Investigating the gendered dynamics of women's access to voluntary testing and counselling in Malawi: A case study of Macro and Napham in Lilongwe

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This work is dedicated to my girl children – Annette, Memory, Constance, Yanjanani and Catherine as you will surely experience the inequalities in the world.

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Abbreviations

ADMARC	Agriculture Development and Marketing Cooperation
AIDS	Acquired immune deficiency syndrome
ARV	Antiretroviral
CAYO	Counselling for Adolescent Youth Organization
CEDAW	Convention on the Elimination of all forms or Discrimination Against Women
HIV	Human immune virus
MACRO	Malawi Aids Counselling Resource Organization
NAC	National AIDS Commission
NAPHAM	National Association of People Living with HIV/AIDS in Malawi
NGO	Non-governmental organization
PLWHA	People living with HIV and AIDS
STI	Sexually-transmitted infection
TB	Tuberculosis
TL	Tubal ligation
VCT	Voluntary counselling and testing

CHAPTER ONE

Introduction

The subject of gendered dynamics to women and men's access to voluntary counselling and testing (VCT) is challenging as a research topic for a number of reasons. Firstly, the AIDS pandemic has brought to the fore the essential and extremely problematic nature of sex and sexuality. Women are generally suffering from unequal access to health care services owing to both biological and cultural factors. Sexually-transmitted diseases in women are usually asymptomatic due to their biological make-up and this, coupled with women's lack of information about their reproductive system, means they may not think of problems like abdominal pains as being a sign of illness. This prevents them from the timely identification and treatment of sexually-transmitted infections. Men, on the other hand, easily identify excessive discharge or penile sores almost immediately following infection and seek treatment. Biological make-up is already a factor for unequal access to health care in the case of women while untreated sexually-transmitted infections are a predisposing factor to HIV infection. Secondly, issues of sex and gender come to the fore with the underlying challenge that cultural factors are imbedded in highly patriarchal societal customs and attitudes that relegate women to subservient positions to those of men, made worse by the low status accorded to women in society and their lack of autonomy relating to sexuality issues (Stein, 1997).

With increasing numbers of women becoming infected with HIV, the virus that causes AIDS, investigating the gendered dynamics of women's access to voluntary counselling and testing (VCT) services then becomes an important area of study considering, as McFadden (1992:158) says, that:

> '… it is those who have least access to information, choices, to health services and rights to critical decisions who are the easiest victims of the disease.'

Policies on voluntary counselling and testing in Malawi are couched in the understanding that both men and women have access to these services and that they are aware that access to health is a human right. However, the reality on the ground is quite different as women's access is hindered by multiple factors ranging from gender inequality to cultural beliefs and practices. Gender and sex become important targets as well as justifications of the cultural beliefs and practices. The human rights debate in the area of voluntary counselling and testing in Malawi has centred more on confidentiality of results, encouraging positive living and to some extent dealing with stigma and discrimination rather than interrogating why women are not accessing services on the basis of equality with men despite promulgation of an HIV/AIDS policy. This luck of disclosure of status by men has led to men who are HIV positive continuing to re-infect and get re-infected from their unsuspecting wives.

Gender is a social construct referring to the social relations between and among women and men, usually asymmetrical divisions and attributes connoting relations of power domination and rule. Gender relations are socially constructed and deconstructed as a result of the behaviour of men and women themselves. Gender relations are therefore historical, changeable, subject to abolition and transformation through everyday happenings as well as periodic moments of crisis and transformation (Mbilinyi, 1992). They vary depending on the particular social, economic, political and cultural context and help to determine women's access to rights, resources and opportunities (Commonwealth Secretariat, 2003). The importance of understanding these

dynamics is the gist of the research which attempts to offer some insights into how gender power relations have been used by men on women and how this has led to women failing to exercise their right to make decisions concerning their lives and access to voluntary counselling and testing services.

Sex, on the other hand, is the biological aspect, given by birth where one is born either male or female. I feel it is the inter-linkages between these concepts that has contributed to women's subordination in society.

Voluntary testing and counselling (VCT) denotes one seeking HIV testing and counselling services based on one's own decision without being coerced.

Background to the study

Malawi, like most sub-Saharan countries, considers voluntary counselling and testing a pivotal entry point to help people cope better with existing infection (WHO/UNAIDS, 2004). The challenge however is to have women access these services equally like men. Available statistics from MACRO show that more men than women access these services and the figures further indicate that of the few women who are tested, over half are found HIV positive.

Malawi is among the countries with higher national HIV prevalence rates in the world. Heterosexual contact is the most important mode of HIV transmission in the country. The first case of AIDS was identified in 1985 and since then the epidemic has spread rapidly. As of 2003, 760,000 Malawian adults were estimated to be HIV positive, representing a national prevalence rate among the 15-49 years age group of about 14.4 per cent. Although the total number of reported cases captured by the National AIDS Commission (NAC) by sex is about equal, female cases are concentrated in the 15-29 age groups, while in males, the figures are higher for those above the 35 years age bracket[1]. For women, this is when they are in the prime of their reproductive period, perhaps explaining NAC's[2] claim that perinatal HIV transmission accounts for about 25 per cent of new HIV infection and that about 30 per cent of babies born to HIV positive mothers are infected during birth or breastfeeding.

Gender differentials continue to exist for people accessing voluntary counselling and testing services. The data consistently show that a smaller proportion of females access stand-alone sites. While there are more males (70 per cent) accessing stand-alone services, there is no gender imbalance in the integrated sites NAC (2003). Integrated sites are those attached to a health clinic where one can be tested and referred for antiretroviral therapy or more HIV-related care and support within the same unit. I was unable to establish this aspect as I needed to get permission from the research board of the Ministry of Health and this was not possible within the timeframe of the study.

Today, in many parts of the world, people who are aware of their HIV status may be able to live longer and healthier lives because of newly available and effective treatments. Testing for HIV, the virus that causes AIDS, is an essential step before infected individuals can seek needed care and is often offered through confidential and/or anonymous sources. One such organization offering voluntary counselling and testing in Malawi is the Malawi AIDS Counselling and Resource Organization (MACRO).

HIV/AIDS statistics the world over further show that there are more women than men infected by the virus. The concern in Malawi is that few women are accessing voluntary counselling and testing services and yet access to information on one's HIV status is a human right and a starting point for someone to access subsequent care and support services. It is also a supportive avenue for learning and can be an entry point to care and support and testing; knowing one's status generally offers an individual peace of mind.

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[1] NAC HIV/AIDS policy 2003

[2] NAC Monitoring and Evaluation report 2004

Location of the study

The prime research sites were Malawi AIDS Counselling and Resource Organization (MACRO) and National Association for People Living with HIV/AIDS in Malawi (NAPHAM). MACRO is a non-governmental organization formed in 1994 to advocate and spearhead anonymous voluntary testing and counselling in Malawi as one way of contributing to the fight against the AIDS pandemic and the stigma and discrimination that characterize the disease. MACRO is a stand-alone centre, not attached to a clinic.

NAPHAM is a local AIDS support organization registered in 1993 by a small group of HIV-positive women and men after observing and experiencing that the needs of people living with HIV and AIDS were not being met. NAPHAM exists to provide quality care and support services to HIV or AIDS infected and affected people in Malawi. This is achieved through a number of activities, such as, HIV and AIDS educational outreach which is done through drama, singing and lectures where NAPHAM members educate the community on HIV and AIDS related issues. People are informed about HIV transmission, prevention and behavioural change. Community members are encouraged to go for voluntary counselling and testing and fight stigma and discrimination attached to people living with HIV and AIDS. NAPHAM educational programmes are done through school, community and company outreach visits. Other NAPHAM activities include: pre-test and follow-up counselling; home-based care; group therapy sessions; child care sessions; and income-generating activities.

NAPHAM was brought in as a research site because, unlike MACRO where more men access the services, the situation is the opposite at NAPHAM where more women than men access the services. The idea was to learn from these case studies and use the best practice as a starting point in advancing possible strategies to improve women's access to voluntary counselling and testing.

Four villages in traditional authority Tsabango and one rural outreach clinic run my MACRO were also included in the research to bring in views from the rural areas.

Statement of the problem

The National AIDS Commission in Malawi has made voluntary counselling and testing one of its priority areas in combating HIV and AIDS. Much as the national HIV policy stipulates human rights and gender equality as major principles, those policy guidelines have not been translated into specific programmes aimed at helping women realize this policy aspiration.

Based on my experience working with a national HIV/AIDS project in Action Aid Malawi, which used to fund MACRO and NAPHAM, the reports from these organizations always showed fewer women compared to men were accessing voluntary counselling and testing services at MACRO although more women than men were ending up joining NAPHAM to seek support services following an HIV positive results. This gendered difference persists despite a lot of discussions on issues that hinder women's access to these services that have taken place in workshops and other different fora, including in the teams that were developing the national HIV policy.

Women and girls suffer from sexual stereotypes that eventually affect their access to information, let alone their ability to make independent decisions to seek health care services. In many societies in Malawi, there are cultural dictates for women to play a passive role in sexual interaction and strong social pressures for women and girls to remain ignorant about sexual matters. The result is that women feel reluctant to go for HIV testing as it would be interpreted to mean they have been engaging in sexual activity. Consequently, there is a reluctance on all fronts to provide education about issues relating to sexuality to girls and they themselves may be hesitant in pursuing the information (UNIFEM, 2004). This has led to fewer women than men accessing voluntary counselling and testing services.

Women comprise 52 per cent (NSO 1998) of the Malawian population, as such, neglecting them would be doing away with over half of the population, especially considering that figures on HIV infection among women are ever increasing and some women are in child-bearing age categories. Hence the need to investigate the problems hindering women from accessing voluntary counselling and testing to allow women and men to enjoy their right to life.

Objectives of the study

This study was carried out with the following objectives in mind:

1 To investigate the factors that affect women's access to voluntary counselling and testing services as compared to men.

2 To explore issues women deal with following access to voluntary counselling and testing services as compared to men.

3 To interrogate the traditional and cultural practices that affect women's access to voluntary counselling and testing services as compared to men.

Study assumptions

The above objectives were arrived at based on the following assumptions:

1 Women are not aware of the existence of the voluntary counselling and testing services.

2 Few women compared to men access voluntary counselling and testing services because women require consent from a husband or male guardian to access the services.

3 Few women compared to men access voluntary counselling and testing services because women cannot afford transport costs as the women are economically dependent on men.

4 Few women compared to men access voluntary counselling and testing services because women fear that they will be blamed for bringing the infection into the family in case of a positive result, leading to violence and stigma.

5 Few women compared to men access voluntary counselling and testing services because married women in heterosexual and monogamous relationships do not consider themselves at risk of contracting HIV / AIDS.

6 The enactment of laws providing for compulsory as opposed to voluntary testing will improve women's access to counselling and testing services.

Research questions

The following research questions emanated from the above assumptions:

1 Does knowledge of existence of voluntary counselling and testing services affect women's access to these services?

2 Do women require consent from a husband or male guardian to access voluntary counselling and testing services; do men seek the consent of their wives?

3 What are the major factors that impede women from accessing voluntary counselling and testing services?

4 Does fear of being blamed for bringing the infection in the family prevent women from accessing voluntary counselling and testing services?

5 Do women in monogamous heterosexual relationships consider themselves not at risk of contracting HIV/AIDS?

6 Will enactment of laws providing for equal access to voluntary counselling and testing services for men and women improve women's access to these services?

From these broad guiding questions, I developed sub-questions to get specific information on the areas under investigation. The question guides are attached to the dissertation as annexes 1 and 2.

CHAPTER TWO

Literature review

This chapter presents literature related to the topic of voluntary counselling and testing. The literature is analyzed to show gaps which this research seeks to address. The chapter also details policy and constitutional provisions which, in the absence of clear legislation on HIV and AIDS, are the basis for advancing gender equality for men and women.

Literature and law review

In Malawi, literature on voluntary counselling and testing centres more on issues like scaling up services and lessons learned from pilot projects. The proTEST project, under the tuberculosis (TB) control programme, in evaluating its project looked more at what needs to be done to scale up service provision without undertaking a gender analysis to see if men and women had equally accessed the services under the project(Chimzizi, undated).

The same emphasis is registered in the national HIV policy where policy statements relate to increasing service points and making sure they are staffed by well-trained counsellors to improve service provision without considering the effects of these services on women.

A study done in Lilongwe urban by Lwanda (2002) entitled, 'The role of gender on utilization of HIV counselling and testing services in Lilongwe urban', concluded that voluntary counselling and testing is influenced by gender in that Malawi society has certain expectations for men and women on sexual matters and behaviour. Men must make decisions on sex and on access to voluntary counselling and testing services for women and men do not seek anybody's permission to seek services. This study was carried out before the national HIV/ AIDS policy was finalized and was limited to Lilongwe urban. Lwanda fails to bring out women's lived realities and experiences as concentration was on those who had not gone for testing and those waiting to be tested.

The research on investigating gendered dynamics of women and men's access to voluntary counselling and testing comes as a backdrop to Lwanda's study, and aims to find out if there is any change in the situation following her recommendations that gender inequalities issues in access to services be addressed through gender education. Also to ascertain if the fact that now there is the national gender policy with emphasis on promotion and protection of human rights as one of the guiding principles has led to any changes in the gender dynamics. The current study used a feminist and women's law approach, seeking to understand women's lived realities and propose recommendations based on law and human rights perspectives.

