to discover how individuals talk about HIV and AIDS and getting tested for HIV, as well as how individuals evaluate the experience of getting tested and receiving counselling. Of particular interest were the following factors:

- Knowledge of HIV and AIDS among adults
- Knowledge about the options for HIV testing and counselling
- The level of interest in learning one's own HIV status
- Experience with VCT and related services
- The implications of positive and negative test results for individuals.

Each of these factors depends to some extent on the others. Thus, a high level of interest in learning one's serostatus is more likely in contexts of detailed knowledge of options for testing, and the implications of test results will be influenced by the experience with VCT services.

3.1 Specific Research Questions

The themes of the study were framed in the proposal as research questions to guide the design and the study implementation. The questions were developed from the overall theme of the study. Each question is followed by elements that were assumed to be relevant to the question.

1. What does the public know about HIV and AIDS?
 - Distinguishing between HIV and AIDS
 - Signs of AIDS
 - Causes of AIDS
 - Prevention of HIV infection
2. What have people heard about getting tested for HIV and being counselled?
 - Options for getting tested
 - Costs of an HIV test
 - Rapidity of obtaining results
 - Advice that may be given
3. What concerns and circumstances currently bring individuals into facilities that offer testing and counselling?
 - Social situation of individuals
 - Life events
 - Discussions with others (i.e., family, friends, sexual partners)
 - Past experience with HIV testing
 - Social and medical services available upon obtaining test results
 - Public discourse on AIDS, HIV testing, and counselling
 - Concerns about stigma
4. What has been the experience of individuals who have used VCT services?

- Speed of obtaining results
- Confidentiality
- Quality of counselling obtained
- Possibility of follow up with sexual partners

5. What elements of testing facilities are most important to the public?

- Independent or integrated services
- Social and medical services offered
- Rapidity of results
- Counselling
- Confidentiality and anonymity

Other more detailed questions considered included—

- How do people talk about being ready for taking an HIV test or not?
- How do men and women respond to a positive test for HIV? To a negative result?
- How does counselling occur before and after a test result?
- What individual or family circumstances may lead to an individual obtaining an HIV test?
- What advantages or benefits are obtained by knowing for certain your HIV status?

Although the study sought to understand public experience with both HIV testing and with counselling, at the outset it was assumed that when an individual comes to a VCT facility, he or she is seeking a blood test and is not thinking about counselling. Thus, the demand for testing and for counselling was considered separately. Assumptions about knowledge and experience related to HIV testing and counselling were discussed during the training as a way of clarifying the perceptions of the fieldworkers who would ask questions in interviews. Such perceptions influence the way questions are asked and the way lines of questioning are pursued. The most important assumptions discussed are found below.

3.2 Assumptions

1. The population in Malawi has a knowledge of AIDS and how it can be prevented that is close to the biomedical view of HIV prevention.
2. Most people have seen individuals who are sick because of an HIV infection.
3. People who come to a VCT facility for an HIV test do not want others to know they visited the facility.
4. Most people who seek an HIV test do so because they are afraid they have been exposed to HIV infection because of their own actions or the actions of another.
5. Urban residents will be more willing than rural ones to take an HIV test.

No assumptions were made about the counselling process, for the training group did not have any information about how counselling was conducted. The group did not formulate any hypotheses about seeking an HIV test or the counselling process. One hypothesis that might have been discussed was that men and women seek an HIV test for different reasons.

CHAPTER 4 METHODOLOGY

The methodological outlines for this study were first formulated in the research proposal written at Macro International Inc., an Opinion Research Corporation company (ORC Macro) and submitted for comments to the National Statistical office (NSO). The proposal presented the overall objectives of the study, a discussion of current knowledge of HIV/AIDS in Malawi and options for HIV testing, the research questions to guide the data collection, a description of the data collection and analysis, and a proposed schedule of activities. After making adjustments to the schedule of activities, the NSO proceeded with organizing the study.

4.1 Data Collection Methods

The study was designed to interview three different groups of people: 1) adults in the general public, 2) clients who came to a voluntary counselling and testing (VCT) centre for an HIV test, and 3) the counsellors who work in those centres. Information about knowledge of HIV, AIDS, and HIV testing and counselling was collected through individual interviews with adults in rural and urban areas of Blantyre and Chiradzulu districts (Southern region) and Lilongwe and Dowa districts (Central region). The study team interviewed clients at VCT centres about the circumstances that had brought them to a testing facility and their experience with testing and counselling at these centres. Counsellors working at VCT centres were interviewed about their prior employment, their training for counselling, their interaction with clients, their job satisfaction, and the advice they give to clients. The interviewers took notes from observations of the welcoming and client flow at testing facilities. The interviews were conducted in Chichewa and tape-recorded with permission granted by those interviewed.

4.2 Training

The training of fieldworkers for data collection over a period of two weeks took place at the Multi-Country Training Centre in Blantyre. Dr. Stanley Yoder from ORC Macro directed the training with assistance from Priscilla Matinga, a local consultant and social anthropologist. NSO personnel provided logistical support and participated in the training. The consultant identified 12 people to participate in the training course for the study. Selection of participants was based on the availability of people for at least three months, previous experience in research work, and education qualification of not less than a Malawi School Certificate Exam level.

The specific objectives of the training were to train the team in principles of qualitative research and in techniques of open-ended interviewing, to develop the research instruments with the team and train them in the use of those instruments, and to develop guidelines for transcribing the recorded interviews in Chichewa and translating the texts into English. The training covered background information about HIV testing in Malawi and the assumptions in the group about interest in HIV testing. The research questions from the proposal were modified to better reflect the situation of HIV/AIDS in Malawi. Research instruments were developed during the training with participation of the entire research team, the representatives of NSO, the consultant, and the training facilitator. At the end of the ten-day training, ten fieldworkers were retained for data collection and transcription. Skills required for the fieldwork included clear self-presentation and easy followup questioning, precise note taking, transcribing, and accurate typing.

An overview of qualitative research methods was discussed, with an emphasis on the use of in-depth interviews in data collection. Discussions during the training also touched on ways of paying particular attention to terms and concepts invoked when discussing the experience of getting an HIV test or of being counselled. After the questioning guide was put together by the team, role-plays were

conducted to practice the interviewing process. Plenary discussions provided feedback to individuals and the entire group on how the role-plays of the interviews were conducted. The group developed the question guide in Chichewa, the main language of central and southern Malawi, from themes formulated in English through group discussions. The question guides were then translated back into English to ensure correspondence with the issues as framed in English. At a later stage, the question guide was also translated into Yao, a language also spoken in Chiradzulu district.

The data collection instruments were questioning guides that followed a logical sequence of general questions about family and individual health, knowledge of HIV and AIDS, knowledge of HIV testing and counselling, and personal experience with HIV testing. These questioning guides were in the form of a 1½-page outline of topics to cover rather than specific questions. Separate guides were developed for interviews with the general public, with VCT clients, and with VCT counsellors. The questioning guide for VCT clients focussed less on the family situation and more on the circumstances that had brought them into a VCT facility and their experience at the facility in being tested and counselled. Interviews with counsellors covered their prior employment history, their training as a counsellor, their job satisfaction, and their interaction with clients.

The instruments developed were pretested in one low-density (more affluent) and one high-density (poorer) residential area of Blantyre. Findings from the pretest exercise were discussed by the entire research team, and appropriate adjustments were made to the research instruments. The questioning guide for the general public is included as Appendix A, the questioning guide for VCT clients is included as Appendix B, and the guide for counsellors is included as Appendix C.

The training was also used to develop a schedule for the fieldwork and allocate responsibilities for fieldwork. One team of three people was assigned to interview clients at the VCT sites and transcribe clients' responses from tape recorders. A second team, also three people, was responsible for interviewing the general public and also transcribing clients' responses from tape recorders. A third team of four people was responsible for data entry, identification of lexicons from text, and translations of data. The consultant was responsible for supervising the interviews at VCT centres, conducting interviews with VCT counsellors in all of the VCT centres, and transcribing and translating the counsellor interviews.

4.3 Choice of Field Sites

The study sites and sample size were determined in consultation with specialists from NSO and the National AIDS Commission (NAC). The demographic variables expected to affect interest in getting an HIV test include sex, age, education, and urban-rural residence. The study was conducted in four sites: two urban sites and two rural sites. Research sites were selected on the basis of availability of VCT services in the district. Thus, Blantyre and Chiradzulu districts were selected in the Southern region, and Lilongwe and Dowa districts were selected in the Central region.

4.4 Sampling

The goal for interviewing adults about their knowledge of HIV, AIDS, and HIV testing was to identify 50 men and 50 women typical of the population in Blantyre (urban) and Chiradzulu (rural) districts and do the same in Lilongwe (urban) and Dowa (rural) districts to obtain a total of 200 interviews equally divided between men and women. In the city of Blantyre, the neighbourhoods of Bangwe (high density) and Nkolokosa (medium density) were visited. Households were chosen by sending each team member down a different street with instructions to contact every third household until the requisite number of interviews had been completed for the day. Only one person was interviewed per household.

The process of choosing households was supervised by a member of NSO. A similar strategy was used in Lilongwe, where the neighbourhoods chosen were Kawale and Area 18. The same strategy to

interview in dispersed households was followed in the rural areas: Chiradzulu district outside Blantyre and Dowa district outside Lilongwe.

The actual sample of general public interviews came close to the desired numbers; 45 men and 61 women were interviewed in Blantyre (urban and rural), and 54 men and 51 women were interviewed in Lilongwe (urban and rural), for a total of 99 men and 112 women. Fieldworkers found it somewhat easier to find women than men at home to interview. The persons interviewed ranged in age from 15 to 55 years old.

The sample sought of VCT clients was 100 men and 100 women, distributed in age from 15 through 49 and taken in equal numbers from the two Malawi AIDS Counselling and Resource Organisation (MACRO) facilities in Blantyre and Lilongwe, plus one other centre outside Blantyre and one outside Lilongwe. The study team considered it important to interview clients in all age ranges, for there may be systematic differences in the clients according to their age. Interviewing clients at the MACRO stand-alone facilities, as well as facilities attached to medical services would provide a wide range of experience in client experiences in getting tested.

Table 1 shows the sample of VCT clients actually achieved. This sample differed from what was sought in that most of the clients came from the two MACRO centres, and many more men were interviewed than women. Only three clients were interviewed in Chiradzulu (Chiradzulu HIV/AIDS Resource Centre [CHARC]) because only a few clients were seen per day, so the site of Thyolo was added as an alternative site, where technical services were provided by Médecins Sans Frontières (MSF) Luxembourg. The number of men exceeded that of women because in the MACRO facilities, the ratio of men to women was about 2/1, making it more difficult to find the desired number of women in a week's time. Nevertheless, the number of women (90) was deemed sufficient for understanding women's experiences as VCT clients, while the number of men exceeded expectations. The table also shows that younger clientele dominated, which reflects the type of clients who come to MACRO for HIV testing.

	Men	Women	Total
MACRO Blantyre	77	46	123
MACRO Lilongwe	66	43	109
Thyolo MSF	9	1	10
CHARC	3	0	3
Total	155	90	245

4.5 Data Collection

The identification of households and the selection of individuals for interviews with the general public did not pose any problems for interviewers. The study team usually completed the interviews in the morning and transcribed the recordings in the afternoons. Interviews with clients at VCT centres, however, proved far more of a challenge. Priscilla Matinga directed the data collection process.

After observations of the testing and counselling procedures at MACRO in Blantyre, it was decided to interview each VCT client at three different points. The interviewers had a brief conversation with a client soon after he or she arrived at the facility and before the first health talks. The second point of contact followed the pretest counselling, and the final interview occurred after the client had received the test results and the posttest counselling. Therefore, the study team divided the question guide for VCT clients into three sections. The first section covered general issues about the client and the reasons for coming for the HIV test. The second section asked questions about the initial health talks and the pretest

counselling to find out what issues the pretest counselling covered and the nature of the interaction. The last section of the topic guide dealt with client's experience with the post-test counselling and testing centre, satisfaction with the counselling process, and client's concerns and/or questions after the test results were disclosed.

All counsellors working at the VCT centres visited were interviewed for the study by Priscilla Matinga, who also wrote a summary of the interviews with counsellors. Counsellors were generous with their time and attention, and they found time during or after working hours to discuss their work.

4.6 Data Processing and Analysis

Most of the recorded interviews were transcribed and translated into English in the regional office of NSO in Blantyre. To formulate appropriate questions, fieldworkers also wrote down terms, concepts, or expressions used by respondents in order to learn exactly how people talk about issues concerning HIV testing. English translations were typed into Microsoft Word and were sent to NSO for safekeeping. A certain number of the interviews were also typed at the NSO office in Zomba.

The files of the English translations of interviews were sent to ORC Macro for review and analysis. The parts of the public interviews that pertained to knowledge of HIV testing and willingness to be tested were extracted and placed into separate files for easier reading. A similar procedure was used for reading the parts of VCT client interviews that related to the circumstances that brought them in for testing and their experience in a VCT centre. Since there were only 27 interviews with counsellors, those texts were read numerous times in their entirety.