The national AIDS policy takes cognizance of the fact that both men and women are affected by AIDS but goes further to point out that women and girls are vulnerable groups socially, culturally and due to gender inequalities. What is striking, though, is that even with this realization, the policy does not in any way go beyond this to prescribe clear ways of dealing with the inequalities.

The need for going beyond realization to action cannot be overemphasized considering that gender relations not only underlie women's particular venerability, they also inhibit women's attempts to protect themselves (Baylies, 2004). Access to voluntary counselling and testing services to know one's sero status is a step towards

protecting oneself and can lead to possible behaviour change, hence the need to find ways of encouraging women, particularly young women, to access these services.

A UNAIDS fact sheet shows that many women want to be tested but do not have access to facilities. This indicates that more needs to be done to bridge the gap between this need by women and the actual access to the services. Realizing that women face challenges is not enough, it calls for specific measures to deal with these challenges to make sure women and men access services on a basis of equality. For women, access to voluntary counselling and testing facilities can further be hampered by other barriers, including fear of violence which prevents some women from getting tested or accessing treatment. Women's experiences and lived realities are necessary for lobbying and planning effective programmes to address persisting gender inequalities.

Another research done by Lwanda (2004) for his doctoral thesis, under the topic, 'Politics, culture and medicine in Malawi', shows the close relationship of these three variables and how this has led to fuelling the HIV/AIDS epidemic in Malawi. Political leaders have emphasized culture which has left women powerless and occupying low status in society. However, Lwanda does not go further to interrogate how this subordination affects women's access to voluntary counselling and testing although he brings out an aspect related to Malawians being comfortable with traditional medicine, as opposed to western medicine which they consider alien. He brings out the fact that in the case of a sexually transmitted disease, men are more likely than women to seek western medicine with women choosing to go to a traditional healer or a traditional birth attendant. Perhaps this explains the generally poor health-seeking behaviours among women. But access to health is a human right even guaranteed by the Malawi constitution under section 13. That is more reason why women's right to access voluntary counselling and testing services needs to be pursued to deal with their poor health-seeking behaviours and to protect them from HIV/AIDS.

A study done by Luhanga *et al.* (2001) in Lilongwe urban on gender differences in access to treatment and care for TB patients within the household revealed intra and inter household differences in access to resources for seeking care. Gender inequality and poverty were found to be factors that, in combination, brought out more problems for female than for male members of the household. Though not related to voluntary counselling and testing, this has relevance to access to these services in that the manifestations of TB are similar to HIV infection. However, Luhanga did not bring out the link between TB and HIV/AIDS and what gender differences would exist between men and women.

In some cases, the decision to seek testing is influenced by risk perception. Married women who are faithful to one partner may not perceive themselves as at risk. Prevention messages in some cases have not encouraged or helped women assess their specific HIV risks that may necessitate going for voluntary counselling and testing.

The study was designed to investigate the gendered dynamics of voluntary counselling and testing using MACRO and NAPHAM as case studies to reach the core issues. The results of the study will add to the growing body of knowledge and be used to plan specific programmes directed at encouraging women to access these services from a feminist perspective. More specifically, the National AIDS Commission can use the results to think through issues of women's rights to health promotion and protection. The findings also can inform guidelines for voluntary counselling and testing service providers to make sure women access to these services is at par with men.

The research is also aimed at generating theories to explain the complex problems affecting women. Although the research sample is not big enough to warrant generalizing findings, the results would in a small way inform HIV and AIDS policy and legal reform in Malawi. The study underscores the recurrent insistence that an analysis of gender reactions requires full understanding of the knowledge, motivation and constraints faced by both men and women, precisely because it is the relationships between men's volition and women's dependence and restricted agency which are at issue (Baylies, 2004).

Legal and policy environment

The Constitution of the Republic of Malawi

The Malawi constitution has gender equality and access to adequate health care as some of the principles of national policy under section 13[3] which states that:

> '…the state shall actively promote the welfare and development of the people of Malawi by progressively adopting and implementing policies and legislation aimed at achieving the following goals:
>
> a) Gender equality to obtain gender equality for women and men through:
>
> Full participation of women in all spheres of Malawian society on the basis of equality with men
>
> The implementation of the principles of non-discrimination and such other measures as may be required
>
> The implementation of policies to address social issues such as domestic violence…….
>
> c) to provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care.
>
> d) to recognize and protect the family as a fundamental and vital social unit.

A close look at these provisions shows that women would face major challenges to get the needed protection as, up to now, there is no legislation on domestic violence and HIV/AIDS and disease is not one of the grounds on which discrimination is prohibited.

Provisions of the Penal Code[4]

The Penal Code in section 192 which deals with negligent acts likely to spread disease dangerous to life says:

> 'Any person who unlawfully or negligently does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life, shall be guilty of a misdemeanor.'

HIV/AIDS is a disease associated with stigma and discrimination. Besides, the current situation is that an HIV positive result remains tantamount to a death sentence and therefore carries with it devastating psychological consequences. This piece of legislation was obviously drafted way before the HIV/AIDS epidemic and would lead to a lot of trauma if all an offender would be charged with is a misdemeanor. The law does not include the realities of partners not disclosing their status the first time they have intercourse, neither does it consider the time between contact and detection of antibodies in the infected person's body. The reality of proving the offence in court may leave women in a disadvantaged position.

The National HIV/AIDS policy[5] named 'A call for renewed action'

The National AIDS Commission is the body entrusted with policy formulation and coordination of HIV/AIDS related initiatives aimed at mitigating the impact of the epidemic and fighting its spread in Malawi. The policy acknowledges that challenges posed by HIV/AIDS are broad based, thereby requiring multi-sectoral collaboration and sustained action.

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[3] Constitution of the republic of Malawi 1994
[4] Republic of Malawi Penal Code Chapter 7:01 of the Laws of Malawi
[5] Malawi National HIV/AIDS policy 2003

One of the guiding principles in the HIV/AIDS policy, number four, is the promotion and protection of human rights:

> 'An effective response to the epidemic requires that the Malawians rights to equality before the law and freedom from discrimination are respected, protected and fulfilled.'

Women and young girls are singled out in this policy as groups suffering from discrimination which makes them vulnerable to infection and stipulates that they need special protection of their rights to equality before the law to ensure them freedom from discrimination in gender relations.

Voluntary counselling and testing falls under the promotion of HIV/AIDS prevention, treatment, care and support. Having singled out women and girls as vulnerable groups needing special care, one would expect that the policy would recognize the inherent and systemic and structural difficulties women suffer from in relation to accessing voluntary counselling and testing services. The policy further acknowledges that HIV/AIDS is a social issue which adversely impacts on families and communities. The policy however falls short of this recognition and hence the challenges faced by women have remained uninterrogated.

The Reproductive Health Policy[6]

One of the programme objectives of the reproductive health policy is to prevent and manage sexually-transmitted infections, including HIV/AIDS. Service providers are further urged to observe and adhere to reproductive health rights when offering all services. But just like the National HIV/AIDS policy, it falls short of clear strategies to achieve these goals in the presence of numerous challenges faced by women.

The National Gender Policy[7]

In this document, HIV/AIDS is considered under the broad theme of reproductive health. The policy recognizes cultural activities and customs which force girls into early marriages and early sexual experiences, together with the lack of information and services that increase the risk of unwanted teenage pregnancies, unsafe abortions, HIV/AIDS and sexually-transmitted infections.

The policy sounds good on paper but little has been done to get to the root of the structural problems women deal with in order to be at par with men. The rigid patriarchal structures and decision-making processes that women face have remained intact, apart from just being mentioned.

An analysis of these policy and constitutional provisions shows that while they take into consideration human rights standards, they seem far detached from reality and, as Tsanga (2001) says of the Zimbabwe constitution, such approaches do not take into account women's experiences and their lived realities.

Human rights instruments

A topic such as the one I have researched on touches on a number of human rights aspects. These form a basis for understanding that gender inequality and discrimination are central to the HIV/AIDS pandemic and set a ground for advancing change on a human rights basis. Below are selected human rights aspects in use in this research.

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[6] Government of Malawi Reproductive Health Policy 2002

[7] Government of Malawi, National Gender policy 2000

[3] See also Ndlovu's work referred to previously.

Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

The women's convention requires elimination of discrimination in all aspects of women's lives. It specifically targets inequality in relation to health services, education, family relations, violence against women, stereotypes and harmful cultural practices (UNIFEM, 2004). Discrimination is the basis for most problems women face in exercising their right to access voluntary counselling and testing services on the basis of equality with men.

CEDAW article 10(h) obliges states parties to ensure access to specific educational information to help to ensure the health and well being of families, including information and advice on family planning.

While article 12(1) states that:

> '… state parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure on the basis of equality with men, access to health care services, including those related to family planning.'

Article 14 of CEDAW mandates states parties to take the problems faced by rural women into account and in particular to ensure rural women the right to have access to adequate health care facilities, including information, counselling, and services. Malawi ratified CEDAW in 1987, initially with reservations to the article relating to culture, which was later withdrawn. However, up to now, apart from the national gender policy, there is no specific piece of law to operationalize CEDAW and protect women's rights.

CEDAW committee general recommendations

The CEDAW committee's general recommendation on HIV/AIDS says that progress to combat HIV/AIDS gives special attention to the factor relating to women's reproductive roles and their subordinate social position which make them especially venerable to HIV infection. Another general recommendation on women's health recommends that states parties implement comprehensive national strategies to promote women's health, including interventions aimed at both prevention and ensuring universal access to a full range of high quality and attainable health care services, including sexual and reproductive health services. Further, states parties are to report on measures they have taken to eliminate the barriers women face in gaining access to health care services and measures they have taken to ensure women's timely and affordable access to such services. The barriers the committee identified include requirements or conditions that prejudice women's access, such as the requirement for preliminary authorization by a spouse, parent or hospital authorities to access services.

The committee noted that acceptable services are those delivered in a way that ensures that a woman gives her fully-informed consent, that respects her dignity, that guarantees her confidentiality and is sensitive to her needs and perspectives.

These provisions in the women's treaty which Malawi ratified in 1987, have been incorporated in the reproductive health, gender and HIV/AIDS policies above. However, as will be discussed under findings, these aspirations are not getting translated into tangible benefits for women who ideally should be accessing voluntary counselling and testing services on the basis of equality with men.

The Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa

The Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa is the latest and quite elaborate instrument that details issues of women's rights in Africa. Coming at a time when HIV/AIDS is top on the agendas of almost all governments, Malawi ratified the protocol in 2005. It has a specific article relating to HIV/AIDS. Article 14(e) of the protocol under health and reproductive rights says:

> '… every person has the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually-transmitted infections, including HIV/AIDS, in accordance with recognized standards and best practice.

The practice on the ground is quite the opposite. Some men do not inform their partners while some women are unable to even go for testing in the first place, let alone know their status. Though the legal and policy environment seem favorable, there are still hurdles women must surmount to get the justice and equality they deserve.

CHAPTER THREE

Methodology

I used three main methodological approaches carefully selected based on my background as a gender and human rights activist and to better collect data that would answer the research questions fully. The methodology chapter discusses the approaches used in this research dissertation. By methodology, I refer to the theory and analysis of how the research was carried out. The overall methodology is the women's law approach within the wider context of a women's human rights perspective. The specific methodological approaches discussed below are: women's law, grounded theory, actors and structures and sex and gender perspectives. The latter part deals with methods of data collection. Since the research questions deal with issues of knowledge, culture, policy and interventions, data collection methods were selected based on their suitability to each category of questions. The data collection methods are discussed in terms of their usefulness and limitations in the following sections starting with methodological approaches.

Women's law approach

The women's law approach is associated with the grassroots-orientated collection of data about lived realities and experiences of women and in this case even girls, in order to gather empirical evidence and use it to understand women's position in law and society (Bentzon *et al.*, 1998). The strength of this method is its bottom-up approach which tends to reveal what goes on in actual practice as opposed to what is included in policies or statutes. My starting point was women's lived realities, where I interviewed and listened to the women themselves talk about their experiences and this formed the empirical data for my research. To thoroughly listen and document the stories of these women, I started off with the assumptions that there were fewer women going to MACRO than men. Throughout the research, I kept my mind open to new issues and insights.

Initially the research was informed by my understanding of human rights issues. However, through knowledge of the women's law approach, I was able to collect data through interviews and observations and interpret this data to get meaning. The flexibility with which I used the women's law approach meant I could, especially in the case of key informants, go back to them to get more information and meaning on their interpretation of policy and constitutional provisions as they relate to access to voluntary counselling and testing services.

The aim was to use empirical data from women's lived realities to understand women's position in society and how the policy and constitutional provisions as highlighted in the literature review section can be used to change women's position.

This approach was ideal because it created room for interrogating customs and beliefs in the ideal situation and how these relate to the HIV/AIDS policy and the Malawi constitutional provisions on gender equality and legal access to health care services and voluntary counselling and testing. Since there is no specific law on HIV/AIDS in Malawi, the research study was seeking to understand what women's experiences are in light of the provisions in the policy and in the constitution. This gave room for women to open up and share their perspectives of the customs and beliefs and how these impact on their ability to access voluntary counselling and testing services, in particular, and health services in general.

Through the women's law approach, the positions and relationships of power dynamics were analyzed from a gender perspective to look at who has power, who controls who and who is vulnerable in such a set-up. It became clear talking to women that the HIV/AIDS pandemic has brought with it a lot of gendered dynamics and challenges with women affected differently from men.

Grounded theory

Grounded theory is an iterative process in which data and theory, lived reality and perceptions about norms are constantly engaged with each other (Bentzon *et al.*, 1998). Although I started off with assumptions, these assumptions were informed by feminist theories relating to patriarchy and women's subordination. The knowledge of grounded theory helped me to, on an daily basis, analyze collected data to get the meaning out of it and identify gaps and other new sources of data to help fill the gaps so identified. For instance, initially I did not consider marriage counsellors as sources of data, neither did I plan to undertake in-depth interviews until I discovered that for a sensitive topic like voluntary counselling and testing, I needed to recast and add on to my data collection tools. As soon as I had made the initial contacts at the research sites, I came up with a research design to guide data collection. At the beginning of the research, my question skills were not good enough. Most of the questions were closed instead of open-ended, giving respondents a chance to talk about their lives.

The grounded theory approach helped me to tackle the broad topic of voluntary counselling and testing a small bit at a time. Throughout the data collection, I was mindful of what Bentzon *et al.* (1998) say about the interaction between developing theories and methodology being constant, as preliminary assumptions direct the data collection which, when analyzed, indicate new directions and new sources of data. As I collected data from these sources, it helped me better understand the feminist radical theory on patriarchy being the root cause of women's subordination. As I moved from one source to another, I came to realize that marriage counsellors are structures in society so important, especially in married peoples lives, that these structures are used to entrench patriarchy. This grounded theories approach helped me to later categorize the findings of the research using gender inequality and patriarchy as major themes. Throughout the research, I was able to rethink the issues of women's subordination and how these affect and influence women's access to voluntary counselling and testing services.

Actors and structures

The study focuses on gendered dynamics thereby implying that there is need to understand relational and power dynamics and how such relationships and behaviour patterns affect women and men's access to voluntary counselling and testing services. During data collection, it became apparent that women and in some cases even men deal with a number of actors within the family structure before they can make a decision to access these services. Such actors include and are not limited to marriage counsellors, chiefs, religious leaders, in-laws and influential leaders, such as members of parliament and political structures, and, in some cases, neighbours. Through this understanding, I was able to include marriage counsellors as a group of actors whose role needs to be understood.

Therefore, charting and delineating the position of women vis a vis men facilitated comparative analysis of women's status and rights with those of men. The actors and structures perspective enabled me to start out with women and girls' experiences in the process of life management and look at normative structures that impinge on their lives (Bentzon *et al.*, 1998:101). The actors and structures analysis is helpful in understanding how people's choice of action may be limited by the social, family, legal, religious or economic structures they think and act within which tends to explain the difficulties related to decision making in the case of a woman whose husband is HIV positive. This methodology was also found relevant in that, if there are changes to be made to the law and gender relations, the actors and structures need to be clearly identified and targeted with clear interventions if women's position and condition is to change.

The actors, norms and structures perspective helped me to understand the different practices adopted and the decisions and arrangements made by the actors, even where the HIV policy gives women equal access to voluntary counselling and testing without seeking consent. This agrees with what Meena (1992) says about kinship as an organizational structure which gives power to men to organize women. While I had assumed that women's oppression originated wholly from men, through interaction with the different actors and structures, I realized that sometimes women are used by men within the structures to enforce what is culturally deemed acceptable behaviour.

It was encouraging though to note that the effect of human rights and freedoms leads to negotiations and argumentations which influence actors' behaviour (Bentzon *et al.*, 1998). Some women were able to go through the impediments and stand up for their rights by accessing voluntary counselling and testing services even without their husbands' consent although they had a price to pay in the form of difficulties disclosing the results to their husbands.

Gender and sex perspective

The study focuses on gendered dynamics of women and men's access to voluntary testing and counseling. The sex and gender perspective therefore became handy in understanding issues which are based purely on one's biological sex and those attributed to a person based on gender which is a social and cultural construct (Bentzon *et al.*, 1998). The realization that women and men do not generally have equal access to resources such as information, power and influence prompted me to use the gender and sex analysis as an organizing principle (Commonwealth secretariat, 2003). It helped me to bring out and clarify the nature of the social relationships between men and women and their different social realities, life expectations and economic circumstances. Throughout the research process the thinking was from a gender perspective. While analyzing the figures from MACRO and NAPHAM, for instance, I was able to pick up the glaring differences between the sexes, indicating power differences. The gender and sex perspective also gave insights into the gender division of labour, the power relations between the sexes and how all these affect particularly women's access to voluntary counselling and testing. Through the gender and sex analysis, I was able to understand that women do not operate under the same conditions as men, that their sex difference can be a hindering or a promotional factor. Even though women are the ones with high HIV infection rates compared to men, their sex hinders them from exercising their right to access voluntary counselling and testing services due to cultural expectations that selectively apply to women and not men.

Data collection methods

In order to generate quality data, a number of methods were used. This allowed for verification or triangulation of data which Bentzon *et al.* (1998) define as trying to address the same research question using more than one source. The choice of method depended on the type of questions to be answered and these are explained in the text below. The different sources and methods used were:

- Interviews with key informants
- Random interviews with respondents
- In-depth interviews
- Group discussions
- Focus group discussions
- Observations
- Individual interviews.

Interviews with key informants

Key informants were identified based on their closeness to and expertise on the topic of gender, HIV/AIDS, voluntary counselling and testing and the organizations where data was collected. The interviews with key informants were meant to give an overview of the topic and set the possible areas of focus as well as identify important documents to be read relating to the topic under study. Key informants were useful in the area of policy and laws related to voluntary counselling and testing and in suggesting possible interventions to issues of women's access to these services.

From MACRO I wanted to know more about the organization and check if my assumption that there were more men than women accessing the voluntary counselling and testing services was holding. I also wanted to ask what the director thought were the reasons why women do not come for testing on an equal basis with men and if the organization was thinking of any particular women centred initiatives to make sure women are targeted and subsequently more come for voluntary counselling and testing. The other area was coverage – did the director feel that the organization was covering a wide enough area and whether he considered the services user friendly.

Interviews with NAPHAM programmes manager centred on what NAPHAM is, its successes and challenges as well as strategies being put in place to make the organization more woman friendly. Though MACRO and NAPHAM were the primary areas of focus, to gain more insight on the topic, key informants from outside these organizations were interviewed based on the value they were perceived to add to the data collected. These were the National AIDS Commission, UNAIDS, Ministry of Health and Office of the President and Cabinet.

The National AIDS Commission is the organization mandated to coordinate policy development, HIV/AIDS programmes and projects in Malawi. The interview centred on their understanding of how voluntary counselling and testing services are going on, why more men that women access stand-alone sites like MACRO and what plans they are putting in place to address the inequality.

UNAIDS is doing a lot in Malawi to coordinate the UN family and work hand in hand with the National AIDS Commission to spearhead the HIV/AIDS impact mitigation initiatives. The interview centred on policy as well as programme initiatives either directly carried out by the organization or those that are known to the organization.

Before the responsibility of coordinating HIV/AIDS services shifted to the National AIDS Commission, the Ministry of Health had a National AIDS Control Programme (NACP) which spearheaded the initial initiatives such as giving MACRO the go-ahead to start anonymous testing. There is a small unit remaining and I visited this remnant unit to get their views on the area of voluntary counselling and testing.

The challenge with interviewing key informants was their availability. Though appointments were made in good time, some of them would be postponed at the last minute making the smooth collection of data rather difficult. Some interviews had to be conducted at opportune times when I met the key informants during work related to the Human Rights Commission where I regularly work.

Random interviews with respondents

The random interviews were helpful in getting the voices of ordinary Malawians on the street, in the village and those coming to MACRO for testing. Structured questions were used to get the respondents views on why more men than women access MACRO and why women need consent and men do not. The initial interviews were done before I mustered the skill of asking people to tell their stories as opposed to using the questions to strictly get the type of information I was looking for. The shortfall with the random interviews is that it was difficult to go back to the respondent and fill in gaps should there be any. In some instances, respondents interviewed at MACRO would come from places outside Lilongwe. Since results are given on the same day, chances of someone coming back are slim. Therefore I lost out on follow-up questions to these respondents. For instance, there were six men who had indicated they would bring their partners for testing,

in two interviews but I had not verified the ages of respondents. The other challenge with random interviews is that some respondents would refuse to be interviewed (it is their right) while others would not be too sure of how the information would be used therefore would self censor the responses to give what I considered in some cases 'socially-acceptable responses'. It was difficult to interview respondents at MACRO after they had received their results. Perhaps they thought I would probe into their personal information. There was one exception of a woman who accepted to be interviewed and I learnt this was her second time to come for the test, she was single and she had tested negative.

In-depth interviews

Individual in-depth interviews for NAPHAM members started with an initial visit to the centre to introduce the study topic and get to know the schedules of group therapy meetings. Respondents were those willing to share their life stories. Once respondents were identified, interviews were conducted over a period of several weeks to establish rapport and get the respondents to open up. In three places, guardians and relatives were interviewed on their general understanding of voluntary counselling and testing, whether they had considered going for a test and what they considered the challenges women face when they test HIV positive. The relatives and guardians are those who had already been told by the NAPHAM member whom I was following up about her status.

To better understand the gendered dynamics and the different experiences between men and women, in-depth interviews were done with fifteen women; ten of them were HIV positive and members of NAPHAM, five were women who had not yet gone for testing who I was able to follow up. These are men and women I know and they were willing to be interviewed as to what they thought about voluntary counselling and testing and why they have not yet considered it as an option. In-depth interviews were also done with ten men, five were NAPHAM members and five had not yet gone for voluntary counselling and testing and were selected from their homes and places of work for ease of follow up. The topic of voluntary counselling and testing is sensitive and I felt I could not ably deal with personalized issues in either group discussions or individual interviews conducted at first contact. This therefore meant establishing rapport with the respondents over a period of time and following up to get more information on their stories. In three cases it was necessary to do home visits to appreciate the challenges they were going through and to get the views of the neighbours and relatives.[8] This gave me a feel of the prevalence of stigma and discrimination HIV positive women put up with. While doing in-depth interviews, I used observation and listening skills to get hidden messages and reactions through facial expressions.

Group discussions

Group discussions proved useful for a sensitive topic like voluntary counselling and testing. The study focused on MACRO and NAPHAM. Group discussions were separately held for men, women, boys and girls. Some of the groups were self-constituted, like those at NAPHAM, since discussions were held on Saturdays which are already meeting days for NAPHAM members. NAPHAM members meet on Saturdays for what is called group therapy. Previously men and women used to meet together until members discovered that there were issues affecting either sex that needed separate spaces for effective and open discussions. The current arrangement is that men meet on their own and so do the women; they also have a joint meeting once a month to discuss common issues.

From the initial group discussions, I was able to identify members who were willing to share their lived realities in depth. The group discussions proved beneficial both for the dynamics and for the information collected. Group members were able to talk freely on issues they knew or had heard about. The difference between group discussions and focused ones is that in the first case the information was general using general questions as shown in annex 1. The benefit is that it gave members a chance to bring out their understanding of a point which someone had raised. A list of the groups and their details is in table 3 opposite.

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[8] These are neighbours and guardians who already know the status of the respondent and in some cases the respondent had referred me to get more information from these people.

Focus group discussions

The focus group discussions on the other hand were planned in good time with clear specifications of who should form the groups in order to have people of similar traits in groups to maximize discussions. In the case of young people, these were from youth groups in traditional authority Tsabango within Lilongwe district. The first two groups represented the urban while the other two were held in the peri-urban area.

The aim was to get detailed information which could not be elicited in a larger group. There were between six and twelve members per group. In total four focus group discussions were conducted for female and male chiefs, boys and girls. The focus group discussions followed up on issues raised in the other discussions and interviews, such as issues related to culture, socialization and unwritten family rules. Since chiefs are custodians of culture, they were seen to be better placed to elaborate on these areas.

Observations

These were made during interviews, group discussions or while waiting to be attended to. Observing the surroundings helped me to find out more during the interviews. For example, at both MACRO and NAPHAM, men sit around a video screen to watch films related to HIV testing and counselling while others spend long hours playing 'bawo'.[9] The observations gave me a picture of the difference between staff members who are open and most of the time jovial while those who come for a service are reserved and sometimes suspicious of other people around them. Through observations, it was clear that there were deep levels of poverty both in the rural and urban parts of Lilongwe where data was collected, except for the offices of key informants which were well furnished. Observations enriched the information gathered through interviews, especially when one observes the non-verbal communication, group dynamics and feelings of group members through facial expressions.

Table 1. Focus group discussions

Group	Female	Male	Total
Chiefs	6	8	14
CAYO	12	14	26

Table 2. Random interviews

Place	Female	Male	Total	Comments
MACRO	15	21	36	Four of these were couples
Kawale	3	2	5	Random interviews at the market
Area 24	4	1	5	The man was with his wife at home
Church	2	4	6	These are marriage counselors

[9] A popular game mainly played by men using equal number of holes and marbles.