CHAPTER 5

INTEREST IN HIV TESTING AMONG THE GENERAL PUBLIC

Adults in the Central and Southern region were interviewed in a semi-structured fashion to get them to talk about the health and illness of their family, their knowledge of HIV and AIDS, their experience with individuals who had AIDS, and their knowledge of HIV testing and counselling. Questions were also asked about why the respondents thought that people get tested for HIV. The main objective of these interviews was to assess peoples' interest in getting tested for HIV at the time or in the future. This chapter presents the results of those conversations.

5.1 Knowledge of AIDS

The interviews began with questions about the illnesses that respondents or their family had. Nearly everyone reported that they often were affected by malaria (*malungo*), and many mentioned asthma or high blood pressure (*nthenda ya magazi*) as an illness that affected them. A small number reported that they or one of their relatives had once had tuberculosis.

Public interest in HIV testing has developed within a social context where there is tremendous fear and stigma associated with AIDS, where denial that a person has died of AIDS is common, and where little treatment—curative or palliative—is available for those with HIV. As in many other countries in Africa, AIDS was initially associated in Malawi only with “high-risk groups,” but that association is being eroded now as HIV infection may affect anyone. For some years now, radio broadcasts have been urging ordinary people (not “high-risk groups”) to get tested for HIV. Some broadcasts have also talked of the importance of counselling (*uphungu*), or advice, that individuals receive when they are tested.

However, in 2003 there were not many places in Malawi able to provide professional counselling along with an HIV test. While a number of hospitals provide HIV testing, they may or may not offer counselling along with the test results, and their counsellors may be volunteers or professional. For example, during the fieldwork, the main hospital in Blantyre relied on volunteer counsellors to advise clients who came for an HIV test. Only a few stand-alone VCT centres with trained counsellors operate in Malawi.

Respondents were asked what causes AIDS, how AIDS is spread, and how transmission can be prevented. Almost everyone said AIDS comes from *chiwerewere*, or “running around.” Most people also mentioned razor blades, needles, and toothbrushes, with some specifying that the danger stems from using blades, needles, or toothbrushes a second time without sterilisation, while others just mentioned the item. However, most women emphasized that AIDS was being spread through *chiwerewere*. If only one way of spreading AIDS was mentioned, it was always *chiwerewere*.

Many AIDS specialists in Malawi have translated *chiwerewere* as “casual sex,” a concept that in American English establishes a contrast between two types of sexual relations: casual sex, which implies sex with no connection or relationship, in contrast to sex as part of a personal connection or relationship. The dominant metaphor of *chiwerewere*, however, focuses not on the individuals and their sexual relationship, but on the actions of the participants: they have been “walking or moving around.” In American English, the expressions “running around,” or “sleeping around” are very close to the Chichewa image, an image of a person moving from one partner to another.

In fact, the Chichewa verb that conveys the meaning of running around is *kuyendayenda*. Although often translated as “to move,” the verb actually includes the image of repetition, of actions being repeated, thus suggesting movement to several partners. In Malawi, just as in Zambia, those prone to having several sexual partners are called “movious.”

One married woman from a rural area in Blantyre said this about how AIDS is spread:

AIDS is brought into the house by a man, for you don't know where he walks; however, a woman who stays in the house, at home, she can remain as she is.

Many women who suspected that their husband had other sexual partners, or who were reflecting on their own lives, expressed themselves with this image of moving around. In commenting on her knowledge of HIV testing, a woman from Lilongwe said—

When you get tested, when you see that you don't have AIDS, you keep doing what you were doing. You are doing things so you do not get that disease (AIDS). So when you get tested and they find you with it (HIV), you know that you should decrease your movements.

When another woman from Lilongwe spoke about why people get tested, she said—

Also, sometimes people get tested when they suspect themselves, because of the way they had been moving.

A man from Chiradzulu, when asked about whether he had ever been tested, said—

I have never been tested because I don't have any doubts, since I don't have sex. People who go for a test, they have doubts about themselves because of how they have been moving.

The concept of *chiwerewere* is important in that the reference point is the home, the household, or the spouse or long-time sexual partner. Thus, any physical movement away from home or a long-term partner may create opportunities for *chiwerewere*. Any movement away from the spouse or partner may raise suspicions.

Just as the respondents knew the ways that the AIDS virus spreads, they also clearly described the ways to prevent the spread of AIDS. Respondents explained that AIDS can be prevented by avoiding the items they had mentioned (razor blades, toothbrushes, needles) as well as avoiding *chiwerewere*. Respondents said they could avoid AIDS by—

Avoiding sex and using condoms. By not sharing razor blades or toothbrushes, also by not sharing needles. That is what I know. (Woman, Blantyre)

What causes AIDS is sexual intercourse, receiving unsafe injections, or sharing of razor blades and toothbrushes and needles. (Young man, Lilongwe)

We can avoid it by using a condom or not sharing toothbrushes and razor blades. (Man, Lilongwe)

Not having sex with people whom we don't know well, like those women in bars, or like those from Tanzania who stay in rest houses. The best way is to deny yourself (abstain) with regard to sex. (Woman, Lilongwe)

One woman from Blantyre gave a long list of ways AIDS is spread:

The main way through which AIDS is spread is by sleeping around (*chiwerewere*), especially unprotected sex. At the same time there are other ways:

- If you come into contact with someone's blood, and you have a cut in your skin
- Sharing toothbrushes

- Mother to child
- Through breastfeeding and delivery
- Using unboiled needles
- Razor blades used by traditional healers.

People's responses to questions about HIV or AIDS transmission were striking in their consistency. They nearly always mentioned *chiwerewere*, razor blades, and toothbrushes. The consistency suggests that the media have been repeating the same message for a long time. No systematic differences in knowledge of AIDS were found in comparing urban and rural respondents.

Although many people may not distinguish between AIDS and HIV, they all understood that one can "contract AIDS" by "sleeping around." Therefore, it stands to reason for them that a person who has AIDS has been sleeping around with multiple partners.

5.2 Signs of AIDS

Nearly everyone interviewed knew of characteristic signs that they associated with AIDS: the body becomes thin, the skin becomes pale, the hair becomes thinner and sparse, and chronic diarrhoea sets in. Quite a few people also mentioned having sores that do not heal. Thus, it seems that people have seen sufficient cases of AIDS or have heard in the media about the signs of illness that suggest an HIV infection when they occur together. When asked about what illnesses resemble AIDS, many mentioned tuberculosis.

Awareness of the common signs of AIDS does not mean, however, that individuals will be willing to acknowledge to others that a particular individual suffers from AIDS. This hesitancy appears most dramatically in discussion of the cause of death when someone dies of AIDS. As individuals remarked—

The way things are, we have different customs, and people are not told that so-and-so died of AIDS. It's very rare for people to admit that a person has died of AIDS. If it should become known that such-and-such a person died of AIDS, people would refuse to wash that body. So it is difficult to say that she or he has died of AIDS. They just say he got sick. (Young man, Blantyre)

It's very rare for people to admit that this person has died of AIDS ... they say he just got sick. (Young woman, Blantyre)

When a person dies, it is not announced that they have died of AIDS. (Woman, Chiradzulu)

There is a disease that is like AIDS, it is known as "*tsempho*." ... Coughing and losing weight are signs, but when you ask them what's wrong, you hear they are OK. But the body is becoming smaller, the hair has started to get thin and weak, and then the person gets really thin. So if we take that person and someone with AIDS, and place them together, you will see that they look exactly the same. But the diseases are different. This one is "*tsempho*." (Man, Blantyre)

Although most people seem to recognize the combination of signs of illness that suggests AIDS, few people are willing and able to state out loud that so-and-so has HIV or AIDS. Most people prefer to hide any symptoms of AIDS, and those who know that someone has the virus avoid discussing the subject as long as possible. Persons with these conditions are described as having certain symptoms, for they are obvious, but no one talks about AIDS as the underlying cause.

5.3 Talking about HIV Testing and Counselling

Respondents were asked what they had heard about getting blood tested for HIV and whether they had heard of counselling. Nearly everyone had heard of blood tests for HIV or for AIDS, and a good number had heard of counselling. They had heard on the radio that a person can get their blood tested to see whether or not they have the AIDS virus. The radio campaign promoting voluntary counselling and testing (VCT) in Central and Southern regions of Malawi has certainly reached the neighbourhoods in which this study was conducted. However, a very small number of respondents had never heard of HIV testing.

The majority of people in the urban samples of Blantyre and Lilongwe had heard about getting tested at the Malawi AIDS Counselling and Resource Organisation (MACRO) facilities. A few mentioned that the test is free or that the results are available in 15 minutes. The quotes below from individuals in urban Blantyre and Lilongwe are typical of what many individuals stated.

I heard about testing on a radio advertisement and from people who have already taken the test. Testing is important because a person can know if they have the virus and how to take care of themselves. If they do not have it, then they should avoid the disease. (Woman, Blantyre)

These things are being said everywhere on the radio and even in churches. Every day the government talks about HIV testing on the radio and sometimes in churches. They say it is good to go for a blood test. (Woman, Blantyre)

I know that at MACRO they do testing and within 15 minutes you get results. Yes, I have heard that before testing, they counsel you, and then they tell you if you have AIDS or not. (Man, Blantyre)

I have heard that it is better to know rather than not knowing, so that you should know how you are and how to take care of yourself. (Woman, Lilongwe)

Testing is necessary. When a person has gone for testing and finds that he has the virus, he will take care of himself so he can live longer, but if you have not been tested, and you have the virus, maybe you can be doing things that will make you die sooner. (Woman, Lilongwe)

Respondents living in rural areas tended to talk about getting tested at a hospital rather than at MACRO facilities. Several mentioned that people get tested at the Médecins Sans Frontières (MSF) Thyolo or the Chiradzulu hospital. These respondents did not specify how they had heard of getting tested.

A small number of men and women said that they had never heard of such a test. It should be noted that one cannot take all such answers at face value, for several of those who said they had never heard of blood tests subsequently said that they knew where one could obtain such a test. Overall, however, these interviews suggest that radio has been used effectively to publicize the possibility and advantages of getting an HIV test.

About one-third of respondents had heard about counselling and could say something about what counselling involves.

They should go where they test blood, like MACRO. After they have been tested, they give counselling on what a person should be doing about abstinence and eating enough. It is possible for one to live for many days even though they have the virus. (Woman, Blantyre)

I hear that first they tell you that whether we find you with the disease or not, you should look after yourself. It is not that when they find you with the disease you will die right away. If you can look after yourself, you will live longer. (Woman, Blantyre)

After a person has been tested, they get advice about what a person should be doing to abstain from sex and eat well. It is possible for one to live many days even though they have the virus. (Man, Blantyre)

If they test us and don't find it with us, they tell us that we should continue with the way we were doing things. They say, do not look at others, look at your husband only. We need to be faithful in the family. If you do so, you will take good care of your children, because you will not get AIDS. (Woman, Blantyre)

When you get tested and find that you have the virus, they tell you what to do. You eat this, you should do that. Maybe they will give you advice on how to live if you are married. So I see that it is good. (Woman, Lilongwe)

The comments about counselling suggest that people have heard that they will be given instructions about how to better live their lives. Such expectations vary somewhat with what counsellors are taught, which is to develop a strategy for reducing risky behaviour in a dialogue with clients. However, the expectations are understandable, for it would be difficult to explain such a strategy in a simple radio message.

5.4 Reasons for Getting Tested

The promotion of HIV testing should produce an accurate understanding of how and why individuals currently seek an HIV test. The reasons for seeking an HIV test are situated at two levels: the social circumstances that push people to get tested and the reasons that people tell themselves or others that they have come for a test. This study approached this issue in three ways. First, the training included discussions of how and why people come for testing, according to the training participants. Second, in the interviews with the general public, individuals were asked why people might come for an HIV test. Third, clients who came for a test at a VCT centre were asked what brought them there.

Respondents were asked why people in general get tested for HIV. Of course, many said it was to know whether they are HIV positive or negative, and so follow-up questions were asked. The ultimate reason for seeking a test was to find out whether they were HIV positive or negative, but the study was seeking to understand how and why individuals, most of whom had never been tested for HIV, think people in general want to know their serostatus.

The reasons given for getting tested for HIV fall into four categories:

1. Response to signs of illness

These people think that some individuals get tested for HIV because they have been feeling sick over a long period of time or they are losing weight or have one or more of the opportunistic infections often associated with AIDS (e.g., tuberculosis, chronic diarrhoea, skin rashes). Others may get tested after their spouse has died of a lingering illness. In the MACRO data on VCT clients, it was older women who were the most likely to be found HIV positive. In 2000, more than 50 percent of women over 30 years old who came for HIV testing to MACRO facilities were HIV positive.

2. When individuals feel at risk or vulnerable to HIV infection

Individuals who have had several sexual partners may begin to wonder whether they have been infected, since the media portray such actions as risky. Others may wonder about their spouse or partner, when for some reason they suspect he or she may be having sex with others. In both cases, there is only suspicion and anxiety. In Chichewa, the words to express the sentiment of doubting oneself is *kukayika* and of doubting someone else is *kumukayikila*.