Table 3 Group discussions

Group	Female	Male	Total	Comments
Lilongwe ADMARC depot	13	-	13	Mixed ages of women waiting to buy maize
Nsonkhamanja CCAP women	15	-	15	This is a women's section of the church
Mdakusungira and Mutchi villages	17 10	9 13	26 23	Boys and girls Men and women

Table 4 Interviews with key informants

Place	Female	Male	Comments
MACRO	3	1	Male director and two female counselors
NAPHAM	2	2	Male P. manager, nurse and support staff
NAC	-	1	VCT officer as on leave
Min of health	1	1	PS responsible for HIV/AIDS and nutrition though under OPC[1] is reflected here
UNAIDS	1	-	P. officer responsible for VCT and gender

The study touches on people's sexual lives since HIV is mostly sexually transmitted. In the course of interviewing respondents, there were emotional moments when some broke down, I felt equally touched in the process. Some information really came from the bottom of interviewees' hearts. I discovered that in some cases it was the first time the respondents were narrating their story yet in others it had become routine to tell the stories to yet another curious researcher. The above methods of data collection were found useful for a sensitive topic that touches on people's intimate lives.

MACRO and NAPHAM statistics

The statistics I perused through at MACRO confirmed my assumption that there are more men than women accessing voluntary counselling and testing at the Lilongwe centre. From the statistics, it can be seen that though fewer women compared to men come for testing, higher numbers of women are HIV positive.

NAPHAM, on the other hand, has more women than men as members. Perhaps this emphasizes the women's need for support which they do not get from the family once they test HIV positive. The Lilongwe NAPHAM has over 1,500 members and 75 per cent of these are women.

Information was also gathered through library and internet search. The internet is awash with HIV/AIDS information in general but scanty on voluntary counselling and testing pertaining to Malawi. What there is on Malawi relates to scaling up voluntary counselling and testing services without considering factors that hinder women's access.

The literature on voluntary counselling and testing helped me to understand some of the theories behind the epidemic in relation to men and women.

Limitations of the study and challenges

The study area was small and therefore would not warrant generalizations for the findings. There are five MACRO centres spread across the country. However, the research was purposefully limited to Lilongwe for ease of transport. Though the findings cannot be generalized, they provide useful insights on the gendered dynamics of voluntary counselling and testing. Though Malawi has made some strides in opening up debates on HIV/AIDS, it was still challenging to get especially women to talk on sexuality issues. The other challenge was the food shortage that kept distracting respondents' attention from the subject of voluntary counselling and testing.

CHAPTER FOUR

Findings and discussions

This chapter details the research findings and analysis. The key questions which informed the study were the following:

1 Does knowledge of existence of voluntary counselling and testing services affect women's access to these services and if women require consent from a husband or male guardian to access the services; do men seek the consent of their wives?

2 What are the major factors that impede women from accessing voluntary counselling and testing services? Does fear of being blamed for bringing the infection in the family prevent women from accessing voluntary counselling and testing services?

3 Do women in monogamous heterosexual relationships consider themselves not at risk of contracting HIV/AIDS?

4 Would enacting laws providing for equal access to voluntary counselling and testing services for men and women improve women's access to these services?

The findings are presented under themes which emanate from the research questions. Each theme has subheadings:

- The first theme is on knowledge of existence of voluntary counselling and testing services under which there are unequal power relations between men and women and low literacy levels affecting decision making as subheadings.
- The second theme is on consent. The subheadings under this theme are: patriarchy manifested through men's control over women, women's lack of control over their sexual lives and the unwritten rules governing the family.
- The third theme is on factors that hinder women's access to voluntary counselling and testing services. Subheadings are the gender division of labour, stigma, discrimination and lack of confidentiality, violence and blame, poverty, economic dependence and the institution of marriage versus HIV risk.

The general picture

The findings confirm that there are indeed more men than women accessing voluntary counselling and testing services at the Lilongwe MACRO centre. The tables opposite show figures extracted from the 2003 annual report for Lilongwe centre.

Some statistics for 2003 MACRO Lilongwe branch

Clients tested by age

Clients tested			Clients tested HIV positive		
Age	Male	Female	Age	Male	Female
15-19	1,471	823	15-19	10	80
20-24	4,850	1,620	20-24	114	278
25-29	2,941	883	25-29	200	276
30-34	1,356	473	30-34	234	191
35-39	679	273	35-39	168	112
40-44	436	175	40-44	116	27
40-44	574	202	40-44	142	54

Statistics by age of clients tested. Extracted from MACRO Annual figures for Lilongwe branch

Clients tested by marital status

Clients tested			Clients tested HIV positive		
Marital status	Male	Female	Age	Male	Female
Married	3,949	1579	Married	571	407
Unmarried	7,603	1,987	Unmarried	255	262
Separated	143	155	Separated	20	47
Divorced	488	464	Divorced	100	157
Widowed	159	295	Widowed	73	169
Total	12,342	4,480	Total	989	1,042

Worth noting is the fact that although fewer women are tested than men, more women than men test HIV positive. The situation is no different even by marital status as shown in the table. More unmarried women compared to those married were tested and more of these were within the age range of 15-24. As articulated by the MACRO director, in terms of the women who come for testing, most of them are young. This makes the quest for increasing women's access to voluntary counselling and testing services even more plausible as one of the strategies for fighting HIV/AIDS.

Theme 1:Knowledge about the existence of voluntary counselling and testing services

Knowledge of the existence of voluntary counselling and testing services was found to be widespread. Messages are aired on radio and television and some people have heard through church or at open-air campaigns organized by non-governmental organizations. For example, MACRO organizes meetings and NAPHAM members do outreach visits where information about HIV in general and testing in particular is shared by those who have undergone testing. The aim is to give the audience a chance to find out more about testing. Some of the study respondents gathered the courage to go and be tested after listening to NAPHAM members at their open-air outreach sessions.

Politicians have also taken it upon themselves to talk about HIV/AIDS at political rallies. However, these messages tend to be too general so not compelling enough for women. In most of the messages disseminated, no effort has been made to include the policy provisions on voluntary counselling and testing as a way of providing legal cover for women to start exercising their right to access these services. One example of a message is:

> 'If you want to know your status and alleviate fear, come to MACRO and get tested so you can plan better.'

This message presupposes that men and women are starting from an equal level of decision making. Yet the reality is such that women would need targeted messages as they do not ultimately make their own independent decisions

Some respondents, especially women, have heard about voluntary counselling and testing through health talks that are given at health clinics. The Ministry of Health has made it a policy that information on HIV testing be part of health talk topics in all health facilities. Women, being the majority of clients who go to clinics, have had a chance to hear about voluntary counselling and testing at these places. The question is how much of this information is used by the women to assess their own risk and use this information as justification to exercise their right to be tested. What seems to happen is that much as women are the majority of those who patronize health clinics where messages on voluntary counselling and testing are regularly given out, something affects their decision making. Young people, on the other hand, were knowledgeable about the policy provision as well as about their rights to access voluntary counselling and testing services. Further probing however revealed that while they know about the services, they have not gone any further to undertake the testing themselves. Reasons cited include fear of stigma and death. One boy at CAYO said:

> 'I know about VCT through programmes our youth non-governmental organization runs with funding from NAC but I have not made up my mind to go and test. My girlfriend asked me once but I told her to go and test first.'

Messages are disseminated in schools. The primary school curriculum has integrated basic facts on HIV/AIDS. However, it was beyond the scope of the current study to assess the extent to which these messages have led to young people accessing voluntary counselling and testing services. It was found that both in the rural and urban areas, messages about voluntary counselling and testing services at MACRO are well known, but these are general, without any reference made to the policy provisions on equality and they do not address the structural problems that women face in trying to exercise their rights to access these services.

Misconceptions and myths about the amount of blood drawn for the test has led some respondents to shun the test. In the women's group at Mutchi village, some women said they fear that a whole bottle of blood will be drawn for the test. Through discussions, one woman who had undergone testing was able to explain that it is a little blood that is drawn after a prick, similar to the one when they want to test for malaria. This underscores the importance of clear and directed messages to help clients make informed decisions. Myths and misconceptions were found to have derailed the family planning services, for example, when women would tell each other that contraceptive pills can pile up in the abdomen (Lwanda, 2004).

Some respondents found messages disseminated by churches were too judgmental as they tended to suggest that those who are infected by the virus are sinners. So some respondents feared that if they went to be tested and were found HIV positive, they would be labelled sinners.

Knowledge of existence of voluntary counselling and testing services however, has not translated into desire to access the services. There are still more men than women registering at MACRO. Providing information alone is proving not to be motivation enough, especially for women to make a decision to go for the HIV test. As Ng'weshami (1997) explains, there is need to go beyond general information provision and touch on risk factors because it is more men than women who feel personally at risk of AIDS and women, on the other hand, tend to have poorer access to proper information. For women, general information may not make them seriously consider themselves at risk to the extent of seeking an HIV test. During the research, most of the men cited their reason for seeking voluntary counselling and testing as their risky lifestyle. Having engaged in sexual relationships with multiple partners was cited by 14 of the men interviewed at MACRO and even during group discussion; this reason kept coming up as justification for men to go for a test. While among women, the issue of multiple partners is not frequently mentioned. Women feel more at risk when they consider their partners unfaithful. Women would cite this as a reason for having a test, alongside wanting to get married or remarried following widowhood, wanting to get pregnant and, in one woman's case, to seek divorce.

Women were said to generally lack the self confidence to stand up for their rights. In the words of the MACRO director (and repeated by almost all key informants from organizations I visited) though without elaborating on what underlies the statement:

> 'Malawian women are not empowered to make decisions.'

While the same messages have made men go for testing, one can only opine that the socialization process of women and girls, which largely emphasizes their subordination to men, has left them unable to make informed decisions to access voluntary counselling and testing services even after hearing about their existence.

One other finding is that beyond listening to the messages, there is total silence around the topic of HIV/AIDS. Female respondents in a group discussion at Mdakusungira village laughed when asked if they take time to discuss the messages they hear concerning voluntary counselling and testing with their partners. One woman emphatically said:

> '*Uyambira pati? Akudabwatu! Aziganiza kuti wayamba zibwenzi mwinanso phokoso lingayambire pomwepo.*' (Where and how do you start from? The husband will suspect that you have a boyfriend otherwise why would you be interested in such messages. Sometimes this can provoke violence in the home.)

This ties up with what McFadden (1992) wrote that even though AIDS is universally recognized as an illness, it is still taboo in most African societies, essentially because of its intimate relationship with the sexual act. The women in this group discussion felt discussing voluntary counselling and testing messages with their husbands is tantamount to saying they are unfaithful. There is need to probe further on what can be done beyond knowledge to effect behaviour change so that women start to access these services. As is generally said, knowledge is power, therefore women need to be empowered with it if they are to stand up for their right to access voluntary counselling and testing services.

Unequal power relations between women and men

Unequal power relations seem to originate from multiple sources: cultural expectations that women are subordinate; low literacy levels; and age differences with some women married to older men.

All men interviewed at MACRO and NAPHAM, whether in a group or individually, said that a woman is subordinate to the husband therefore cannot make her own decision concerning testing unless she has been having extramarital affairs. However, the same men were quick to say they access services when they have engaged in extra-marital affairs. There is a double standard in the way society handles sexual behaviour for men and women. This has further intensified the difference in power relations. Through such cultural norms which restrict female sexuality, men end up with greater decision-making power regarding sexual matters. Since women are socialized to be ignorant about sexual issues, as a result, they are not expected to initiate discussion on sexual issues.

The close link between sex and AIDS therefore has left women more marginalized than men in terms of information and protective alternatives. Men, on the other hand, use this culturally-sanctioned control over women's sexuality to oppress the women. This subordination and lack of control over one's own sexuality is a major setback to women's right to access voluntary counselling and testing services. Stein (1997) says that women's low status compared to men means low self esteem and lack of autonomy. And lack of autonomy means lack of decision making ability with regard to personal affairs, such as accessing voluntary counselling and testing services to know one's status as ably provided for under article 14 of the Protocol to the African Charter which says:

> '…every person has the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with recognized standards and best practice.'

During focus group discussions with girls at CAYO, six out of fourteen girls said they would need consent from a guardian or boyfriend, yet these are the same girls that said access to voluntary counselling and testing was their right. These girls have had a chance to discuss the HIV/AIDS policy which states that every person aged 13 years and above, can access voluntary counselling and testing services without seeking consent. The boys at the same place felt that at their ages (16–22 years) they were old enough to make independent decisions provided they consider themselves at risk. This seems to suggest the deep-rooted idea about girls subordination and boys supremacy which is affecting the girls' ability to make their own decisions concerning their lives. This perhaps emphasizes the point advanced by UNIFEM (2004) that there are strong social pressures for women and girls to remain ignorant about sexual matters and the subsequent reluctance among duty bearers to provide education about issues relating to women and girls' sexuality. The women themselves are equally hesitant to pursue the information themselves, thereby cementing the unequal power relations.

MACRO, as a resource organization, needs to vigorously pursue the issue of women's empowerment by offering reader-friendly information to women. Currently, one has to actually come to the centre to watch videos on the testing services and positive living. MACRO may need to consider that, because of their sex, women and girls have limited access to HIV/AIDS related information (UNIFEM, 2004). MACRO therefore needs to provide more targeted information for women if the inequality is to be bridged. CEDAW, which Malawi is party to, oblige states to ensure that prevention education programmes are specifically designed to reach women and girls, that programmes take into account the barriers posed to accessing information by stereotyped gender roles for both men and women, as well as cultural norms about gendered sexuality during public awareness raising. MACRO has already taken steps to conduct focus group discussions with women-only groups in companies. The call now is for MACRO to act further on collected information to encourage women to come for voluntary counselling and testing.