Some go for testing because they doubt themselves, because of how they have been moving around. The problem is, you don't know how your partner is moving. That is why many people I see get tested. (Woman, Dowa)

People get blood tests to see if they have the AIDS virus in their body or not. But other people just want to know how they are, for maybe sometime they did not move well. (Man, Blantyre)

Sometimes people go for testing because of the way they have moved in the past, and they are anxious (having doubts) about themselves. (Man, Lilongwe)

3. Many individuals said that people will come for an HIV test when they are planning an event in their lives, such as having a child, getting married, or getting a new job. Many people mentioned that couples should get tested together before getting married so they both know what to expect and so they can relax and not worry.

When one wants to get married, it is good to go for testing with your partner, so that you are sure. (Man, Blantyre, urban)

4. Another common response was “just to know how I am” or “to know how my blood is.”

Such responses are likely an indirect way of saying that they want to be sure they do not have the HIV virus, for they realize that they may have been infected. In fact, such responses seem like the equivalent of the second reason (above), when individuals feel they have placed themselves at risk for HIV infection.

Even though you are tested, they don't give you treatment. If you know that you have the virus, you can die faster because of your own worries. (Woman, Blantyre)

Testing blood is important because it tells a person what their status is. You can make future plans that way, but you also know that when you have it, you should protect yourself. (Woman, Blantyre)

I have heard that people should go for testing to know if they are positive or negative. The advice that is given there may help that AIDS should not spread. (Woman, Lilongwe)

One person actually mentioned all four reasons, in saying that people get tested because—

They want to know how their body is, they want to get married, or they may want to give blood. Or if you are doubting yourself, or you are suffering from a disease. (Man, Lilongwe).

Although the responses to questions about what brings people for testing varied, the most commonly cited reason was having doubts about one's own actions or that of a spouse, indicating a fear of possible exposure to HIV infection. As will be seen in the next chapter, such reasoning fits with what actually brought clients to VCT facilities.

5.5 Readiness for an HIV Test

After questions about knowledge of AIDS testing, counselling, places where one can obtain an HIV test, and reasons why people seek a test, respondents were asked whether they had ever had a blood test. Some reported that they had chosen to get an HIV test, but others said that they had been tested because they wanted to give blood or because they were pregnant, or for some other reason. Those who said that they had never been tested were asked whether they planned to get tested in the future.

Table 2 summarizes the answers to these questions (classified by having been tested or not, and the purpose of the blood testing) for women and men.

WOMEN								
	Not tested				Tested			
	No interest	Wait	Want now	No info	Malaria	Pregnancy	Donate blood	For HIV
Lilongwe	14	20	7	2	0	0	3	5
Blantyre	16	10	12	4	1	3	1	14
Total	30	30	19	6	1	3	4	19
MEN								
	Not tested				Tested			
	No interest	Wait	Want now	No info	Malaria	Other	Donate blood	For HIV
Lilongwe	17	15	6	3	1	3	2	12
Blantyre	7	18	3	3	0		4	5
Total	24	33	9	6	1	3	6	17
TOTAL								
Total	54	63	28	12	2	6	10	36

The table shows that the large majority of respondents (175, or 74 percent) had never been *voluntarily* tested for HIV, but a small number (17 percent) had gone to MACRO or a similar facility for HIV testing. A total of 54 (26 percent) said that they had never been tested for HIV and were not interested in getting tested. Slightly more (30 percent) said that they had not been tested but might get tested in the future, usually if their situation changed. A total of 28 (13 percent) indicated that they would like to be tested soon. Only two persons (both female) said that they would like to be tested but were not able to be tested: one for lack of money, the other for lack of transportation.

The significance of Table 2 lies not so much in the actual numbers, for the sample is small and was not chosen to be representative of Central or Southern regions of Malawi, but rather that individuals composing a core group say they do not want to be tested for HIV and that individuals composing a larger group say they might be tested in the future but have not taken action. The proportion of those who had been voluntarily tested for HIV (17 percent) is not so different from the percentage tested in the 2000 Malawi Demographic and Health Survey (9 percent for women and 15 percent for men).

The category of those who had not been tested contains three types of individuals: those with no interest in testing, those who want to wait awhile, and those who say they would like to be tested now. Those classified as “wanting to wait” first said that they would like to be tested, but on further

questioning, it turned out that they were not interested in being tested. This evidence suggests that in a survey context, asking individuals simply if they want to be tested creates a false impression of readiness to be tested. Most likely, affirmative answers to this question show a recognition that testing is a good thing in general rather than a declaration of a willingness to be tested now. It would be better to also ask when they would like to be tested: very soon, sometime in the future, or when they are ready.

How do individuals explain their desire not to be tested or their failure to be tested so far? A number of people explained their position.

No, because I'm sure of myself, there is no reason. (Man, Blantyre)

Most of the time the problem is that people are afraid of going for the test because there is no medicine. If there were medicine, many people would be going for a test. (Man, Blantyre)

No, I have never been tested. I have no reason to go for testing, but when I want, I will go. (Man, Blantyre)

It is good to be tested, because if you don't have it, you take care of yourself. But we young people, we don't go for testing because we are afraid. For example, some girls have a number of boyfriends, so they think they already have HIV, and so there is no reason to stop having relationships. But I personally say that sometimes you think you already have HIV when actually you don't have it. When you continue, you may get the virus, so it is better to be tested so that you know that this practice can stop, and you can abstain because of the advice you will be given. (Woman, Lilongwe)

Among women who did not want to be tested for HIV, most stated simply that they are not at risk for HIV: either they do not have sex or they are in a monogamous relationship. A few mentioned that they will not get tested because they are afraid of the results, and several said they were too old for testing. Among men who did not want to be tested, most said that they were sure of themselves, that they were sure they did not have HIV because of how they lived. Only three men mentioned being afraid of hearing the results.

The predominant position of men interviewed was that they may get tested in the future, but at the moment they do not have time, or they are not at risk. As this individual said—

A person who is not sure of himself is the one who goes for a blood test, because he has done a lot of running around. But as for me, I don't doubt myself, I protect myself very well. But it is good to have a blood test, because there are lots of ways you can get AIDS. (Man, Blantyre, urban)

What should we make of comments like the ones below? Will these people be willing to have an HIV test some day?

No, I have never been tested. I have not had the time or the will to get tested, but in the future I feel I can go for a test, especially if I feel myself getting sick more often. Then I will be able to go for a test. (Man, Blantyre)

Ah, I can be tested, there is no problem. In the future I will be tested. I have never gone there (MACRO). No, there isn't anything that stops me, but I know myself. To me I know that I am very fine. (Man, Lilongwe)

No, I have not been tested. The people who have been tested suspect themselves according to the way they have moved. I do not suspect myself, but in the future, if I find a man whom I want to marry, I might get tested. (Woman, Lilongwe)

No. I have heard that nowadays everyone has AIDS, so I can't go for testing. It is better to stay without knowing anything. I will go for testing only if I can have the courage to know that I am HIV positive. (Woman, Blantyre)

These comments show the fundamental ambiguity that many of the respondents expressed in talking about possibly getting tested. The large majority were not ready to take a test anytime soon. The final comment reveals a fear of being tested that others also expressed—a fear of being HIV positive—and a preference not to know their HIV status.

The women who decided to have an HIV test did so because they thought their husband had other sexual partners, they themselves had a lover or two, or they decided with friends to take the test. Among the men, a certain number were anxious because they had several sexual partners, they were sick, or they were tested at school or at their work place. Among those who had already been tested for HIV, a number of women were worried about the sexual activities of their husbands. The men who had been tested did not invoke concern about the sexual activity of their wives.

CHAPTER 6 EXPERIENCES OF VCT CLIENTS

The study team interviewed clients of voluntary counselling and testing (VCT) centres to understand the circumstances that brought them into the centre, to listen to their experience in getting tested and receiving counselling, and to learn what advice they were given during the counselling sessions. The study team interviewed VCT clients at three different points in their visit: 1) when they first arrived at a VCT centre, 2) just before or after they took their blood test, and 3) after they had received their results.

The initial interview included questions about their personal attributes (e.g., age, education, occupation, family living situation) and the circumstances that brought them for testing. Clients were also asked where they had heard about the VCT centre, what services they expected, and whether they had discussed their visit with anyone. The second interview focussed on the conversations they had during their welcome to the facility and their pretest counselling: what they had been told, what questions they asked, and what answers were given. The final interview, conducted after clients had received their test results, focussed on the advice that counsellors had given them and their overall impression of the VCT services. In a few cases, clients were not interviewed after they received their test results, either because they left too quickly or refused to answer more questions.

6.1 Sample of Clients

The study team interviewed 155 women and 90 men who had come to several centres as VCT clients. This sample tended to be skewed toward younger rather than older men and women. Table 3 shows the number of clients in each age group of the sample.

The annual report of the Malawi AIDS Counselling and Resource Organisation (MACRO) for October 2002 to October 2003 for the three facilities shows that in the younger age groups (15 to 19, 20 to 24, and 25 to 29), men outnumbered women by about two to one and that there were nearly twice as many clients in this group as in the older age groups (Malawi AIDS Counselling and Resource Organisation, 2003). These figures suggest that in terms of age and gender, this sample, though not chosen to be statistically representative, resembles the MACRO clients in general.

Age group	Men	Women	Total
15-19	26	17	43
20-24	61	28	89
25-29	20	16	36
30-34	18	9	27
35-39	12	13	25
40-44	10	3	13
45-49	8	4	12
Total	155	90	245

6.2 Seeking an HIV Test

Nearly all MACRO clients had heard on the radio that MACRO facilities offer HIV tests. Many had understood that they could obtain an HIV test free of charge, and a few said that they expected test results to be available in 15 minutes. A small number mentioned that the facilities also conduct tests for a

sexually transmitted infection (STI), usually syphilis (*chindoko*). About one-third of clients said that they expected to receive advice about how to protect themselves against HIV infection or how to live longer with HIV infection. All of the clients from the Thyolo and Chiradzulu VCT centres ($N = 13$), clinics located far from urban centres, reported that they had heard of the services from friends or relatives rather than from the radio.

The usefulness of radio to advertise MACRO services was confirmed by MACRO staff in Blantyre, who reported that the number of clients increases each time they launch a radio campaign. The fact that many clients mentioned details of the service, such as the availability of syphilis testing, the 15-minute wait, or the counselling that forms part of the services offered, suggests that the radio messages are being widely heard and understood.

Researchers asked whether clients had discussed their coming for an HIV test with anyone, hoping to get information about the circumstances that brought them to the VCT centre. The study found a systematic difference between men and women in whether or not they had discussed their coming for an HIV test with someone else. Most of the women said they had discussed their coming with someone else, most often with their spouse. A small number, in fact, said they had been asked to come by their spouse. The young and unmarried women said that they had discussed coming with a friend or a relative. On the other hand, more than half of the men said that they had not told anyone they were coming. Most of those who had told someone said they had discussed coming with a friend. Very few men said that they had discussed their coming with their spouse or girlfriend.

This difference by gender stems in part from the large numbers of young unmarried men that come to MACRO facilities, numbers reflected in the MACRO reports of their clients. The study team thus found it easy to find young men to be interviewed and relatively more difficult to find women or older men. The difference may also reflect a contrast in the relative autonomy between men and women in Malawi.

Most individuals came alone for a blood test, though a small number came with their spouse or boyfriend or girlfriend so they could both be tested. A total of 11 of the 155 male clients came with their wife or a girlfriend, while 5 women arrived with their husband or boyfriend. One married man with children came with a girlfriend so they could both be tested before beginning to have an affair, saying that they wanted to have safe sex. At the MACRO centres, couples followed the general discussions together but were alone for receiving results and being counselled about HIV prevention. In a few cases, a man came with his spouse but merely waited for her to be tested without being tested himself.

6.3 Reasons for Seeking an HIV Test

The study team asked clients what had brought them to the VCT facility, often asking a number of times in different ways for more specific answers. Many clients, particularly the younger ones, began by saying things such as “I just want to know how my blood is,” “I just want to know how my body is,” or “I want to know if I have the virus” (heard less often). Two examples from Médecins Sans Frontières (MSF) Thyolo illustrate this situation well. In the examples, {I = interviewer and R = respondent}.

Example 1:

- I. What do you know about this place?
- R. I know they help people by giving them good advice on health, so that if they have AIDS they can give advice so you will not die so quickly.

- I. What have you come to do?
- R. I have come to have my blood tested so I know how my body is now.
- I. When you were coming here, did you discuss this with anyone?
- R. No.
- I. So your wife does not know?
- R. My wife doesn't know. (27-year-old man, Thyolo).

Example 2:

- I. So what exactly has brought you for a blood test?
- R. Nothing. I have just come.
- I. But what is the real reason you came for testing?
- R. There is no reason, I have just come. (17-year-old man, Thyolo)

More often the client would explain what aspect of his or her social situation had pushed them to come for an HIV test. Those reasons are presented below. They have been grouped into five categories and presented in the order of the frequency they were mentioned:

- Fear of having been exposed to HIV by one's own actions
- Fear of having been exposed to HIV by the actions of one's spouse or partner(s)
- Feeling sick
- Family events (e.g., marriage, pregnancy, reunion, new partner)
- Job circumstances (e.g., new job, scholarship, application requirement).

Although clients talked about reasons or circumstances that fit into these five categories, the large majority of clients fell into the first two categories: fear of having been exposed by one's own actions or those of a spouse or partner. The fact that family events were so seldom cited suggests that media efforts to encourage people to come for such circumstances have had little effect as yet. The next sections discuss in more detail how individuals talked about what had brought them into a VCT centre.

6.3.1 *Fear of having been exposed to HIV by one's own actions*

The single most common explanation from male clients for why they had sought an HIV test was that in thinking about their own past actions, they became afraid they might have been exposed to HIV infection. In other words, they have been running around with "other women," and some expected they might be punished for engaging in *chiwerewere*. The dozens of quotes that illustrate this concern include the following:

Because in the past I have been sleeping with many girls. (Man, Lilongwe)

I have been sleeping with ladies; not a lady, but ladies. (Man, Lilongwe)

I slept with a woman without a condom. I did not use anything. (Man, Blantyre)

I just want to know my status. Sometimes when you think of testing, you reflect on what you have done in the past, and you are not sure. (Man, Blantyre)

In the past six months, I was sleeping around. So I want to stop, but when stopping I should first of all know how I am. (Man, Blantyre)

I discussed with my brother saying we should go for a test. If we are tested, we can change our sexual actions. If I am negative, I will stop these sexual relations and concentrate on school. (Man, Lilongwe)

A number of men stated explicitly that they were going to change their actions now that they were being tested for HIV; that is, while they used to have lots of girlfriends, now things were about to change. Some men mentioned specific partners with whom they had sex for shorter or longer periods, saying that they had just reformed.

Only a few women mentioned their own past behavior as a source of concern for their HIV status. Examples include—

My first sexual partner, I slept with him without a condom, and I don't know how he was moving. (Woman, Lilongwe)

I slept with a man in 1999 [without a condom]. (Woman, Blantyre)

Many men and relatively few women cited their own past sexual adventures as a reason to come for an HIV test. According to men's accounts, sometimes it was their own actions that were problematic or cause for concern. At other times, it was because of the character of the women involved with these men; that is, a small number of men were concerned about HIV infection because of what they had heard about a sexual partner. That partner, however, was usually a girlfriend and not a wife. Their comments show that they consider themselves in danger of HIV infection not for having had sex with someone other than their spouse, but for having slept with someone who had been sleeping around herself. Three comments illustrate their concern:

I had a lover, but women are untrustworthy. I cannot trust her now, so I want to know my status. (Man, Lilongwe)

I slept with two women in Lilongwe, and I am not sure about these women. (Man, Lilongwe)

I slept with a girl whom I had just met. After that, I heard that her behaviour is not normal, she has sex with different people. (Man, Lilongwe)

6.3.2 *Fear of having been exposed to HIV by the actions of one's spouse or partner(s)*

The majority of women who came for HIV testing were afraid of having been exposed to HIV infection through their husband's infidelities. Some women found vivid ways to express their situation:

I have been thinking that maybe my partner is not moving properly. Maybe he is lying, saying he is going to work, later to find that he was with girlfriends. (Woman, Blantyre)

He is a driver, moving here and there, so it is easy to suspect him. I did not come with him today, he is at work. He travels outside Blantyre. (Woman, Blantyre)

I have been thinking about how my husband suffers. He gets sick very often, maybe two or three times per month. This is why I have come here. I would like to know if I have the virus,

and if I have it, what should I do. If I don't have it, again what should I do. (Woman, Blantyre)

My husband, I doubt his movements. He loves women so much. (Woman, Blantyre)

I have been thinking of coming here for a long time, because my husband spends nights out without informing me. (Woman, Blantyre)

The other reason I doubt myself is that I do not trust my husband. People have been telling me that he has several girlfriends. Most of the time he is away during the night; he just comes home to change clothes in the morning. (Woman, Blantyre)

The contrast between men and women in reasons for coming for an HIV test should not be read only as an indication of what is most commonly practised, though that is tempting. One should, rather, consider the difference as evidence for the kinds of circumstances that push people into VCT facilities. Many men who were interviewed have often become concerned about their own past actions, and they recognise they may have exposed themselves to HIV. Many women who were interviewed, on the other hand, recognise or suspect that their partner has other lovers; thus, they become truly anxious about having been exposed to HIV.

The difference by gender may also be related to the contrast in the responses to the results of an HIV test on the part of spouses and/or other family members. Men may be more willing than women to get tested because even if they test positive, they expect others (spouses mostly) to care for them. Women are concerned not only about their own test results, but also about the reaction of their husband to a positive test result. Women are likely to be punished if found to be HIV positive, for HIV infection is regarded as a demonstration of *chowerewere*. Since, in Malawian society, it is more socially acceptable for men to have several sexual partners than it is for women, they can more readily report on past partners than can women.

While both men and women may seek an HIV test out of fear of being positive, the possible ways of reducing the risk of HIV are dramatically different. A man fearful of being punished for his own actions can simply stop what he was doing; a woman fearful of the repercussions from her spouse's action must change how they have sex in that relationship. How can a person change their actions to reduce the risk of HIV infection after a test if their spouse or partner was never told they went for an HIV test? Does this imply that men and women should be counselled differently about reducing risky actions? Should counselling tackle the issue of power dynamics in social relations as they relate to gender? This study did not examine the advice given to men and to women in such detail as to provide evidence for what counsellors are doing with respect to gender-specific counselling, but the issue deserves attention.

6.3.3 *Feeling sick*

Some of the interviewed clients came for a test because they already felt sick and were concerned that they may have HIV. This was the case for 9 of the men and 11 women. Not all of them had symptoms normally associated with AIDS, but they were all worried their illness may have been caused by HIV infection.

I had sex the past few months with two girls. So I have some signs in my body. That is why I have come to this place. (Man, Blantyre)

I really want to know. I should know how my blood is. Right now, regarding my body, I'm not feeling well. (Woman, Lilongwe)

I have come for testing because I am sick. I feel sick most of the times, every month. I can't sleep, I don't feel well, and I have a cough that does not end. I take the medicine but there is no change. (Woman, Blantyre)

Overall, most clients came for testing out of anxiety that they had been exposed to HIV through their own actions or those of their spouses or boyfriends or girlfriends. They had understood how HIV is spread and felt vulnerable themselves. The symptoms of illness accentuated their fears of having been infected.

6.3.4 Family events

The National AIDS Control Programme (NACP) and the National AIDS Commission (NAC) have long encouraged individuals to take an HIV test before marriage or pregnancy. The MACRO annual report for October 2002 to October 2003 discusses the reasons given for seeking an HIV test, as found in precoded answers on the registration form (Malawi AIDS Counselling and Resource Organisation, 2003). Two categories on that form fit into the category of "family events": marriage and planning for the future. A total of 14 percent of men and 19 percent of women in that report cited one or the other as the reason they were seeking a test.

Relatively few clients in the study had come because they wanted to get married or have children. Clients who came for those reasons described their situation as follows:

- **Marriage**

Right now I want to find a partner to stay with, so I want to test my blood before I find a partner. (Woman, Blantyre)

Now my mother has decided that I should have a blood test before I marry this man. (Woman, Lilongwe)

Because I am preparing to get married, it is better to know if I have the virus. Then I will tell my girlfriend to come for testing as well.. (Man, Blantyre)

- **Pregnancy**

I want to know before I have another pregnancy, because I cannot know about his movements. (Woman, Lilongwe)

- **Reunion**

She has been asking advisors about how we might get together again. Before we do that, I want to get tested, so that I know how I am with regards to HIV. (Man, Lilongwe)

I am married to the man who came with me. He left me and married somewhere else, and when that failed, he came back to me because of the children, who kept saying their father should come back. So they said that before we start sleeping together, we should test to find out if we have HIV. (Woman, Blantyre).

- **New partner**

We want to have an HIV test before having sex. I just want to have a girlfriend and have safe sex. (Married man, Blantyre)

So now that this man is asking to marry me, I said, mmmm, it is good to test both of us before we start doing anything. That is why we have come. (Woman, Lilongwe)

The study team initially expected that family events would figure more prominently in the explanations offered for getting an HIV test. Why are there not more people coming for a test before getting married or becoming pregnant? Are visits to a VCT centre for preparing for family events also stigmatised, despite the image of care and responsibility it projects? In this study, very few people mentioned such reasons. In the 2003 MACRO annual report, only 5 percent of male and 10 percent of female visits to the three MACRO facilities were from clients preparing to be married.

Although it is tempting to think of getting tested before a pregnancy or a marriage as somehow different from other reasons, the HIV test results do, in fact, provide information about one's sexual history and thus are not so different from other reasons. The goal of getting tested before such family events is to demonstrate that one is free of HIV infection; if that is not the case, then the client and his or her family may need to change plans for pregnancy or marriage. Promotion of HIV tests for such reasons may need more attention in Malawi.

6.3.5 Job circumstances

Very few examples of this category were found, despite rumours that some companies require an HIV test for employment. Three examples are cited below.

The main reason is that I want to find a job in a certain organisation looking after orphans. So they want a person to go for a blood test since they employ only those who are not infected. (Woman, Blantyre).

There is a rumour that they will want people who have been tested or who are willing to get their blood tested. (Woman, Lilongwe).

[She came for a test because the American embassy asked for it.] (Woman, Lilongwe).

During the training, the fieldworkers talked about businesses they knew that required an HIV test (with a negative result) for employment, or foreign governments or foundations that required the same for acceptance into a scholarship or training program. The hospital at Ekwendeni (Northern region) offers HIV tests to students of a nearby school who need a certificate showing they are HIV negative if they receive a bursary.

6.4 Clients' Experience at a VCT Centre

The system of processing clients at the two MACRO centres features three tasks, each one accompanied by counselling: 1) registration, 2) giving blood for a test, and 3) hearing the test results. Most clients listened to health talks or watched videos in a group as they waited to be registered or waited for their turn to give blood for the test. Just before or just after having their finger pricked for the blood test, clients had an individual discussion with a counsellor who verified that they wanted to take a blood test and get the results. After the results were given, clients were given advice about actions to take to protect themselves from HIV infection or to assure some resistance to the HIV virus. This section addresses only what was observed and reported in the two MACRO centres, since all but 13 clients were MACRO clients.

6.4.1 Welcome at VCT centre

The MACRO facilities have a receptionist to register clients in a registration book, where each client is identified by a number. The receptionist also records the client's age, sex, and household location. The clients are given a card with a number that serves as their identity for each aspect of their visit. No names are taken. During this process, a staff member asks a few more questions and marks answers on a two-page form with precoded categories. Before or after the registration, clients can watch

videos and listen to health education talks given by counsellors about AIDS and STIs. Clients wait in one large room to be called for their blood test as others register.

A young woman from Blantyre described her reception this way:

I was well received. The whole group was asked questions, and we all responded. For example, questions like, “How can we avoid AIDS?” “What is the difference between HIV and AIDS?” “How can a person get the virus that causes AIDS?” We were given numbers and a form to fill out individually. Then I was asked personal questions, such as whether I was married, how many men I had slept with since October last year, whether I have a child, when I was born, what made me marry, the level of my education, and what made me come to MACRO.

A young man from Blantyre described his experience in this manner:

At first we were asked some questions. Then we were told to feel free if we wanted to ask questions. Questions were asked like, “What is HIV?” “What is AIDS?” “Do people with AIDS die of AIDS?” “How can we prevent the disease?” “How can we get this virus?” They told us about other diseases like *mauka* and *chindoko* (STIs).

6.4.2 *Counselling and the blood test*

Clients were called by number individually to another room where the lab technician pricked the client’s finger for a few drops of blood for a test with filter paper. Most clients were counselled privately before they met the lab technician to give blood. Counsellors usually asked about what they knew about HIV and AIDS, whether they really wanted to test, and what they would do if the tests were negative and if they were positive.

It was not easy for the study team to obtain a full picture of these conversations, since the team relied on clients’ reports. However, the interviews occurred right after the time spent with counsellors. A reading of the accounts shows a tremendous variation in the way that counsellors and clients interacted during this session. Judging from the comments of clients, the counsellors tried to determine why the client had come, what he or she knew about HIV and AIDS prevention, the client’s recent sexual activities, and what they would do if they were found positive or negative. Some clients reported having been asked lots of questions about their personal life, while others said that they were not asked personal questions. Some clients asked numerous questions, while others said nothing.

An interviewer asked an older woman from Lilongwe what the counsellor told her before she gave blood. She replied—

They received me well. I entered the room alone so they asked me how I can protect myself and asked how I will feel in my heart when I hear the test results. So I explained that I am ready to hear anything. So they said that I should be eating food from different food groups, any food that can be found. And they told me how I can take care of myself if they find me positive, not to infect other people.

A young man from Lilongwe had this to say in response to the same question.

When I entered alone, she asked me what I know about AIDS and what would I do if they found me with HIV. They also explained about the window period. I was asked what I would do if I have HIV. So I said I would abstain, avoid *chowerewere*, and eat food from three food groups. So they told me that if you are married you should avoid pregnancy and drink less beer.

Clients had little to say about the test itself except that it went well. The client's identifying number was attached to the testing filter paper. Only two clients complained that the finger prick caused pain or discomfort.