Low literacy levels affecting decision making

During the research, it was found that women respondents generally had a low education status, unless they were key informants. Out of the 25 women interviewed at NAPHAM, only five had reached secondary education. The rest had gone up to primary level. While interviewing Joyce, a school leaver who had come to MACRO to test because she was planning to go for a course outside the country, she actually said:

> 'Most women are illiterate therefore they cannot understand what is good for them.'

This illustrates how an illiterate person has problems asserting her rights which leads to her continued marginalization. Grace, another respondent I interviewed at NAPHAM, said she had to leave school in standard 7 to look after her siblings and she regrets this because she feels that perhaps if she had continued with school, she would not have married early and got the HIV infection.

During discussions with Margaret, a NAPHAM member, she equally alluded to the problem of low literacy levels and said of her husband:

> 'Men are bread winners; they are authoritative and usually look down upon women. Some of the reason is because of illiteracy. Just imagine I only went up to standard 8 so chances of me telling my husband off are very slim.'

Similar views were shared by a NAPHAM programme manager who said as NAPHAM, they are working out how best to get people who are educated and are HIV positive to join their organization. The idea is to encourage information sharing and boost the image of the organization. Malawi demographic and health survey (2000) findings show that low education is strongly related to poor understanding of HIV/AIDS prevention and HIV testing.

Three male members of parliament said:

> 'The women we have in our constituencies are not like those of you in town who are educated and working. If a woman is not educated, she has problems making simple decisions, what more with HIV testing.'

Low levels of education tend to limit women's decision-making power. Van Ginneken quoted by Stein (1997) says better education results in someone having greater decision-making power on health-related and other matters and greater access to resources and education is closely related to health-seeking behaviours.

Culturally, women and girls have not been given priority in literacy issues. Women's literacy levels in Malawi stand at 51 per cent.[10] Even though the world is gradually acknowledging that because of their sex women and girls have limited access to HIV/AIDS related information (UNIFEM, 2004), with low literacy levels, it becomes difficult for women to stand up for their rights. They lack the power and autonomy that come with increased literacy levels.

[10] 1998 National statistical census report

Theme 2: Is consent really an issue?

The study question was to find out if women were not accessing voluntary counselling and testing services because they require consent from their husbands and if men also required consent from wives to access these services. The issue of consent has been a sticky one in Malawi, especially where women's health-seeking behaviours are concerned. As Palamuleni (1998) quoted by Lwanda (2004) puts it:

> 'Historically low status of women extends to sexual power in the family planning where women may not be able to make major decisions on their own, requiring the consent of their husbands or partners and sometimes key extended family members to approve their use of contraception.'

As the findings below show, this historical phenomenon still prevails in Malawi. Although consent does not necessarily come from guardians (except for the girls at CAYO who indicated so), husbands and sexual partners exercise a lot of control over women through the practice and expectation of women and girls seeking consent before they can access voluntary counselling and testing services.

From my experience working as a nurse and later in the Family Planning Council of Malawi,[11] I am aware that in practice it was a long time before women who wanted to undergo tubal ligation were allowed to sign their own consent forms; yet men could sign for any medical procedure on their bodies without seeking a wife's consent. Even where the policy clearly stipulated that women could sign for themselves, in practice health workers would be resistant. Although respondents in this study did not bring up cases women being sent back because of consent, this does set the background.

Consensus was found in responses from both women and men in rural and urban Lilongwe that, culturally, a woman needs to seek consent from her husband before she can access voluntary counselling and testing and family planning services. From the very first respondent, it was apparent that the two sexes simply live different lives, experience different things and of course have different perceptions of the reality surrounding them (Dahl, 1987). While the women are the ones heavily affected by HIV, it becomes difficult for them to stand up and seek voluntary counselling and testing services.

What was equally surprising was that girls who have boyfriends felt they needed to seek their boyfriends' consent, citing culture as the reason. This confirms the deep-rooted cultural and patriarchal ideologies that groom girls to be subordinate to men (McFadden, 1992).

Some respondents explained how they spent time trying to convince their husbands on the need to go for voluntary counselling and testing since the women were sick on and off but the husbands were uncompromising so that in two cases, the women only went for testing after the husband's death.

> 'My husband was harsh. The mere mention of MACRO would earn me a thorough beating. If he were alive, I do not think I would have gone for testing. Maybe I would have died like him. He did not want to be tested though his relatives told him more than once. He was just impossible.'

Asked if the consent is only for voluntary counselling and testing, a group of women from Nsonkhamanja CCAP Women's Guild said:

> '… a good woman should tell her husband anything related to her sexuality. If it is malaria, one can go to the hospital and explain later but things like family planning and this AIDS testing, surely a woman needs to seek her husbands consent.'

It was found that while consent is almost always necessary for a woman, men could decide to go for a test without their wives knowing. The reason was that they are the heads of the family and do not need any consent to do what they want. Some male respondents said culturally they are not expected to seek consent from their

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[11] It was a government organization mandated to coordinate family planning services in Malawi but was closed in 1999.

wives but should they feel like it, they can tell the wife of their own volition. One man in a group discussion at Mdakusungira village actually said:

> 'If I want, I can tell her that I am going for HIV testing but I am under no obligation to do so. But if she goes to test without me giving her the go ahead, then I can send her to her parents or marriage counsellors; a woman is subordinate to the husband.'

The research found that some women gather the courage to go behind their husband's back and access voluntary counselling and testing services. The reasons usually cited are frequent illnesses, suspecting the husband of having extramarital affairs and suffering from sexually-transmitted infections frequently, yet the wife being forced to get pregnant. Often it was found that if getting pregnant is used as the reason, consent would readily be given, suggesting that men want to control women's sexuality.

It was also found that some women knew they could have been infected, yet their husbands refused to give them consent to go and test. Some of these women went for testing without consent but had difficulties breaking the news to the husband, especially in the case of an HIV positive result. The women respondents concerned indicated that they did not disclose immediately but joined NAPHAM to learn tactical communication skills from other members; in the meantime, the women were not able to use protective measures or demand safe sex. This brings to light what McFadden (1992) says about AIDS being a phenomenon which has thrown the inequalities of decision making and relationships of men and women sharply into focus. Women largely find themselves in a passive situation where they are unable to protect themselves from infection.

It was equally found that since men did not feel duty-bound to seek consent from their wives, let alone disclose the test results, some men went ahead and started taking antiretroviral (ARV) drugs without the wife knowing. In such cases, the issue of safe sex becomes problematic.

Jane, one respondent from NAPHAM, explained how her husband had divorced her without her knowing that he was HIV positive already:

> 'I was married once and had a child who died when she was one year old. Then I started being sick on and off. My husband started abusing me and later he took me to my brother and said I should not get back to his house. That was the end of our marriage. I only learnt later that he had tested and knew all along that he was HIV positive. He had never told me. He married another wife and they are both dead now'

A married woman who does not seek consent from her husband is accused of infidelity, may lose her marriage and may even be killed by her husband and in-laws who accuse her of bringing shame to the family.

The study established that married women can access health services related to antenatal and child care without consent but will need consent to access family planning and HIV testing. Women do not enjoy the same rights in decision making as men (Meena, 1992), even in issues of life and death such as voluntary counselling and testing. The condition is worsened by the fact that they do not enjoy equal rights to access these services and to control their own lives.

It was also found that not all women adhere to the idea of seeking consent from their husbands. Some make their own decisions based on their assessment of risk and go for an HIV test. One respondent I interviewed at MACRO was a married woman and she had come to be tested because her husband was forcing her to get pregnant. She had been using a family planning method without the husband knowing because she would not have been given the consent to control her fertility. So using the same trick of not letting the husband know that she was on Fa family planning method, she went to MACRO with the aim of establishing her sero status before succumbing to the husbands demands of pregnancy. She said:

> 'I know that my husband has girlfriends. Now with this AIDS, I cannot just get pregnant. For the past five years, I have been using the injectable contraceptive without his knowledge. I hide my health

passport at my sister's place since all my relatives know his behaviour. He does not know that I have come for testing. If I test positive, I will open up the discussion so that we both come for testing and should we be found positive, that will be the end of the pregnancy story.'

Though some women have learnt to negotiate the issue of consent, it has not been without problems. The problems arise because, with positive status, it will only be a matter of time before the symptoms start to appear. And as Makoni (2004) says in her dissertation, most women immediately disclose their status to the husband but the reverse is not always the case, men often hide their status.

Is couple counselling an option?

The National AIDS policy statement 3.2.2.1.2 states that government shall undertake to 'promote and encourage couple counselling and partner disclosure of HIV test results'.

During the research, a total of 15 couples were seen at MACRO. Four of these couples accepted to be interviewed. The first two were young people who were planning to marry. They had agreed to test so that they could plan their family better. They were non committal on what would happen if one of them was found HIV positive.

The other middle-aged couple were a widow and widower also intending to marry. Both felt they needed to establish their status, especially after the death of both their partners.

While waiting to interview one of the MACRO counsellors, I observed a couple come out of the counselling room with the woman crying uncontrollably. She was not in a condition to be interviewed. It was found out later that this was a discordant couple (the man was negative and the woman was positive). The woman was three months pregnant and they were planning to formalize the marriage.

Although couple counselling would be ideal in reducing problems of consent, stigma and discrimination, it was found that very few couples consider it as an option. During discussion with MACRO staff, it was found that they have tried to encourage couple counselling through the messages they send out on radio and during outreach clinics. However, the limitation is that they offer voluntary testing and counselling therefore they can only suggest and not force someone to disclose to the partner, as that would suggest that MACRO staff can force disclosure, thereby breaking one of the values of the organization which is confidentiality.

While some widows and widowers are willing to go to MACRO together for voluntary counselling and testing, Esther's story is different. I met Esther at Chileka MACRO outreach clinic[12] where she had gone to be tested. She was 39 years old and widowed since 1996. She heard about voluntary counselling and testing at the hospital when she was caring for her mother whom she suspects died of AIDS. She also heard more information through the village health committee members in her village who were encouraging people to go for voluntary counselling and testing before getting married. Since the death of her husband, Esther had not had a sexual relationship but now she has a man friend who wants to marry her. For the past three months, they have been discussing the issue of going for voluntary counselling and testing but the man has refused to come. He keeps deferring it to another time. Esther wants to test to know her status so that if she is negative, she may change her mind on getting married to the man who has refused to test. Before this time Esther never considered testing because she never considered herself at risk.

The reasons Esther, George and most respondents gave for accessing voluntary counselling and testing services at MACRO are similar to those expounded by Hubley (2002) such as deciding to get married or start a relationship, the onset of pregnancy and following sexual relations outside usual partners. Most men interviewed at MACRO agreed that they had partners and that they were coming to check their status based on risky behaviour but most of them came without these sexual partners.

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[12] MACRO centres are concentrated in town and rural areas are under-served – see newspaper cutting from Blantyre.

Some respondents did not even tell their partners they were going for a test. The case of George Patrick is an example. He was 29 years old and married without children. On the morning of the interview, he was waiting to be tested at MACRO. There were only men; no women clients were spotted apart from MACRO staff in the waiting room, a situation described by the staff as the trend at the testing site. George Patrick was randomly selected by MACRO staff as a person willing to be interviewed. He stays in Area 3 which is walking distance from MACRO but came without his wife. He decided to leave home and go to work where he asked for permission from the employer to go to the hospital. He decided to come for an HIV test because he considers his lifestyle risky and although he indicated he would allow his wife to come for the test, the question is why did he not bring her that day or even tell her that he was going for an HIV test? Moses replied:

> 'Men have risky lifestyles unlike women so men want to check if all is well.'

Men's risky lifestyles, as opposed to most women's, could be the main challenge with couple counselling. Men may have extra-marital affairs with women other than their wives. Couple counselling therefore would be tricky as the men would be at a loss as to whether they bring their real wife or the many girlfriends.

Another example is that of Moses. Moses was randomly selected by MACRO staff among the 11 men waiting to be tested at MACRO the morning of the interview, based on his willingness to be interviewed. He said the reason he came for testing was to know his sero status. Since the death of his wife in 2002, he had had sexual relationships with two women and now he wants to marry one of them. Surprisingly, he did not bring the women to be tested, he came alone. Asked why he did not bring the woman knowing that HIV is sexually transmitted, Moses said he would rather know about himself first before he gets the woman involved.

But asked what he would do if he was to be found HIV, Moses says it is up to the woman to decide but usually women accept to take care of the man unlike men who chase women away and terminate the relationship if it is the woman who is infected.

Pressed further about why he did not bring the girlfriend or why women are not accessing MACRO, Moses said:

> 'Men are promiscuous but women are faithful, women also do not consider themselves at risk because of their being faithful therefore do not see the need for coming to test.'

With this general reluctance of couples to come and test, and the general non-disclosure of results based on the right to privacy, women shall continue to suffer unless the state takes it upon itself to come up with measures that will encourage couple counselling and ensure protection of women. With a clear policy statement as the one quoted at the beginning of this subtopic, one can think that government, through NAC, has not been serious in delivering on this policy statement. Within this area of voluntary counselling and testing, there is another statement:

> 'Government shall promote and provide high quality, cost-effective, totally confidential and accessible voluntary counselling and testing services country-wide, in particular, youth-friendly services and services that are adequate and accessible to vulnerable groups.'