6.4.3 *Final counselling and test results*

A short time after the clients had their blood test, they were called by number for an individual conversation with a counsellor who asked them whether they were ready to hear their test results, gave them the results on a sheet of paper, and then talked to them about actions to take to avoid HIV infection. The study team interviewed clients at the VCT facility right after they had completed their conversation with the counsellor. The interviewer usually said the following:

We are now meeting after you have heard your test results. You do not need to tell me the results, but what advice did the counsellor give you?

In many cases, the client told the interviewer what the test results showed, and then explained the advice they had been given. With the exception of two or three cases of incomplete final interviews, it was always possible to tell whether the client had tested negative or positive by examining the advice given. For example, nearly all persons who tested negative told the interviewer that they were asked to return again in three months. Since the interviewers know that a person who has tested positive will not be asked to return at all, they also know that all clients asked to return in three months have tested negative.

The following are a few examples of what clients told the interviewer about their test results.

I met the counsellor and I was told that I do not have the virus. (32-year-old man, Blantyre)

I was asked if I was ready to hear my results. So I have been told that they have found that I have the virus (25-year-old female, Blantyre)

I was asked if I was ready to hear my results, and I said I was, sure. I was also asked if I would be happy or sad if the results showed that I was positive, and I said I would also be happy because I would then know how to keep myself. (23-year-old man, Blantyre)

They said I don't have HIV or *chindoko*. So I asked, does that mean I don't have any illness at all? They told me that they do not test for any other diseases, that I do not have AIDS because I do not have the virus that causes AIDS, but I should come back for another test the end of August. (20-year-old woman, Lilongwe)

He said I have no HIV or *chindoko*. So, since I have slept with my girlfriend recently, my blood could not show anything, but the virus starts working after six months when it is still being made in the blood. So I will come back in September to be tested again. (35-year-old man, Lilongwe)

The counsellors told me that my blood has been found with the virus that causes AIDS. (39-year-old woman, Lilongwe)

In most cases, clients were then asked about the advice they were given. For example, this last woman from Lilongwe was asked whether they gave her any advice. She said—

Eeh, they did give me advice. The way things are, I should not be having sex often, that I should avoid sex, that I will not die right away, no. They also told me I should eat food from

different food groups and that I cannot buy the drugs they talked about here. I should go to Central Hospital and buy them.

The reason it was easy to judge the test results was that the advice given by counsellors was consistent from one person to another. Those who were negative were nearly always told the following:

- Continue to take care of yourself
- Avoid *chiwerewere*
- Use condoms
- Encourage spouse or partner to come for a test
- Return after three months.

The persons who tested positive, on the other hand, received the following advice:

- Go to the hospital when sick
- Eat food from three food groups (balanced diet)
- Exercise but do not overwork
- Use condoms in sex
- You can live well for quite awhile.

Some clients were certainly told other things in addition to elements from these lists, for the lists come from client recall just after their conversations. In addition, some clients were given advice that may have been unusual but that fit well with their own situation. The items of these two lists were, however, the ones that were heard from clients repeatedly.

The study team was surprised to find that clients rarely mentioned being referred to further contact with a service or medical institution, whether the client's result was positive or negative. Only 2 clients out of 245 mentioned that they had been referred to a support group. Perhaps some clients were given referrals and simply forgot to mention them, or they thought that a referral was not part of the advice the interviewer was asking about. Many of the counsellors said that they referred clients to post-test clubs or to other support organizations.

The clients interviewed at VCT facilities expressed satisfaction with the services they had received when the study team invited them to comment on their experience. Of the 245 clients interviewed, about 12 said they were disappointed: the wait was too long, the counsellors did not answer all of their questions, or they were embarrassed at being asked personal questions in a group. There is always a positive bias in such exit interviews, but respondents were consistent in their positive responses about the services offered.

Interviewers' discussions with clients indicate that they find what they are seeking at MACRO centres, and they have few suggestions for how services might be improved. Many counsellors encourage clients to ask questions, but few provide any referrals to other services. On the basis of the client-counsellor interaction as reported by clients, counsellors should be encouraged to vary their advice to fit with the particular circumstances of the individual experiences of clients and to refer clients to social or medical services whenever possible.

CHAPTER 7

THE WORK OF VOLUNTARY COUNSELLING AND TESTING COUNSELLORS

The study interviewed individuals working full-time in counselling clients at five voluntary counselling and testing (VCT) centres to learn about their background and work experience. These VCT centres were the ones that were visited for client interviews. The consultant Priscilla Matinga had extended conversations with nearly all of the counsellors working in these facilities to discuss how they came to take the job of VCT counsellor, their previous work experience, the nature and duration of their training, the way they guide clients through the services, the advice they provide to clients, and the particular challenges they face. The counsellors readily talked about themselves and their work experiences.

Using a questioning guide, the study interviewed 27 counsellors working at the five facilities. Most worked for the Malawi AIDS Counselling and Resource Organisation (MACRO) in Blantyre (10) or Lilongwe (8). Three worked in the hospital complex in Thyolo supported by Médecins Sans Frontières (MSF) Luxembourg, and two worked in the Chiradzulu HIV and AIDS Resource Centre (CHARC) supported by MSF France. Finally, four counsellors (one full-time employee and three volunteers) were interviewed in the Mponela AIDS Information and Communication Centre (MAICC) in Dowa district of the Central Region. While all of these centres offered VCT for HIV, the two MACRO facilities also offered testing for tuberculosis and syphilis, health education for HIV/AIDS and other sexually transmitted infections (STIs), training in counselling, and referrals to support services.

7.1 Background and Training

The counsellors at the two MACRO facilities all had post-secondary training, most often as nurses or midwives. Nine out of the ten counsellors interviewed at MACRO in Blantyre had a qualification in the field of health. The nurses and midwives had from 10 to 20 years experience in that profession. At MACRO Lilongwe, five counsellors were qualified in a medical profession, while the others had degrees in teaching, social science, and computer programming.

The two counsellors at CHARC had a Malawi School Certificate; one of these had a certificate in counselling obtained in Kenya. The three counsellors at MSF Thyolo had a post-secondary qualification. One counsellor was a qualified nurse/midwife, and the other counsellor was a medical officer.

The four counsellors at MAICC had the lowest levels of qualification, but three were volunteers. One of the four counsellors had a Malawi School Certificate, which is given after the successful completion of four years of secondary education. The other three counsellors had a junior certificate, which is given after passing exams in the second year of their secondary education.

Judging from the training and experience of the counsellors employed, in all facilities there was a preference for hiring nurses or midwives or persons with a health background as counsellors. A number of the nurses also had a background in counselling in domains other than HIV/AIDS.

The training the counsellors had received before beginning work varied tremendously. At the time of the study, a standard training in counselling was a six-week training course conducted by the National AIDS Commission. Within the six-weeks course, the first week covers the theoretical part of counselling, followed by four weeks of practising counselling at the VCT site, and the last week also covers the theory of counselling. However, few of the counsellors had followed that training schedule. Some had received two weeks, and others received six or eight weeks. Several counsellors said that they had had only one week of training so far and were expecting to get the other week eventually. Several staff members had further training in professional counselling in Kenya. The interviews revealed that all

of the counsellors felt that training was valuable and wanted to complete at least the orientation and the six-week training course, and perhaps more.

The majority of the counsellors described counselling as an interesting and challenging job that permitted them to help others to live better lives. The magnitude of HIV/AIDS in the country was cited as another reason why these persons felt there was a need to work towards reducing further HIV infection. Some of the nurses had previous training in counselling while they worked in a hospital, and this background helped them decide to become an HIV/AIDS counsellor. Several nurses said that they had even come out of retirement to make a difference. For example, a retired nurse from Thyolo with more than 20 years experience said—

What made me continue with counselling is that I saw the increase of different illnesses nowadays, so this is what made me really consider the job—because we do assist people with their problems they face, how they can help themselves in their lives from day to day. Also, encouraging people who have HIV not to feel that it's the end of their life ... just as any other person who may not have the virus.

A few counsellors from MACRO cited monetary reasons for taking the counselling job, saying that the job offered them a career opportunity with a better remuneration package than their previous employment.

7.2 The Counselling Process

The study's interviews and observations indicated that the counselling process at both MACRO centres (Blantyre and Lilongwe) is organised in the same fashion. A senior counsellor is assigned to supervise fellow counsellors as well as interact with clients in order to assess the quality of the counselling process. The senior counsellor also verifies that all necessary materials and equipment are available and in working order. At the end of each day, the senior counsellor compiles information on the number of clients received at the centre and reviews the kinds of services the clients had sought. The senior counsellor then discusses the findings with all of the counsellors the next morning before counselling resumes.

Counsellors at MSF Thyolo and MAICC described a process that varied from MACRO on key features, such as how they ensure anonymity, how they provide health education, how they ensure that testing is voluntary, where they perform the test, and how long it takes. These differences will become apparent in the presentation of the different steps of the counselling process described below.

7.2.1 Importance of counselling

Counsellors stated that young men and women often have sexual intercourse at a young age, and it was important that they know their HIV status if they are sexually active. For young unmarried people, a benefit of having an HIV test is to ensure that young people marry a person without the AIDS virus. Some counsellors talked about the importance of people learning their HIV status early in life. A person who learns that they are HIV positive still has a chance of living a long life, even with the virus. As one counsellor from MACRO suggested—

It's like when a person knows that this car is not in good condition, it has no brakes, no oil, no petrol, you become very careful when driving it so that you can reach your filling station. I should replace the missing things. The same way when you know that you have a problem in your life, you have to take care, what to do to live longer.

One of the goals of the counselling process is to help the client reflect on his or her situation, assess the risk of HIV infection, and plan ways to reduce that risk. Counsellors mentioned that clients

often remember recent events in their sexual history but tend to forget actions in the more distant past. In the process of questioning, a counsellor can often help a client recall more distant events that may be related to the risk of HIV infection. Any plan formulated to reduce the risk of HIV infection begins with the client's previous risky behaviour in the past, so the client realises that being HIV negative means that there is more work to be done to avoid getting HIV.

Counsellors often mentioned telling their clients about the services available to them, whether they are HIV positive or negative. They mentioned that they refer people with HIV to a hospital or clinic dealing with HIV-related opportunistic infections. They also mentioned the existence of AIDS support organisations for people living with HIV.

There are not many support groups operating in Malawi for those with HIV. MACRO has a post test club, composed of young people who may either be HIV positive or HIV negative. The group members support one another and discuss issues that concern their lives. The group also works in a number of communities, schools, and markets to create awareness of HIV testing and to provide information about VCT services offered at MACRO. Another group supported by MACRO is the Youth Ambassadors—a group of youth who are HIV positive—who encourage young people to have a blood test and talk about how to cope with having the virus. Clients who test positive for HIV may also be referred to a branch of the National Association of People Living with HIV and AIDS in Malawi (NAPHAM).

MAICC had home-based care and support groups to which HIV-positive clients could be referred if they wanted to be visited at home. CHARC clients who tested positive had their CD4 count done by MSF doctors. The CD4 count would determine whether the client should start taking antiretroviral medications (ARVs) which MSF provides free of charge. In addition to receiving ARVs, clients benefitted from frequent assessment of their condition by a doctor.

7.2.2 *Receiving clients*

Nearly all of the counsellors mentioned the need to welcome clients in a systematic and structured manner. When a person enters the MACRO clinic, they are greeted by the receptionist and asked why they have come. As one MACRO counsellor pointed out—

We can't assume they are here for an HIV test. They may have come for another reason.

Although relatively few in number, people coming for reasons other than blood testing are directed to a different bench to await service. Services offered in addition to HIV testing at the two MACRO facilities include testing for another STI (such as syphilis), making followup contacts for an STI or tuberculosis treatment, or providing condoms and/or counselling. All are welcome, as one MACRO counsellor indicated:

Here we receive people well because we believe that a person who has decided to come here should be shown due respect ... clients should be welcomed well starting from the reception area.

The Mponela clinic does not have a receptionist, but several counsellors said that they greet the client themselves and make them feel comfortable.

7.2.3 *Ensuring anonymity*

The receptionist at the two MACRO centres records a number in the register for each client coming for a blood test but does not write a name; the client is given a card with the same number. Next to the number in the book, the receptionist also records the client's age, sex, where he or she lives, and

whether this is a first visit or a followup. One MACRO counsellor in Lilongwe described how the receptionist instructs clients about the clinic process after registering them as follows:

Here we test for HIV, but also we test for *chindoko* (syphilis). We don't ask a person's name so you should not mention your name to us. We registered you. Counsellors will be coming to pick you to go to the counselling room. When you've gone to the counselling room, that particular counsellor will escort you to the laboratory.

Similarly, the MSF clinics record only a number for the client without writing a name, and the counsellor does the testing himself or herself. At MAICC, however, the clients names are recorded in a book along with where they live and their age, religion, and type of counselling received (i.e., preventive, pretest, post-test). The lab test form given to the client to take to the hospital for testing is identified by a number rather than by name. The same number is recorded in a book so the numbers can be matched when the client returns. When asked how they keep the identity of those tested anonymous, the counsellor replied that the book is kept in the office and is available to them only.

7.2.4 Health education

While waiting in the MACRO reception area for a counsellor, clients are invited to watch videos on various topics concerning counselling, HIV, and family planning, as well as videos just for entertainment.