Within the policy itself, women and girls are singled out as vulnerable groups. The argument therefore is that government needs to seriously consider the plight of these vulnerable groups by coming up with clear ways of enforcing this policy on couple counselling to benefit women as well. There should be concerted efforts between NAC and partners like MACRO and NAPHAM to encourage couple counselling as a way of solving the problem of women seeking consent in order to access voluntary counselling and testing services.

Patriarchy manifested through men's control over women.

Patriarchy is defined by Walby (1990) as a system of social structures and practices, in which men dominate, oppress and exploit women. Patriarchy is the root cause of women's oppression. Understanding this concept helps to capture the depth, pervasiveness and interconnectedness of the different aspects of women's subordination. The concept of patriarchy is indispensable for an analysis of gender inequality. Patriarchy is manifested through culture that always emphasizes women's subordination to men while men seem to be their own boss, make their own decisions and engage in risky behaviours. Women are almost always disciplined if they try to break away.

It was found that men who go for voluntary counselling and testing without seeking consent from their wives are not blamed as much as women. This difference in treatment of the two sexes on the issues of consent as well as blame could be explained through the ideology of patriarchy or male dominance over women. Women are left to seek consent from men while men do not bother. Asked what they would do if they discovered their husbands had tested without their knowledge, one woman from the church group said:

> 'The best one can do is to report to the marriage counsellors. But the counsellor will usually ask the woman what her problem is, they will say, "Don't you know that a man sometimes gets tempted and engages in an affair with another woman?"'

Marriage counsellors are a structure that society uses to institutionalize patriarchy. It was found that these same counsellors would plead with a woman whose husband has been found HIV positive so that she stays with him and looks after him yet the same counsellors are not so cooperative when it is the other way round. This brings out the issue of oppression and exploitation. Through the double standards condoned by these structures, men are able to engage in risky behaviour, come home and infect the innocent wife whom they will easily blame if she went to test and was found HIV positive. Most marriage counsellors are men therefore they advance men's interests at the expense of women. The church comes in strongly as the basis upon which women are oppressed.

During the group discussion with women, both at the church and in the two villages, women elaborately explained what a good woman is expected to do and it was clear that most of the women would want to conform to this prescribed code of conduct of the good women, even at the expense of their health. A good woman cannot access voluntary counselling and testing services without her husband giving her permission, agreeing with Lwanda's (2002) findings that gender inequality affects the use of these services in Lilongwe urban, with men expected to make all decisions relating to consent for testing. This is not in tandem with the provision in the HIV/AIDS policy under HIV testing which says that 'every person shall be entitled to access voluntary counselling and testing services without the consent of a guardian or other adult'.

Neither does it tally with the constitutional provision in section 13 which guarantees men and women equal access to health care. McFadden (1992) explains this situation rightly when she says that women have in the process internalized the patriarchal ideology which defines them as subordinate to men. They cannot exercise their right to seek to be informed of their status. This contravenes the provisions of the African Protocol to the Charter on Human and People's Rights on the Rights of Women in Africa article 14(e) which says:

> '…every person has the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with recognized standards and best practice.'

The recommendation of the CEDAW committee on women and health also urges states parties to deal with issues that hinder women's access to health such as issues of consent from spouses.

Women's over-dependence on men for economic support is another reason why they accept subordinate status as seen in the case of Margaret who suffered because she could not have sex regularly, neither could she bear more children as per her husband demands as she had genital sores. The husband ended up divorcing her. But in her own words she indicated:

'Although I felt severe pain every time we had sex, I persevered because I was dependent on him. '

Men take advantage of women's lack of independence to further assert themselves and dominate over women. Patriarchy is seen here as the root cause of women's subordination and, unless it is uprooted, women shall remain subordinate to men.

Women's lack of control over their sexual lives

During discussions with chiefs, emphasis was put on cultural expectations that women would surrender themselves to their husbands upon marriage. The husband is the one who makes decisions on sexual matters. Both women and girls separately in group discussions said if one is seen to be knowledgeable, one is labelled as being loose. So for fear of this label they pretend that they do not know anything. It is not strange, according to the group of women at Nsonkhamanja church, for a man to have multiple relationships but for a woman, she would be seen as betraying her husband.

At the group discussion with women at Mdakusungira village the women said they are counselled to take care of their husbands' sexual desire, not be too knowledgeable and to listen to what the husband says without asking questions. The husband or male partner therefore is the one that decides on sexual matters and makes all decisions in that regard and the woman is passive and on the receiving end. This scenario creates tremendous barriers to women in controlling their own sexuality.

One woman explained how someone who tries to control her sexual life is described and labelled as a prostitute. This lack of control over one's sexual life was related more to family planning where some women have had to hide contraceptive pills in flour baskets so that the husband does not know they use the methods. The challenge now is that AIDS is a disease that shows anyway. The women chiefs had these sentiments on this topic:

'This democracy has brought problems. During our time we never had women who did things behind their husbands' backs. If I needed to rest between pregnancies, I would ask my husband to send me home for one year but now with this disease, it cannot work. Women have no respect for husbands and husbands are now behaving like they are children, having affairs everywhere.'

This attitude makes women's subordination even more pronounced. Women are socialized to be subordinate and, coupled with low literacy levels, may not realize that their rights are being abused. For a woman who grows up knowing it is her husband who has the final say over her sexual life, such a woman would have problems developing the autonomy to access voluntary counselling and testing services.

The unwritten rules governing the family

The question on consent, elicited a lot of responses from both men and women about the unwritten rules governing the family. These rules relate to women's subordination to men. One man at MACRO said the woman needs to get consent because she has to follow '*malamulo a m'banja'*, literally meaning 'family rules'. Asked further who sets these rules and why they only apply to women and not men, he said women are inferior to men and so they need to listen to men. Three men at MACRO, however, said they do discuss anything that concerns them with their wives. But asked why they had not brought their wives for testing, they said sometimes you do not share everything. This gave me the impression the first response was just window-dressing but that they too consider their wives as subordinate. George Patrick, one of the respondents I interviewed at MACRO, said he knows the importance of both he and his wife undergoing HIV testing but he thinks women are not able to readily come for testing due to what he calls:

'…unwritten rules that govern the different families leading to violence if a woman contravenes them. The rules are put there by men but strictly apply to women.'

It was found that the rules are given to women throughout their lives while preparing them for marriage. They relate to faithfulness and submissiveness. Therefore even if the woman knows her husband has gone for voluntary counselling and testing without telling her, she cannot start to question him as this would be going against family rules. Hellum (1999) articulates these behaviours which she found in Zimbabwe when she says rural women, poor township women and women from the old generation often act as upholders of the gender system embodied in the patrilineal kinship complex. Some of the women have internalized this and feel comfortable reinforcing it, especially if they feel there is little they can change.

Theme 3: Factors that prevent women from accessing voluntary counselling and testing services

The initial study assumption was that few women compared to men access voluntary counselling and testing service because women cannot afford transport costs as they are economically dependent on men. This assumption changed in the field because it was restrictive and rather closed ended. It was finally opened up to include all possible factors that prevent women from accessing these services. Reasons cited for accessing these services have already been discussed above.

It was found that factors related to limited access to deeper information sexual health and the importance of voluntary counselling and testing consistently came up as being a factor that prevented women from accessing the services. The female respondents who had not yet undergone testing seemed not to appreciate the importance of it. Traditionally issues of sexuality are not discussed. McFadden (1992) explains this well when she says that for women, and especially the poor, young and illiterate, the intimate connections of the virus with sex and sexuality have meant that, on one hand, they tend to be most vulnerable to the disease yet, on the other, they generally have least access to information, protection and health services in all the countries of the African continent. The expectation that women remain ignorant of sexuality issues means that they are not well informed. Their male counterparts on the other hand indicated they had more detailed information on voluntary counselling and testing due to a number of factors, such as having other avenues where they obtain more information like at workplaces, on the radio and through written materials. Although printed information is available on voluntary counselling and testing, women often have less access to it due to low literacy levels, insufficient time to sit and read the facts and, generally, they do not consider themselves at risk as they usually remain faithful.

Gender division of labour

Lack of time due to multiple roles and numerous household and community chores was cited by both girls and women's groups in rural and urban Lilongwe as being a factor in not accessing voluntary counselling and testing services. The research period coincided with severe food shortages and it was not uncommon for women to spend nights in queues at ADMARC[13] trying to buy maize for the family. One woman interviewed at Lilongwe ADMARC depot actually said:

'I have been here since yesterday and I am not even close to the buying point. My concern now is what my children will eat. Would I have time to go for HIV testing while my children are starving? I still need to go to the garden and to attend funerals. I have no time left to go to MACRO. Maybe if I go to the hospital with a child, maybe I can think of testing.'

[13] Grain marketing board in Malawi

During discussions with girls at CAYO, the issue of household chores as a factor came up. The girls said some parents do not even allow their girls to join youth non-governmental organizations where they can learn about sexuality issues. The girls are kept at home doing housework while their brothers are free to walk around, joining organizations, learning more about their bodies and making better decisions. From this finding, two issues emerge. The unequal gender division of labour leaves girls and women with little time to seek information on HIV/AIDS in general and to go for voluntary counselling and testing, in particular. Secondly, the pressing household work leaves them with no time to go for testing unless they feel at risk. But these girls have boyfriends who are more knowledgeable than them, perpetuating the power difference further.

The UNAIDS programme officer talked about a youth initiative that was underway in Lilongwe rural whose preliminary findings were showing that dynamics at household level, which leave women and girls with too much work, have a bearing on their ability to access services. In this initiative, distance was said to be a factor that hinders women and girls from accessing services and that once services were brought closer to home, the their access improved markedly. Perhaps this could explain the piece of information from the MACRO director who said that the MACRO outreach clinics which are held in the communities in the rural areas, access is almost 50-50 for men and women. Therefore, unless women can be relieved from household work, given more detailed information to allow them to assess their risk and make their own decisions as men do, their access to voluntary counselling and testing services will continue to be low.

Stigma, discrimination and lack of confidentiality

Stigma was found to contribute to keeping women from accessing voluntary counselling and testing services. Those who have undergone testing and are known to be HIV positive are usually discriminated against. They are in some cases not allowed to participate in communal work and just the mention of AIDS is taboo. The story of Agnes explains this factor even more:

'I went for testing when I started being sick on and off. I was found HIV positive. The counsellor advised me to join NAPHAM and I complied. One day I was assigned to go for an outreach session at a market place close to where I was staying. Some people heard me talk about my status and they reported to my landlord. The following day, he sent his wife to tell me to move out of the house since I was HIV positive. I was very close to the landlord's children but immediately they were told not to come near me.'

Findings further show that the mere visit to MACRO in the case of three NAPHAM members was enough to have the neighbour segregating them. By the time they got the results, they had noticed a decline in friends. One man explained how his workmates would not share a cup with him and they would always demand that he tells people wherever they went to do outreach work that he was HIV positive. He felt this further marginalized him and increased the stigma.

Lack of confidentiality was found to contribute to women not wanting to go for testing. During in-depth interviews with all the five women who have not yet decided to go for testing, they alluded to the fact that they were not sure if their findings would be kept confidential considering how the counsellors in some cases share the results with other people, leading to stigma and discrimination. Two men interviewed at MACRO had come from distances of over 100 kms to test at the Lilongwe centre. The reasons given were that they do not trust the personnel at the testing place in their district. They were afraid that the results would not be kept confidential. One of the men actually had heard of a friend who tested and his results were known all over the place. While waiting to interview a respondent at MACRO one morning, one man walked in, sat down and suddenly walked out. Out of interest I asked if he wanted any help. He said he wanted to be tested but had just spotted someone he knew and he did not want to stay for fear that they would disclose to other people that he had come for testing.

Most of the clients at MACRO were reluctant to be interviewed for fear that their information may be exposed. Moses, for example, had to ask what I was going to do with the information, indicating his fear that I may not keep the information confidential. Though not unique to MACRO, based on the two men who were referring

to hospital testing sites, stigma and discrimination is still a factor keeping women and men away from these services. Discrimination is a violation of women's rights and contrary to the non-discrimination principle of the CEDAW. If men are not able to stand the stigma and discrimination, it would be worse for women who grow up with low self esteem. As women are already subordinated, they may be reluctant to seek testing where their privacy is not guaranteed. They may choose to suffer in silence rather than go through the stigmatization following an HIV test. The Commonwealth Secretariat (2003) alludes to the fact that in cultures where HIV is seen as a sign of sexual promiscuity, HIV positive women face greater stigmatization and rejection than men. The story of Margaret whom I interviewed explains the double stigmatization associated with promiscuity and an HIV positive status.

I met Margaret during one of my many visits to NAPHAM where she is a member. I asked her if she was prepared to share her story with me. Initially she just laughed and asked me to come back the following week so that she could make up her mind. When I went again after one week, Margaret agreed to talk to me.

Born in 1949, Margaret has been married to three different men due to problems she faced which I will indicate as I continue with her story. Margaret says she got married when she was young and spent eleven years with her first husband with whom she bore five children. Then she was working in ADMARC (the national grain marketing board). In 1993 she says she and her husband got very sick. She survived but her husband passed away. They both suffered from tuberculosis (TB).