Clients watch films about AIDS, but we also show films purely for entertainment. AIDS messages should be coupled with entertainment, counselling. In addition, there are materials for the clients to read (Counsellor, MACRO Blantyre).

Pamphlets with information about HIV and AIDS, the benefits of VCT, and the services offered by MACRO are also available in these centres. Pamphlets, but no videos, are available at MAICC. It was not clear from the interviews what educational materials were available at the MSF centre, besides a radio for clients to listen to while they wait.

In addition, counsellors may give a brief educational talk and answer general questions about HIV and AIDS before the formal counselling and testing. At the MACRO centres, if several clients are waiting for a counsellor, the counsellor will present the general information on HIV to the whole group and ask for general questions. Counsellors said that clients ask questions about the difference between HIV and AIDS, and questions related to testing and the development of HIV and AIDS over time. They (clients) sometimes ask, for example—

If you are exposed to the virus, how many months does it take to start showing that he has HIV? What signs are there? Why does it take time for HIV to appear in the blood?

The relationship of HIV to other STIs is also a common topic for questions. As one counsellor said, clients might ask, "Do other STIs change to HIV?" Counsellors are trained to invite clients to ask questions on what they have seen or heard during the time the client is alone with a counsellor.

First of all, I have to give them a chance to explain whatever they know about HIV/AIDS, just a few points because you don't take a person as if he does not know anything. ... Whoever comes here ... must have something at heart to say as he comes for HIV testing. (Counsellor, MACRO Lilongwe)

7.3 Pretest Counselling

In the Blantyre MACRO facility, the group of clients was given the basic HIV/AIDS information at the reception area, sessions known as “motivation talks,” before a client went for an individual counselling session. The counsellor giving the motivation talk would either give out information or ask clients to provide information about modes of HIV transmission, HIV prevention, condom use, STIs, and services being offered at MACRO. During the motivation talks, clients were given a chance to ask any question relating to HIV/AIDS, STIs, the counselling procedure, and testing.

MACRO Lilongwe gave the basic HIV information through initial group counselling involving three to four clients at a time. In addition, counsellors covered the first phase of the counselling process, in which individuals in the group were asked to provide general information about themselves. Clients were then seen individually so they could provide detailed information about their sexual life and reasons that prompted them to get a blood test. At CHARC, MSF Thyolo, and MAICC, all clients were seen individually throughout the counselling sessions.

The counsellors clearly understood the client need for privacy for certain aspects of the counselling process.

It is not recommended to take two clients at a time. You should take one client at a time, just one; so what we do, we do take two people just to give information together, but on sensitive issues we do separate them. (Counsellor, MACRO Lilongwe)

Counsellors were also aware of the importance of ensuring that the HIV test was voluntary. Though none of these centres used written consent forms to be signed by the client, counsellors asked verbally for permission, apparently at different points in the process. The MACRO counsellors said that the clients are free to leave at any point. A counsellor pointed out, for example, that a client may just need information or may not wish to be tested:

When we have given the information (video) the people have got the freedom, like maybe after getting the information some change their mind right there, [thinking] that ah, maybe I should come another time. Or maybe they decide to continue (with the process). It's up to them because the freedom is there. (Counsellor, MACRO Blantyre)

All counsellors thought that it was important to determine how much a client knows about HIV transmission and prevention by asking the client to describe what he or she knows. The counsellor would then briefly go through modes of transmission and prevention of HIV if a client seems to be well versed with basic HIV/AIDS information. If a client gives very little or incorrect information, the counsellor fills in the information gaps with correct information.

During pretesting conversations, counsellors often asked clients what type of test results they were expecting and what action the client would take if the test results were negative, and if they were positive. Counsellors were also interested in learning how clients would protect themselves from HIV infection in the future.

Since the sharing of test results is an important topic of counselling, clients were asked with whom they were going to share their test results and whether the person chosen would be supportive if the client was HIV positive. The information given was followed up during post-test counselling to find out whether a client would share the test results. Often, counsellors encouraged clients who tested positive to share their results with their partners. There was little emphasis on sharing of results for clients who tested negative.

Similar information was given by all counsellors about the importance of counselling before getting an HIV test. According to them, the most important reason for providing counselling was the psychological preparation of clients to deal with the test results. In the way they talked about giving advice, counsellors talked as though they expected that people who are aware of their HIV status would change their behaviour by not having unprotected sex.

7.4 The Testing Process

The HIV tests are conducted using two tests: one is Determine HIV 1 and 2, and the other is Unigold HIV 1 and 2. When the results from the two tests are the same, the test results are accepted as conclusive. When the two tests give different results, another test—more sensitive than the previous tests—known as Hema-Strip, is used to determine a client’s HIV serostatus. The test result from the Hema-Strip test is the result taken to be the valid one.

Blood for HIV testing is drawn through a finger prick at MACRO. The two MACRO centres have a separate laboratory within the centre where a client has the blood drawn by a laboratory technician. A laboratory technician, in the presence of the client, writes the client number, which was assigned at the reception area, on the bottle containing the client’s blood specimen. The client then waits for the results at the reception area. At some point, a counsellor will call the client’s number to give the test results. A client’s result would show after 15 minutes for Determine HIV 1 and 2, Unigold HIV 1 and 2, and the syphilis test.

Blood samples at MSF CHARC were drawn from a vein on the arm and then taken to the hospital laboratory for a CD4 count. At MSF CHARC and MSF Thyolo, a client’s blood was drawn in the counselling room. At MAICC, clients are referred to the Mponela rural hospital for blood testing. A client’s waiting time at the hospital to have blood drawn for testing depends on the number of requests by medical personnel to have tests done for hospital patients. When the results are available, the form where the test results are recorded is either given to the client to take to MAICC for post-test counselling or it is sent to MAICC through a counsellor from MAICC. With the exception of MAICC, all testing centres reported that they were well equipped with material resources, such as test scripts for the laboratory, reagents, stationary, and reference materials.

The procedure for giving test results was the same in all VCT centres for persons with or without HIV. The only difference among these centres was that clients would get their results the same day at all MACRO centres and at MSF Thyolo, while at CHARC, the results would be available the following day.

7.5 Post-Test Counselling

When clients come for their test results, they are asked whether they are ready to receive the results. In cases where clients seem not ready, the counsellor talks with them until they accept to get their results. The client is often reminded about the previous discussion during the pretest counselling about readiness for results. The results are then disclosed when the counsellor hands the form on which the results are recorded to the client.

The positive and negative test results were differentiated using different ink colours. A positive HIV test result was written in red ink and bore the word “reactive,” while a negative HIV test result bore the word “non-reactive” in blue ink. According to the counsellors at MACRO, by using red or blue ink, people who cannot read English would still be able to know their results. At MACRO, where clients’ blood was also tested for syphilis, positive test results for syphilis were also indicated in red. The syphilis and HIV test results were recorded on the same form.

All counsellors interviewed indicated that when a client has been given the results, the counsellor waits for a reaction from the client, observing his or her reactions and dealing with them accordingly. If there is silence, it is broken by telling the client that “these are your test results.” If the client cries after being told he or she is positive, the counsellor allows the client to release his or her emotions before asking how he or she feels about the results and what action will follow.

Counsellors said that they try to help clients find a solution to their own situation rather than telling them what to do. The counsellor is supposed to ask the client questions to make the client feel free to talk about the issues at hand, and from what has been discussed, the client should state how he or she is going to arrive at a solution. Counsellors stated that the counselling profession requires that the clients should think on their own about the dangers, the advantages, and the consequences of their decisions.

Counsellors believed that HIV positive women should not get pregnant, and they told this to clients.

But also like us women, who bear children, it’s good that we should know that, do I have HIV or not? You should not become pregnant just make sure that if you have HIV you should try not to get pregnant, because you can pass it to your child, which is not good. (Counsellor, MACRO)

Post-test counselling includes the discussion of a risk reduction plan, which involves identifying the client’s actions related to the risk of HIV infection and what triggered such action in the past. The client is then asked what he or she will do in order to deal with the situations that placed him or her at risk for HIV. At the end of the counselling session, a counsellor draws a risk reduction plan with the client laying out what he or she has suggested to do after leaving the counselling room. The counsellor also asks the client to state how the counsellor will be able to follow up on the execution of the risk reduction plan. Drawing up a risk reduction plan was one way counsellors encouraged their clients to critically look at their past actions and decide how best to change to reduce risk.

Post-test counselling was said to take on average from 10 to 30 minutes; interviews with clients suggested the counselling took far less time than that. The length of time was contingent on the test results and the client’s response to the results. Most counsellors said that they often spend more time with clients whose test results are positive. According to them, clients with HIV are much affected with the results and need more information about how they can cope with knowing that they are HIV positive. On the other hand, some people with negative test results had to be calmed down so they could follow what the counsellor was saying. It was always important for the client to understand the need for a second test in case the client is in the window period and for the client to undertake prevention measures to prevent HIV infection in the future.

The topics most often covered in the advice provided to HIV-positive clients were diet, exercising, seeking health care immediately when they are sick, and abstinence or condom use. The common diet advice for HIV-positive clients was to eat a daily diet containing three food groups: protective foods, such as vegetables and fruits; body-building protein sources, like beans, meat, eggs, and fish; and energy foods, such as the staple dish *nsima* (maize), and other carbohydrates like cassava, rice, and potatoes.

One of the counsellors explained the advice to HIV-positive clients this way:

I ask about *zamaculu* (nutrition) and *zakasintha sintha* (varying the diet) ... the importance of going for treatment when sick because we Malawians wait until the illness has reached a point where it is very advanced ... the person should do exercises to strengthen the body, jogging, running, pushups, and also take a rest. Advise against smoking and drinking alcohol

because they destroy the body's immunity—alcohol, the liver. If married, use a condom ... if a woman, we advise against getting pregnant because she will get sick more quickly if she continues to bear children. (Counsellor, MACRO Blantyre)

Another major part of the counselling process is to help the client deal with misconceptions. Some common misconceptions held by clients are that “if you are found HIV-positive, you will start getting sick at the same time” and “if you are HIV-positive, you cannot marry, cannot have sex with partners, cannot do work, and must stop school. As one counsellor rhetorically asked—

Then what will you do, because some people think that if they are found with the virus that means that is the end of their luck, everything is finished. But when they come here, they discover that life goes on. (Counsellor, MACRO)

How to handle sex and spousal relations was another issue that sometimes arose. Besides counselling on using condoms, issues of how to tell the sexual partners about the results, or advising whether to stay with a partner when there is discordance in their HIV status were often raised. For example, one counsellor explained how he counselled a man to think through whether or not he should leave his wife when the couple was found to be discordant (she was HIV-positive, and he was HIV negative:

So if you leave her, how is your decision going to help you?... Imagine that you were infected with the virus and the wife was not infected and your wife decides to leave you. How would you have felt? (Counsellor, MACRO Blantyre)

To help those who are HIV-positive to move on with their lives, some counsellors said that they refer clients to HIV support groups like NAPHAM.

The person from NAPHAM may testify to the client that I tested positive in such and such a year I have the virus ... he looks just (like) all of us. This makes people to have a strong heart (be brave) that oh, then it is not the end of life when I go and take care of myself and follow what is being said.... I can stay for a long time. (Counsellor, MACRO Blantyre)

Clients with negative test results are encouraged to “continue protecting themselves.” Most counsellors seem to assume that these clients were protecting themselves from HIV infection prior to seeking an HIV test. At the same time, counsellors were aware that clients who tested negative for HIV may have engaged in risky actions, and therefore, counsellors sought to find out how they were going to protect themselves from HIV infection.

Counsellors said that the main benefit of counselling HIV-negative clients is to prevent them from getting HIV in the future.

Those ones (*anthu woyendayenda*: those who often change sexual partners) are very useful (to counsel) because they can live very dangerously, they can also get (contract) HIV very fast because they will be thinking that ah! I cannot get (AIDS) but they don't know that they can get HIV (Counsellor, MACRO Lilongwe)

Clients who were HIV negative were encouraged to return for another test after three months because the HIV test identifies antibodies that take several months to develop after infection. Counsellors did not encourage people who tested positive for HIV to return to the centre unless it was to join a support group. Very few counsellors mentioned that it is important to know how a person with HIV is coping after knowing his or her HIV status and to be assisted accordingly if he or she is experiencing difficulties.

People who tested negative for the second time were not encouraged to come again after their second test, because they were expected to follow the preventive measures discussed during the counselling session. Sometimes a client would come again after having unprotected sex, which discouraged counsellors, because they expected them to change their actions after having tested negative.

Counsellors at MSF Thyolo mentioned that most of their clients wanted to have copies of the forms on which their test results were recorded. Some of the clients failed to understand their results and asked the researcher to explain to them what the words written on their cards meant.

7.6 Challenges of Counselling

Some aspects of their job that counsellors find challenging are intrinsic to the work of HIV counselling itself. These include trying to convince clients of the reality of HIV when they are in denial. One counsellor said the purpose of counselling clients is to “prepare them psychologically, to break their fears about HIV” which allows them to see “reality.” Some clients simply do not want to hear their test results, and they resist efforts by others to inform them.