At that time she did not think of HIV and so she remarried two years later. She had two children with the second husband and stayed with him for eight years. The second husband divorced her because she was frequently suffering from genital sores. Margaret says what made her sad is that she never suffered from the genital sores during her first marriage. However, the second husband said he could not stay without having sex, let alone use condoms consistently:

> 'Because I could not continue to bear more children and the frequent sores, he abandoned me to marry another woman. He later died after our divorce. He refused to go for an HIV test despite me telling him that I had been tested and found HIV positive. Initially I persevered because I was dependent on him though I felt severe pain every time we had sex.
>
> Men are still in denial, they do not believe AIDS is real, they do not accept using condoms, they blame the infection on women yet they are the ones who are promiscuous'
>
> 'After him, I briefly got married to another man but we did not stay long together because the sores came back. When I came to NAPHAM they called me a '*hule*'[14] and I was very isolated but now members have accepted me and I do not think I will get married again.'

The challenge posed by stigma and discrimination is that it robs women of their right to access voluntary counselling and testing and subsequent care thereby risking loss of life or passing on the infection to unborn babies in the case of pregnant women. Margaret's story also brings to the fore the other reasons why women persevere which are dependence and to bear children. Society has socialized women to look at themselves as being incomplete without children, regardless of the risk.

The intimate relationship of HIV with the sexual act, as McFadden (1992) says, has led to an increase in stigma and discrimination. Some respondents felt they would be accused of infidelity since those who go to test are considered to have engaged in risky behaviour. In the case of a married woman who is considered faithful, it would raise suspicions if she decided to go and test. Some women respondents were afraid of a family breakdown which would lead to suffering since most of them are dependent on men for support. Women in rural Lilongwe at a group discussion felt that knowing one's status is the same as being told that one is dying. They felt they would die of stress and leave their children behind. Apart from dwelling on issues of gender equality, this can be a way of building women's self esteem which I think is another issue one can deduce from the findings.

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14 *Hule* means prostitute

Violence and blame

The study findings show that fear of being blamed for bringing HIV infection into the family and the violence that followed a positive HIV result was cited more by female than male respondents.

One woman in a group discussion at Lilongwe ADMARC in a rather shocked tone said:

> 'I have heard that it is my right to go for the test but my husband has said if I go for the test then he will know that I have been unfaithful and have brought the infection to him. I wish you knew what people go through in these families. Can you even start to argue? He would beat you and that would even be the end of you (*meaning the end of the marriage*).'

While interviewing Joan at her home, she broke down and cried for some time before she could compose herself to narrate how she suffered blame and violence from her husband. She had been in hospital with her one year old child who was generally not growing well and having frequent pneumonia. Joan was counselled and tested. Her husband was working far away.

> 'When my husband came to see the child, I told him about the HIV result. He started shouting at me right there in the ward in front of people. He accused me of being a *hule*, unfaithful and that I wanted to bring shame to his family. He even told his mother who was in hospital with me to go back home and leave me alone with my sick child. What made me sad is the fact that it was him who had several girlfriends and I am sure he brought the infection to me. Do you think the women who were in the ward with me would dare go for voluntary counselling and testing? How about those who know my story? Women cannot go for testing because they fear losing their marriage.'

Male respondents in a group discussion in Mdakusungira village equally indicated:

> 'If a woman goes for testing without the husband knowing and she comes back with a positive result, yes, she is to blame. The question is if she is faithful, why would she want to be tested? You know with democracy these days, women are no longer faithful.'

The blame here is going to women yet in the same discussions, men allude to having extra-marital affairs. Yet when it is a woman, she really gets humiliated.

Much as voluntary counselling and testing is a pivotal entry point to help people avoid HIV and cope better with existing infection, the reality on the ground is quite hostile. A report by SAFAIDS shows that women in many countries have been abused, assaulted and divorced because their husbands blame them for the infection (Jackson, 2003). A UNAIDS documentary confirms that women are blamed for bringing HIV into the family and are at risk of abuse or ostracism. Moses, a man I interviewed at MACRO had this to say relating to blame and violence directed at women who test HIV positive:

> 'In some cases, men stop women from testing and blame the women for bringing the infection where a woman is found HIV positive. There are families that have broken apart because the woman has been found HIV positive.'

NAPHAM female respondents cited examples of women whose families broke up and in-laws ganged up to chase the woman away. On the other hand, treatment of men found HIV positive is different. Women are counselled to forgive their partners, stay on and look after them and they are even reminded that in marriage, they vow to look after the husband till death do us part. A senior counsellor at MACRO said in the case of couple counselling, it has been observed that if a man is found HIV positive, the women is more tolerant than if it is the other way round.

This perhaps links with what Ng'weshemi (1997) calls some cultural norms that include a double standard which gives men freedom to be more sexually active while restricting female sexuality. He goes on to say

that in some communities it is more or less taken for granted that men need to have sex regularly and that they should be dominant, deciding when, how and with whom they will have sex. Women on the other hand, are expected to remain faithful, do what their partner wants and not question their partners' behaviour. This does not mean women have no possibilities for negotiation but it can be deduced that the possibilities are limited and even more so if the woman is married. As McFadden (1992) explains, women have internalized the patriarchy ideology which defines them as subordinate to men. The fear of violence, especially following previous experience of such violence in the home disempowers women, limiting their ability to access voluntary counselling and testing services, and consequently women accept their fate as victims of the virus (Kaleeba, 1991). Surprisingly, the findings tend to suggest that women are more often blamed for spreading HIV/AIDS than men. Those respondents who have already tested shared stories of friends they know who experienced violence following a positive result. Some of the women interviewed at NAPHAM had to wait until after the death of their husbands to go and test even if all along they had suspected they could be HIV infected.

Walby (1990) calls violence another aspect of patriarchy, usually perpetrated by men over women, based on cultural dictates and physical strength. During the research period increased incidents of domestic violence were reported in the local newspapers, perpetrated by men on women. One woman (see newspaper cutting) was reported killed by her husband because she refused sex following a positive HIV result. Women suffer violence in the homes mostly because the homes are considered private spheres where the state cannot legislate.

Poverty and economic dependency

The initial assumption was on transport as a factor affecting women's access to voluntary counselling and testing services. However the findings reveal that while transport is a part of the problem, high levels of poverty were frequently referred to as a general setback. Women at Mutchi and Mdakusungira villages explained about the long distances they cover to get to Kang'oma and sometimes Kawale which are the nearest health centres. There are no buses covering this part of Lilongwe, perhaps explaining why transport did not feature as a factor.

Men sometimes threaten women with divorce; it was learnt during individual interviews with several NAPHAM members like Agatha, Mary and Joan whose stories have been referred to in this dissertation. Their stories show how poverty and economic dependency on their husbands made it difficult for them to go for voluntary counselling and testing even when they were sick on and off, had heard about AIDS and were convinced they could be infected.

Agatha, for instance, had a junior secondary education certificate and had been working before getting married. But the husband stopped her from working so she could totally depend on him. Agatha sadly told me during one of the interviews:

> 'Most of us women depend on men for survival. I was working before I got married but my husband was so jealous and protective so he made me stop working. I was totally dependent on him and how can one think of going for testing when she is totally dependent on the man and the man says you can't go.'

The findings show that apart from economic dependency and poverty being factors hindering women from accessing voluntary counselling and testing services, they are fuelling the further spread of the AIDS pandemic in that even if a woman may know that a man is HIV positive, they go ahead and engage in unprotected sex to get money. Low educational levels, already discussed above, is another factor that exacerbates women's poverty and economic dependence on men. As McFadden explains :

> 'AIDS cannot be separated from the extreme poverty, lack of resources and the burden of work for women, nor can it be separated from problems of female subordination, oppression and exploitation through perpetuation of patriarchal cultures and traditions which underpin most African societies to the present day.'

I cannot agree with her more if the experiences I got from the research are anything to go by. Ng'weshemi (1997: 25) strengthens the socio-economic perspective further when he says:

'Women who are economically and socially dependent on men are in a poor position to insist on a larger share of household resources being allocated for their own and their children's needs and health. They also have less power to insist on their own wishes and rights even with regard to protecting themselves against HIV/AIDS.'

Other major issues related to stigma, blame and generally poor health-seeking behaviours among women. Due to poverty and over dependency on men, women both at individual level and in group discussions, said they had to choose between going for a test and becoming destitute or dying without knowing whether they have HIV or not. One woman in Mutchi village said:

'When one is tested, the advice they receive is to eat good food, now if your husband sends you away, where will you get the good food from?

Stain (1997) explains that generally women suffer from unequal access to health care services owing to both biological and cultural factors; these factors range from the low status accorded to women in society and their lack of autonomy relating to sexuality issues. Luhanga e*t al*. (2001) highlighted the link between gender, poverty and access to services for women who usually are the last to seek services giving priority to other family members.

The institution of marriage versus HIV/AIDS risk

The research went into issues of risk assessment since the general feeling is that faithful married women in monogamous relationships would not consider themselves at risk of contracting HIV. The study however found that married women themselves feel they are at risk of infection from their partners who are promiscuous. Culturally, men get away with extramarital affairs, have many sexual partners and may not even use condoms with these other women. They can end up contracting HIV which they pass on to their wives. The quote below is part of the story of Margaret, one of the NAPHAM members whom I had interviewed.

'Some women are literally dying close to where I live, I have talked to them about voluntary counselling and testing but they fear their husbands, they cannot go for testing. One man told me in my face that if his wife goes for a test, the marriage will end. So you can see that men are culturally cruel. It is not acceptable in our culture for a woman to make her own decisions. The in-laws and marriage counsellors will not rule in her favour and she becomes an outcast.'

The institution of marriage is surrounded by different actors such as the couple with their parents from both sides, brothers and sisters and marriage counsellors who feel they are a social entity therefore have a part to play in decisions affecting the couple. In the case of a woman, she has to negotiate all these as she deals with either seeking consent or a positive HIV test.

The story of Agatha explains the challenges of a married woman. I met 37 year old Agatha at NAPHAM and listened to her story after she had accepted to share it with me. She has a junior certificate of education. She got married at the age of 21 in 1990. She had three sets of twins and one singleton, making a total of seven children within the 13 years she was married. Her husband was very protective, never allowed Agatha to go outside her compound. He bought everything needed at the household and even took the children to the hospital. The only time Agatha moved is when she was pregnant and needed antenatal care. Therefore she had no chance of knowing what the lifestyle of her husband was like. Neither did she have a chance to mix with friends as her husband felt she could start gossiping.

In 1999, Agatha's husband suffered from TB and died the same year. At that time Agatha had a three month old baby that was always sick. A nurse at one of the clinics advised her to go for a test together with the baby. She was found HIV positive. The same nurse advised her to join NAPHAM for support. Agatha faced one challenge, she could not disclose to her mother why the nurse had advised her to stop breastfeeding until she one day brought her mother to the clinic for counselling. From that time her mother has been very supportive. The child has been tested several times and is still HIV negative.

Agatha thinks that if her husband was still alive, he would not have allowed her to go for a test, it was easy in her case to go for testing since she did not need any consent from the husband. She however was quick to say that a lot of women are suffering because their husbands control them. Her husband was so protective under the disguise that he was protecting her from HIV, meanwhile he brought the infection to her at home. Agatha says many faithful married women are at risk of the infection because of promiscuous men.

> 'If I tested during his time, it was going to be impossible to disclose and I am sure he would have divorced me and accused me of infidelity. As women, we suffer without saying a word! We are not free to make decisions; we cannot do anything without a husband's consent. Most of us women depend on men for survival. I was working for an Indian before getting married to him but he made me stop work and I was totally dependent on him.'

Married women themselves in separate group discussions at church and in Mutchi village confessed that they feel they are at high risk of contracting HIV since their husbands are all over with girlfriends and are the ones who bring the infection to them. Yet they are the ones who will not allow the woman to check on her own health status.

At a trading centre called Chileka where MACRO holds an outreach clinic once a month, three women who were selling mangoes said:

> 'The problem we have is that men are the heads of the families and as a woman you do not have much say on what the man does. Some men here are working in town as watchmen, while there they engage in love affairs. We are just on the receiving end. Traditionally a woman cannot question the husband here.'

Asked if they have considered going for voluntary counselling and testing since they know that their husbands can infect them, one woman said she had already tested when she was pregnant and was lucky to be found HIV negative. The other two said they were still thinking about it but were quick to say they are yet to find openings for starting such a discussion with the husband without provoking him.

A chief's wife at Mdakusungira village said she has always been faithful and she got tested when she went for antenatal clinic. However, her husband has always refused to go for testing and she always wonders what he could be afraid of. The chief's wife narrated in a matter of fact but rather sad tone that:

> 'Married women in this village are particularly at risk because if their husbands have money, then young girls have love affairs with the married men to get the money. Women here cannot stop their husbands from having extra marital affairs because the men say they are heads of the family. I know my husband has girlfriends but if I was found HIV positive, I would face many problems such as frequent illnesses due to lack of support and worries, and my in-laws would also blame me for infecting myself.'

Marriage poses two challenges for women. It is an institution used by culture to systematically oppress women. Structures such as marriage counsellors and extended families are well placed to facilitate this oppression. Women are left in a tight corner where it becomes difficult to make independent decisions. Marriage is also found to be a risk factor as Beyer (1998:120) says:

'By far the most common risk factor for HIV among women in Thailand is marriage.'

This to me shows that the equality of men and women as provided for in CEDAW and the protocol in article 6[15] as well as the Malawi Constitution under article 22(2)[16] is just on paper. Women are not being treated as equal partners with men in marriage.