Counsellors find it difficult to talk to people who come repeatedly for testing because they do not accept their HIV-positive test results. Other clients want the counsellor to change the test results recorded on their result form so they can retain their job or continue to have access to certain insurance policies or scholarships. The study team heard of a few examples of a counsellor being requested to record HIV-positive results for a client who actually did not have HIV. A positive result can guarantee early retirement, or in the case of a man who does not want to marry his pregnant girlfriend, it may scare off her parents if they want him to marry the girl.

Another challenge is counselling women who are HIV-positive but who want to have a child. Counsellors discouraged women with HIV from getting pregnant. Some counsellors tried to convince women not to conceive, while others referred such clients to specialized programs that deal with the prevention of mother to child transmission of HIV. Many women still wanted to have a child irrespective of the advice from the counsellor.

Counsellors stated that they find it a challenge to counsel a couple if a woman’s test result shows she is HIV-positive while her husband is negative. According to the cases they have seen, most marriages break up when the woman is infected and the man is not infected. However, when the woman is HIV negative and the man is HIV-positive, women most often stay in their marriage.

Another challenge counsellors cited was being unable to answer clients’ questions. They acknowledged that there were some clients who read more widely than they did and who wanted information clarified. Sometimes the counsellor may not even be aware of new developments in the area of HIV/AIDS.

Counsellors also face challenges that are not related to the counselling process itself. For example, the physical features of the facility, in particular the layout of the entrances and exits, make it difficult to maintain privacy of the client.

The body speaks, so when the person does not have HIV, or has got it, they (people observing) can tell from the way the person walks or looks. Maybe they are reactive or not, depending on the way the body has spoken; so is important to use two separate doors to go in and out. (Counsellor, MACRO Blantyre)

Besides the problem of entrance and exit, one counsellor pointed out that he thought the clinic is too close to the road and needs a fence around it “because a relative might see them.” The MSF clinic

solved a similar problem by adding a separate exit at the back for people to leave without being seen by those entering the building. They also added an enclosed veranda for those waiting.

The MACRO counsellors thought that there are too few counsellors at the MACRO centres, for they have to see too many clients. Most MACRO counsellors complained about exhaustion. MACRO Lilongwe had fewer counselling rooms, and as a result, some counsellors had to wait with their clients for the rooms when they were in use.

According to the counsellors, MACRO was experiencing a lot of staff turnover. Within the study period of six months, four counsellors had resigned from MACRO Blantyre. Some counsellors felt that their salary did not compensate them enough for the amount of work they did, and they were seeking other employment opportunities. Some counsellors stated that after working for some years at MACRO, they find the counselling profession not challenging enough for their intellectual development because it turns into routine work. A few MACRO counsellors felt that staff members are not sufficiently involved in decision making and that it is always the same counsellors who attend the workshops and seminars.

Counsellors at MAICC and MSF CHARC were not seeing many clients. Their main challenge was dealing with clients who were in denial after being told of being HIV positive. Counsellors at MSF Thyolo had a very busy workload because they were also providing HIV/AIDS testing and information to inpatients from the hospital.

Suggestions from counsellors about how to improve their services included providing refresher courses in counselling or seminars related to HIV/AIDS or organizing the training course so that counsellors complete the course before beginning work as a counsellor. This suggestion was made because most counsellors started work after only one week of orientation in a course, followed by supervision from an experienced counsellor. Many counsellors began to counsel clients without having received comprehensive training in counselling.

Frequent training provided to counsellors was seen as one way of boosting individual confidence. An example given to support this suggestion was that a newly recruited counsellor is ill equipped with knowledge and may feel inferior to some clients who are more knowledgeable. Another suggestion was that counsellors should be able to attain a higher qualification, such as a diploma level in counselling.

CHAPTER 8 CONCLUSION

Voluntary counselling and testing (VCT) for HIV has been available in freestanding facilities in Malawi for about five years, with steadily increasing numbers of clients. The number of clients seen in the three Malawi AIDS Counselling and Resource Organisation (MACRO) facilities exceeded 50,000 from October 2002 through September 2003. Among the MACRO clients ($N = 51,178$) of that reporting period, 14.5 percent tested positive for HIV. This result means that during those 12 months, about 1 percent of adults thought to be HIV-positive in Malawi (760,000) were tested and counselled. Several privately funded hospitals also provide counselling and testing for HIV, along with other services, and many hospitals offer HIV testing with or without counselling.

The Malawi Ministry of Health and Population and donors plan to rapidly expand voluntary testing facilities in Malawi as soon as technically feasible. It is unclear to what extent the expansion of testing for HIV will also include professional counselling. In order to attract the maximum number of clients, those responsible for designing the services should consider the likely response of the population to increased opportunities to be tested, the services that are most attractive to clients, ways the population can best be encouraged to come for HIV testing and counselling, and how the clients who come for an HIV test are alike or different from those who do not seek such a test.

Knowledge of HIV transmission

The way that respondents interviewed in the general public understood how HIV is transmitted or how people contract AIDS is very close to the biomedical view and thus does not present a problem for AIDS prevention programmes. Some individuals make a distinction between having HIV as a virus (*kachiroambo ka edzi*) and having AIDS, while others do not. Practically everyone interviewed said the same thing about transmission: HIV or AIDS is transmitted through sexual intercourse and the sharing of razor blades, toothbrushes, and needles.

Knowledge of service availability

Most people interviewed in urban areas had heard about the possibility of testing at one of the MACRO facilities, the freestanding VCT service centres in Blantyre and Lilongwe. The media is being used effectively to advertise the availability of services in urban areas. Rural residents had heard of local sites for HIV testing from friends and family.

Readiness for an HIV test

Interviews with the public in the Central and Southern regions suggest that most individuals in the neighbourhoods visited are not quite ready to be tested. When they were first asked whether they would be tested sometime, most said “yes”, but further discussion revealed that they were not thinking of getting tested in the near future. Respondents said that they might be tested at some point in their lives, but they were not yet ready. The main reasons cited or suggested for not being ready included the following: they are not at risk; they do not want to be seen going to a VCT centre, for that would be recognizing that they may have HIV; and they are truly afraid they have HIV and are very worried about what that would mean for their lives. The fear of being told they are HIV positive clearly keeps people from being tested.

However, only a small minority said that they did not ever want to be tested. The small number opposed to getting tested provides some hope that people might be persuaded to come for testing with the right kind of encouragement.

Conditions of HIV testing

The interviews with the public and with VCT clients clearly demonstrated that they want VCT services that are free, that provide rapid results, that ensure privacy and anonymity, and that include time with a counsellor to ask questions and be advised about how to protect themselves from HIV infection. Many VCT clients told interviewers that they had heard that HIV tests are free and provide rapid results. Some VCT clients said they had come for testing at a facility far from home so they would not be recognised by anyone. The elements of VCT services that should be emphasized as the Ministry of Health and Population expands VCT services throughout the country are as follows: free tests; same-day results; anonymous records; private counselling; and counsellors who ask and answer questions. These conditions can be easily satisfied in centres that provide free services, use rapid test kits, guarantee anonymity, and hire professional counsellors.

Reasons for seeking an HIV test

Clients who came to VCT centres were asked what brought them into the VCT centre. The reasons they gave fall into five categories, presented in the order of the frequency they were mentioned:

- Fear of having been exposed to HIV by one's own actions
- Fear of having been exposed to HIV by the actions of one's spouse or partner(s)
- Feeling sick
- Family events (e.g., marriage, pregnancy, reunion, new partner)
- Job circumstances (e.g., new job, scholarship, application requirement).

Most clients who came for an HIV test differed in two ways from those who did not come: 1) either they or their spouse had several sex partners recently, and 2) they thought they had been exposed to the HIV virus. Both factors needed to be present: multiple partners and high anxiety about having been exposed to HIV. Most men who came for a test were worried about HIV infection because of their own actions, while most women were afraid they were at risk for HIV because of the actions of their spouse. A small proportion of clients came because they were planning a family event: a marriage, a possible pregnancy, or a new sexual partner.

VCT clients of the MACRO facilities are not more likely to be HIV positive than the general population. In the reporting period of 2002-2003, 14.5 percent of VCT clients tested positive for HIV, which is the same as the national prevalence figure for Malawi, but somewhat less than the prevalence of 23 percent for the urban areas in which the facilities were located.

Importance of counselling

VCT clients appreciated the fact that the service was free, that they received the results in an hour or two, and that counsellors invited them to ask questions. Many clients said they were grateful for the information they had been given about the difference between the HIV virus and AIDS, about how HIV is and is not transmitted, and the significance of the window period. These were issues that puzzled many clients. The conversations with clients about their contact with counsellors underlined the importance of the counselling process as both an occasion for health education and for discussing ways to reduce the risk of HIV infection. Some came expecting to hear instructions about how to avoid HIV infection, while others expected information about how to live longer with the virus. A few complained that their contact with counsellors was simply too short. The comments of clients about the counselling process showed that they consider that aspect of HIV testing to be important.

Possibilities of referral

The policy of the National AIDS Commission (NAC) and MACRO encourages counsellors to refer VCT clients to social and medical support services, whether they test positive or negative. In 2003, there were still very few such services available in the country, except for several private facilities with outside funding. The counsellors interviewed talked about the referrals to medical services that they routinely provided to clients. However, the clients interviewed did not report being referred to any support groups of any kind, social or medical. It is possible that some clients who had, in fact, been referred to a support group simply forgot to mention it. It is also possible that counsellors often forgot to mention that possibility, given the limited services available. It is unknown what importance counsellors actually gave to that aspect of the service.

Counselling in VCT services now has several objectives: to provide an opportunity for health education, to provide information for reducing the risk of HIV infection, and to refer clients to support services. Conversations with clients indicated that they were grateful for the HIV and AIDS information they were given and that they learned from the experience of counselling. Clients also recognized they were given instructions about how to reduce risky actions. They were not, however, often referred to support services. That aspect of counselling clearly deserves more attention.

The future of VCT in Malawi

The form that VCT services take in Malawi depends to a great extent on the decisions by the Ministry of Health and Population and NAC about several issues:

1. How should VCT services be marketed?
2. How will individual permission to test for HIV be obtained?
3. What importance will be given to the role of counselling?

While this study found that respondents had heard about VCT services on the radio, suggesting that radio is an effective channel, what should the messages be? Should promotion mainly emphasize that people should come for testing if they believe they have been exposed to HIV infection? Or should promotion materials focus largely on being tested for planning for the future? What is the current strategy of the Ministry of Health and Population and NAC to promote HIV testing, and how clearly has it been articulated?

An examination of the radio messages broadcast in the past year or two would show the relative importance given to various messages about the reasons for coming for an HIV test. The relatively small numbers of clients among those interviewed who come for an HIV test to plan for the future suggest that more emphasis should be placed on encouraging individuals to come for testing for that reason.

The issue of how to obtain permission to test for HIV arises in antenatal clinics, where program directors seem to have two options for women: to “opt in” or to “opt out.” The first option (opt in) means that women will be asked whether they agree to have their blood tested for HIV, or not. Only those who say “yes” will be tested. The second option (opt out) implies that blood will be taken and tested unless a mother specifically asks that no HIV test be conducted. But similar ethical dilemmas may arise in other circumstances where individuals are present for a particular service or activity that includes the drawing of blood, such as testing for syphilis in a clinic for sexually transmitted infections. Should doctors be certain that tuberculosis patients have agreed to an HIV test before they do the test? What individual rights are assumed?

The relative importance of counselling in the testing process has been the subject of debate in government and donor circles for some time. As medical services with antiretroviral therapy (ART) begin in 2004, will information about ART be included in the counselling process? Some might be tempted to expand HIV testing rapidly without counselling in order to increase access to services to all of the population, because maintaining and expanding the role of counselling in the testing process take time and resources to train and supervise counsellors. Yet the counselling process is central to better inform the population about the risk of HIV infection and ways to protect against it, as well as to provide an entry point for social and medical services. Some of the counsellors interviewed said that they do not have sufficient time with clients and that they need more support. The role of counsellors in VCT services should not be compromised as services expand.

REFERENCES

- Cheesbrough, J.S. 1986. Acquired Immunodeficiency Syndrome in Malawi. *Malawi Medical Journal* 3:5-13.
- Coates, T., The Voluntary HIV-1 Counseling and Testing Efficacy Study Group. 2000. Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania, and Trinidad: A randomised trial. *Lancet* 356:103-112.
- Coates, T., The Voluntary HIV-1 Counseling and Testing Efficacy Study Group 1998. O. Grinstead, S. Gregorich, and G. Sangiwa. Voluntary HIV counselling and testing (VCT) reduces risk behaviour in developing countries: Results from the voluntary counselling and testing study. Paper presented at the International Conference on AIDS, Geneva, Switzerland.
- Coombes, Y. 2001. National HIV/AIDS/SRH behaviour change intervention (BCI) literature review. Consultant report. Lilongwe: Ministry of Health and Population.
- Fylkesnes, K., A. Haworth, C. Rosenvärd, and P. M. Kwapa. 1999. HIV counselling and testing: Overemphasizing high acceptance rates a threat to confidentiality and the right not to know. *AIDS* 13:2469-2474.
- Horizons. 2001. HIV Voluntary Counselling and Testing Among Youth Ages 14 to 21. Washington, DC: ICRW and Population Council.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 1999. Knowledge is power: Voluntary HIV counselling and testing in Uganda. Geneva: UNAIDS.
- Lwanda, J. L. 2004. Politics, culture and medicine: An unholy trinity. Historical continuities and ruptures in the HIV/AIDS story in Malawi. In E. Kalipeni, S. Craddock, J.R. Oponng, and J. Ghosh (eds.) *HIV & AIDS in Africa: Beyond Epidemiology*. Malden, MA: Blackwell Publishing.
- Malawi AIDS Counselling and Resource Organisation (MACRO). 2003. Annual report (October 2003 to October 2003). Blantyre: MACRO.
- Malawi AIDS Counselling and Resource Organisation (MACRO). 2001. Annual report (January–December 2000). Project Life document. Blantyre: MACRO.
- National AIDS Commission (NAC). 2003. *HIV sentinel surveillance report 2003*. Lilongwe: NAC Malawi.
- National AIDS Commission (NAC). 2001. National HIV prevalence estimates from sentinel surveillance data. Lilongwe: NAC Malawi.
- Sweat, M., S. Gregorich, G. Sangiwa, C. Furlonge, D. Balmer, C. Kamenga, O. Grinstead, and T. Coates. 2000. Cost-effectiveness of voluntary HIV-1 counselling and testing in reducing sexual transmission of HIV-1 in Kenya and Tanzania. *Lancet* 356:113-121.
- Taha, T.E., G. Dallabeta, J.D. Chipphangwi, L.A.R. Mtimavalye, N.G. Liomba, N. Kumwenda, D. Hoover, and P. Miotti. 1998. Trends of HIV-1 and sexually transmitted diseases among pregnant and postpartum women in urban Malawi. Unpublished manuscript. College of Medicine Library, Blantyre.
- Umoyo Network. 2000. Year 2 Work Plan (June 2000-September 2001). Unpublished paper, Blantyre.

APPENDIX A
QUESTIONING GUIDE FOR THE GENERAL PUBLIC

1. Information about the respondent
 - a. History of the client (age, education, profession)
Family situation of the client (whether married, divorced, has/had children)
Other people living with the respondent
 - b. Health of respondent
Illnesses he or she suffered from
Common illnesses suffered by the respondent
Recent illness
Hereditary diseases
Ever suffered one of the illnesses that are now common in society (tuberculosis, shingles, etc.)
What respondent does when sick (treatment sought for each illness mentioned)
 - c. Family health
Common illnesses suffered by children, husband/wife, extended family living in the house
2. Employment history

Day-to-day chores/work
What they like to do
3. What they have heard about HIV/AIDS

The origin of HIV/AIDS
People they know who have HIV/AIDS, or died of it
How HIV/AIDS affect relatives, friends
Prevention of HIV/AIDS transmission
Illnesses similar to HIV/AIDS
Signs and symptoms of HIV/AIDS
People suspected to have HIV/AIDS
4. What they know about HIV testing and counselling

What they know about HIV counselling
What they heard about HIV testing
What they know about HIV testing centres
Knowledge of HIV/AIDS counselling and testing centres
Importance of counselling
Importance of HIV testing
5. News about HIV testing

People who have undergone HIV testing
Reasons for going to get tested
Where he or she got tested

If he or she ever been tested

When
Where
Why

Experiences at the counselling and testing centre

- a. The way he or she was welcomed
- b. The counselling process
 - What the counsellor told him or her
 - Questions asked by the client
 - Questions asked by the counsellor
 - Satisfaction with the counsellor's responses
 - Questions and concerns he or she still has
 - The test results he or she expects

If the client has never been tested, does he or she want to get tested

When
Where
Why

How can the counselling and testing process be designed so that it can fully address the reasons that makes people not to go for an HIV test

MAFUNSO A KWA ANTHU

1. Mbiri ya odzalandira chithandizo
 - a. Mbiri ya (zaka zawo, maphunziro awo, ntchito yawo)
M'mene palili pabanjapo (ngati aliokwatira, banja linatha, ali/anali ndi ana)
Anthu ene amene akukhala nawo
 - Umoyo wawo
 - Matenda amene anayamba adwalapo
 - Matenda amene amadwaladwala
 - Matenda anadwalapo posachedwa
 - Matenda akumtundu
 - Anayamba adwalapo matenda ena aliwonse amene afala masiku ano. (Matenda a TB matenda a ma Shingles ndi ena otero)
 - Kodi amachitachiyani akadwal (chithandizo chomwe amapeza pa nthenda iliyonse yatchulidwa)
 - b. Umoyo wabanja
 - Matenda amene amadwaladwala ana, amuna awo/akazi awo, achibale amene akuwasunga
2. Ntchito zawo
Ntchito za tsiku ndi tsiku
Zokonda kuchita
3. Zomwe anthu amanena zokhudzana ndi Edzi

- Chomwe chimayambitsa
- M'mene inayambira
- Anthu amene akudziwapo akudwala/anamwalira ndi Edzi
- M'mene anakhudzidwira achibale, anzake
- M'mene tingapewere/kudziteteza ku Edzi
- Matenda ofananira ndi Edzi
- Zizindikiro za Edzi
- Anthu amene akuganiziridwa kuti ali ndi Edzi

4. Zomwe akudziwa pa za uphungu ndi kuyezetsa Edzi

- Zomwe akudziwa pa zakuyezetsa Edzi
- Zomwe anamvapo pa za kuyezetsa Edzi
- Zomwe anamvapo pa za uphungu
- Zomwe akudziwa za malo oyezetsela
- Kudziwa za malo amene amapangako uphungu ndi kuyezetsa
- Kufunika kwa uphungu
- Kufunika kwa kuyezetsa

5. Za kuyezetsa Edzi

- Anthu amene anayezetsapo
- Zifukwa zoyezetsera
- Anayezetsa kuti

Ngati iwo anayezetsapo

- Liti
- Kuti
- Chifukwa

Ngati angafune kuyezetsa

- Liti
- Kuti
- Chifukwa

Zomwe anakumana nazo ku malo oyezetsera ndi uphungu

- a. M'mene anawalandilira
- b. M'mene uphungu unayendera
 - zomwe phungu anawauza
 - mafunso omwe munafunsa
 - kukhutira ndi mayankho
 - mafunso ndi nkhawa zomwe akadali nazo
 - zotsatira zomwe akuyembekezera

APPENDIX B
QUESTIONING GUIDE FOR VOLUNTARY COUNSELLING
AND TESTING CLIENTS

1. Information about the client
 - a) History of the client (age, education, profession)
Family situation of the client (whether married, divorced, has/had children)
 - b) Health of client
Hereditary diseases
Illnesses he or she ever suffered from
Recent illness
What client does when sick (treatment sought for each illness mentioned)
2. Receiving the services
 - a) What they know about the place (counseling and testing centre)
 - b) Expected services (testing, counselling, getting medication, etc.)
 - c) Thoughts about getting tested
Persons consulted (before getting tested)
What was discussed
Reasons for coming for the test
3. Experiences at the counselling and testing centre
 - a) The way the client was welcomed
 - b) The counselling process

What the counsellor told the client
Questions asked by the client
Questions asked by the counsellor
Satisfaction with the counsellor's responses
Questions and concerns the client still has
The test results he or she expects
4. Post-test Counselling
 - a) What the counsellor told the client
 - b) Questions asked by the client
 - c) Questions asked by the counsellor
 - d) Satisfaction with the counsellor's responses
 - e) Advice given by the counsellor
 - f) Decision about coming back
5. Perception of the services
Perceptions of
.....reception

-counselling
-testing
-satisfaction with the whole testing and counselling process

What else can be done to improve the services

MAFUNSO A KWA ANTHU OFUNA CHITHANDIZO

1. Zokhudza ofuna chithandizo
 - a) Mbiri yawo
 - Zaka, maphunziro, ntchito
 - Zokhudza banja lawo (ngatiali pa banja, anakhalopo pa banja, ngati ali ndi ana)
 - b) Zokhudza umoyo wawo
 - Matenda a ku mtundu
 - Matenda omwe anadwalapo
 - Matenda omwe anadwala posachedwa
 - Zomwe amachita akadwala (chithandizo chomwe amafuna panthenda iliyonse yatchulidwa)
2. Kubwela kudzalandira chithandizo
 - a) Zomwe akudziwa za malo wo
 - b) Chithandizo chomwe akuyembekezera
(Kuyezedwa, kulandira uphungu, kulandira chithandizo cha mankhwala)
 - c) Kuganizira zokayezetsa
 - Aamene anakambirana nawo
 - Zimene anakambirana
 - Zifukwa zokayezetsera
3. Zomwe anakumana nazo ku malo oyezetsera ndi uphungu
 - a) M'mene anawalandilira
 - b) M'mene uphungu unayendera
 - Zomwe phungu anawauza
 - Mafunso omwe munafunsa
 - Kukhutira ndi mayankho
 - Mafunso ndi nkhawa zomwe akadali nazo
 - Zotsatira zomwe akuyembekezera
4. Uphungu atadziwa zotsatira
 - a) Zomwe phungu anawauza
 - b) Mafunso omwe munafunsa
 - c) Kukhutira ndimayankho
 - d) Mafunso ndi nkhawa akadali nazo

- e) Malangi zo apadera omwe anapatsidwa
- f) Maganizo obweranso

5. M'mene achionera chithandizo

Maganizo awo paza

.....Kalandilidwe

.....Uphungu

.....Kayezedwe

.....Kakhutitsidwe ndi chithandizo chonse

Zina zomwe angachite kuti chithandizo chinke mtsogolo

APPENDIX C

QUESTIONING GUIDE FOR COUNSELLORS

1. Information about the counsellor

a) Knowing the counsellor

When started working (as a counsellor)
Choosing the profession
Professional qualifications
Satisfaction with the profession

b) Information about education

Educational qualifications related to the counselling profession
Education related to HIV/AIDS
In-service or refresher training
Other relevant training

2. The Counselling Profession

a) Preparation (before counselling process starts)

b) Reception

Greetings/introduction
Where clients are received
Printed text, audiovisual materials in the reception area

c) The counselling process

Time spent on discussions
What determines the duration of the counselling process

What the counsellor thinks about the clients
Questions the client asks
Questions the counsellor asks
Other issues discussed

d) Importance of counselling

Counselling for HIV-positive clients
Counselling for HIV-negative clients
What assists the counsellor

Networking among the counsellors
Materials (e.g., books, audiovisual materials, research reports)
Networking with other people (e.g., organisations, other professionals)

Post test

a) The results

Procedures followed when giving test results

Information about other services (e.g., organisations providing other services, referral, antiretrovirals)

Discussion about followup visit to the counseling and testing centre

- b) Challenges
Problems/challenges faced by the counsellor
Solutions to the challenges
- c) Improving the counselling process
Promoting voluntary counseling and testing
Other activities

3. An example of an experience with a specific client

An account of an experience with a specific client

Special things/behaviour noted

Similarities/contrast with other clients

MAFUNSO OFUNSA APHUNGU

1. Zokhuza phungu

a) Kudziwa mphungu

- Ntchito anayamba liti
- Kasankhidwe ka ntchito
- Maphunziro a ntchitoyo
- Kakhuntitsidwe ndi ntchito

b) Mbiri ya Maphunziro

- Maphunziro okhuzana ndi ntchitoyo
Maphunziro a za Edzi
Maphunziro owonjezera
Maphunziro ena apadera

2. Ntchito ya uphungu

a) Kukonzekera (asanayambe ntchito ya uphungu)

b) Kalandiridwe

- Malo nje
- Malo ofikira
- Zowerenga/ zowona pamalo olandirira anthu

c) Kayendedwe ka Uphungu

- Nthawi yomwe amatenga pokambirana
- Chomwe chimapangitsa kuti nthawi yoperekera uphungu ichepe kapena

ichuluke

- Zomwe phungu amaganiza za anthu amene akudzalandira chithandizo
- Mafunso amene phungu amafunsidwa
- Mafunso amene phungu amafunsa
- Zokambirana zina

d) Kufunikita kwa Uphungu

- Uphungu wa amene ali ndi kachilombo
- Uphungu wa amene alibe kachilombo

e) Zothandiza phungu

- Mgwirizano pakati pa aphungu
- Zipangizo eg. mabukhu, kadi, kafukufuku
- Mgwirizano ndi anthu ena eg. Mabungwe, akachenjede ena

f) Zotsatira

- Ndondomeko yakaperekedwe kazotsatira
- Uthenga wa zithandizo zina, eg. mabungwe, mankhwala
- Kukambirana zodzabweranso kudzaonana ndi phungu

g) Zovuta

- Mavuto amene amapezeka
- Njira zothetsera mavutowo

h) Kupititsa ntchito yanu patsogolo

- Njira yakafalitsidwe ka ntchito zawo
- Ndi zina

3. Chitsanzo chamomwe munachezera ndi m' modzi mwa anthu

- Panachitika zotani ndi m' modzi mwaanthu amene anawonedwa
- Zosiyana zotani/kapena mtchitidwe umene unaonedwa
- Zofanana kapena kusiyana ndi anthu ena odzalandira chithandizo