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[15] States parties shall ensure that men and omen enjoy equal rights and are regarded as equal partners in marriage.

[16] The family is a fundamental

Makoni (2004) made a similar observation in her Masters dissertation when she quoted Jackson (2002: 111) who says:

> 'The bitter truth is that marriage is probably the relationship through which the majority of women in Southern Africa become infected.'

However, section 20(1) of the Malawi constitution states:

> 'Discrimination of persons in any form is prohibited and all persons are under any law guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political or other opinion, nationality, ethnic or social origin, disability…'

Again, section 22(r) says:

> '…each member of the family shall enjoy full and equal respect and shall be protected by law against all forms of neglect, cruelty or exploitation.'

There is need for government, through NAC, to uphold these constitutional provisions otherwise women are not guaranteed protection within the family on the basis of equality with men. The status quo perpetuates gender inequality in the family which Lwanda (2002) found to be the reason for the under-use of voluntary counselling and testing services in Lilongwe urban.

Compulsory versus voluntary testing – which way to go?

The study question posed was would enacting a law calling for compulsory testing improve women's access to voluntary counselling and testing services? The sub-questions aimed at finding out whether respondents were aware of the prevailing laws and policies governing voluntary counselling and testing but further to find out about any proposed legislation on HIV/AIDS in general and voluntary counselling and testing in particular. Respondents were also asked to share their views on the contents of a law in the case where respondents felt a law should be enacted and which areas it should cover.

Legal and policy provisions

Most respondents interviewed at MACRO, NAPHAM, Chileka outreach clinic, Mutchi and Mdakusungira village did not know about the existence of the HIV policy.

The National HIV/AIDS policy considers voluntary counselling and testing an essential component on the continuum of prevention, treatment, care and support for people living with HIV/AIDS. The policy says to be effective, voluntary counselling and testing services must be of good quality, accessible, affordable and totally confidential. The policy is silent on the special needs of women who are mentioned together with men, women, boys and girls.

An interview with the MACRO director revealed that he thinks the HIV/AIDS policy is comprehensive but has not been widely disseminated. His view is that knowledge of one's sero status does help in behaviour change, especially for those who are HIV negative; the problem is that many people are not aware of the policy provisions. He thinks there is need for organizations to undertake advocacy work to effect behaviour change. He thinks compulsory testing would scare people away. This explains the finding that most respondents are not aware of the existence of the policy and its contents. What is worrying is that this is a fairly new document which was developed in a consultative manner and if the people who are supposed to benefit from the policy are unaware, it is easy for those people to violate each other's rights, even where they are well articulated in the policy.

The policy statements under voluntary counselling and testing mainly relate to improving service provision at centre level, that is accessibility and staffing levels, to improve efficacy. No mention is made of the systemic and structural inhibitors of women from accessing the centres.

There were mixed reactions on whether testing should be compulsory or we should continue with voluntary testing. The women who had already been tested and feel they were infected by their husbands while they were faithful, felt it should be compulsory.

These feelings are understood coming from respondents who have already been infected, and have been through testing therefore having nothing to lose. Most key informants however said the policy as it is now is fine but should be widely disseminated so that people are aware of what it contains. The UNAIDS programme officer as well as the NAPHAM programme manager were firm on the need to respect people's right to choice as well as confidentiality. They were not keen to support compulsory testing. George Patrick, a respondent at MACRO wanted testing to be voluntary for fear that compulsory testing would lead to some people developing high blood pressure.

Chiefs from Mutchi village did not know the policies on HIV/AIDS but one of them remembered that previously a person could be prosecuted for infecting someone with a venereal disease such as syphilis and gonorrhea. He however said with the coming of '*matenda a bomawa*'[17] he has not heard of anyone going to court because of HIV infection. A concept which Lwanda (2004) attributes to the difficulty with which the disease was generally described physiologically and the fact that there is no cure. Most respondents in general did not know the policy on voluntary counselling and testing except for young people (boys and girls) from CAYO who were able to even cite some portions of the policy based on an awareness creation project the organization implemented with funding from NAC. While the policy is in place, there does not seem to have been any purposeful effort to popularize it. Even those that have undergone testing merely moved because they felt they needed to find out about their status.

It was found that HIV /AIDS testing elicits a lot of stigma and discrimination but the laws of Malawi are silent on this. The Bill of Rights under chapter 4 of the Malawi constitution provides for areas upon which discrimination is prohibited but disease is not among the listed issues. Although a law may not be the whole answer to the problem of access to voluntary counselling and testing by women, Malawi being party to international treaties that aim at promoting and protecting women's rights such as the CEDAW and the Protocol, needs to domesticate these into local legal statutes.

The UNAIDS programme officer said the policy provides for no consent after 13 years but practice is different, with women experiencing more problems than men. She suggested need for legal provisions on issues of disclosure which is not well articulated in the current policy. This has led to some men getting antiretrovirals without their wives knowing. The NAPHAM programme manager felt there is need for a specific piece of legislation to deal with issues of stigma and discrimination such as the definition, manifestation and type of redress one may seek.

Within the HIV policy, there policy statement 3.2.2.4 says:

> 'For national security reasons, it is important that the army, police, prisons and immigration be permitted to carry out HIV testing as part of their pre-recruitment and periodic general medical assessment of staff for purposes of establishing fitness.'

The scope of this research did not give room to explore how compulsory testing has improved women's access to voluntary counselling and testing. NAC should make a follow up on how compulsory testing in these areas is making a difference to women's access to services compared to where it is voluntary.

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17 AIDS is popularly known as governments disease in Chichewa is matenda a boma.

Gaps between policy and practice

The current HIV/AIDS policy has 'promotion and protection of human rights' as one of the key principles.

Women and young girls are singled out in this policy as groups suffering from discrimination which makes them vulnerable to infection and that they need special protection of their rights to equality before the law to ensure them freedom from discrimination in gender relations. In its current form, the HIV/ AIDS policy may not lead to promotion and protection of women's rights since there are no clear policy statements directed at issues of unequal access to voluntary counselling and testing and gender inequality in general apart from it being mentioned in the preamble. There are no clear mechanisms to guide policy implementers on how they can translate this policy to make sure the women benefit.

Asked how they understand the policy, most counsellors felt violations of human rights happened at family level, away from MACRO and NAPHAM, making it difficult for follow up.

The policy provides for equal access to voluntary counselling and testing services but the research findings show that in practice more men than women access the services at MACRO, due to the multiple factors women face as expounded above. Although this cannot be attributed to any one organization, it does call for all organizations mandated with voluntary counselling and testing services to popularize the contents of the policy so that both men and women can make informed decisions. Promotion and protection of human rights should be seen to be broader than just confidentiality. It should embrace deliberate efforts to protect women's rights through information sharing to help build women's self esteem.

Discussions with a senior counsellor at MACRO revealed that the organization has already started conducting women-only focus group discussions in workplaces to find out the challenges that keep women away from using voluntary counselling and testing services. While this is a move in the right direction, the suggestion is that MACRO starts to interpret the findings of the discussion groups and to plan women-centred programmes to promote their access to these services, as part of the wider fight against HIV/AIDS.

The legal provision of the Penal Code under section 192 was cited by two of the key respondents and one chief from Mdakusungira village which could mean that it is not known by many people. A close look at it shows that it is equally weak. HIV/AIDS is a disease associated with stigma and discrimination. Besides, the current situation is such that an HIV positive result remains tantamount to a death sentence and therefore carries with it devastating psychological consequences. This piece of legislation was obviously drafted way before the HIV/AIDS epidemic and would lead to a lot of trauma if all an offender is charged with is a misdemeanor. The sentence it carries is less than the magnitude of the offence but also the burden of proof of infection rests on the woman. Yet men do not disclose their positive HIV status to their sexual partners, let alone to their wives. Also the law does not consider the time between contact and detection of antibodies in the infected person's body. This piece of legislation needs to be reviewed to take into account women's experiences and to keep up with the realities of a difficult epidemic like HIV/AIDS.

There is need to work toward harmonizing the policy and practice to protect women's rights. There is need to undertake what was suggested by the MACRO director, the UNAIDS programme officer and the principle secretary responsible for HIV/AIDS and nutrition, that cultural practices need to be opened up for discussion and to see whether they are still relevant in a time when HIV infections are on the increase. The consensus reached during these discussions could then be used to tighten up the policy as a way of harmonizing it with the practice on the ground.

CHAPTER FIVE

Conclusions and recommendations

Conclusions

This research investigated the factors that affect women's as compared to men's access to voluntary testing and counselling and interrogated traditional and cultural practices and how these link to the gendered dynamics of women and men accessing these services. From the findings presented, it can be concluded that both women and men have heard about the existence of the services although more men than women are accessing them at MACRO. This is in line with the research assumption that more men than women access voluntary counselling and testing services although the low attendance cannot be attributed to lack of knowledge about the services. The figures as well as the observations on all the days I visited MACRO showed that men patronize MACRO more than women. While physical and informational accessibility is quite good, women have problems accessing MACRO due to a number of factors. These factors seem to affect women more than men based on their sex. It can be concluded that women are discriminated against which is discouraged in international human rights instruments such as the CEDAW and the Protocol to the African Charter on Human and People's Rights. Malawi is party to both of these provisions which have been ably reflected in the Malawi constitution as well as in policies such as the HIV/AIDS, national gender policy and reproductive health policies.

The research results also give an insight into the challenges women deal with in their quest to exercise their right to access voluntary counselling and testing services on the basis of equality with men. Women deal with a lot of violence, stigma and blame, moreso than men, even where it can be seen that the man is the one to blame. Women face more challenges in the areas of economic dependency due to poverty and low literacy levels, lack of decision making power, other cultural aspects and the unequal gender division of labour.

It can be concluded that gender inequalities are persisting in Lilongwe urban and rural and that it is a factor that has left women subordinated to both men and to senior women who have power over their fellow women. Women consequently fail to exercise their right to access voluntary counselling and testing services on the basis of equality with men. Unless these systemic and structural gender inequality issues are addressed collectively under the leadership of NAC and all partners in the fight against HIV/AIDS, and women are empowered enough to access services on a basis of equality with men, realizing the HIV/AIDS policy shall remain just an aspiration on paper. Women's rights will not be achieved and women will continue to be discriminated against, contrary to the spirit of the CEDAW.

Traditional and cultural practices are deep-rooted and well-established, using structures such as marriage counsellors and the church to further subordinate women. Culture always seems to be invoked when it pertains to a woman. The double standards in terms of expected behaviours between men and women are so glaring that it seems that culture is systematically used to oppress women.

It can be concluded that for the areas researched, consent is a big factor in keeping women away from voluntary counselling and testing. Although the policy states that every person is free to access services, practice is different, with men playing a big role in withholding consent from women, propagating abuses following a woman's positive result and wielding their economic supremacy over women.

Marriage as an institution is an arena where women have problems exercising their right to access voluntary counselling and testing; they suffer violence and blame as well as the inability to make crucial decisions concerning their sex and sexuality. Married women are increasingly getting infected within the confines of their homes, even if they are faithful themselves. The number of married women who access voluntary counselling and testing services is fewer than those who are not married, suggesting that marriage can be a factor for not accessing services, especially if the husband does not grant the wife consent to access them. Yet men in these marriages are free to exercise their rights without hindrances. The double standards displayed by marriage counsellors, the church and in-laws following a positive result explain the challenges married women face in exercising their rights to access these services on the basis of equality with men. Marriage counsellors and the church were found to match what Bentzon *et al.* (1998) calls 'rule-generating and rule-upholding institutions' leading to women's subordination.

Low education and literacy levels and scanty knowledge on gender equality as it relates to HIV/AIDS prevention messages are factors that need to be considered. Many respondents did not know that a policy exists. If people are going to exercise their rights, they will need to be equipped with knowledge of protective instruments like policies on voluntary counselling and testing. Non-dissemination of the HIV/AIDS policy is a violation of people's right to health and reproductive information. The whole section on HIV testing needs dissemination to highlight areas such as 3.2.2.1.2 which says that the government undertakes to do the following:

> 'Promote and provide high quality, cost-effective, totally confidential and accessible voluntary counselling and testing services country wide, in particular, youth-friendly services and services that are adequate and accessible to other vulnerable groups.
>
> 'Ensure that voluntary counselling and testing shall only be carried out with informed consent of the person seeking testing, who is provided with adequate information about the nature of the HIV test, including the potential implications of a positive or negative result, in order to make an informed decision as to whether to take the test or not.
>
> 'Every person aged 13 or above shall be entitled to access voluntary counselling and testing without the consent of a guardian or other adult.

If these portions of the policy could be well disseminated, they would deal with most of the issues that the research found to be hindrances, especially for women and girls to access voluntary counselling and testing services.

Stigma and discrimination both for women and men is still very high. Malawi has high HIV infection rates and cannot afford to have stigma keep away HIV infected individuals who are ready to go and test.

It can also be concluded that the legal provisions of section 192 of the Penal Code are too weak to adequately deal with the magnitude of challenges faced by women in the context of HIV /AIDS.

MACRO is a good initiative away from a hospital setting bringing in the multidimensional approach to the fight against HIV, as opposed to letting it be the monopoly of the health sector. As a stand-alone centre, away from a hospital setting, with well qualified staff and donor resources, it can make a difference in increasing women's access to these services. However the institution itself is associated with only HIV testing, thereby bringing in stigma and discrimination to those who are seen accessing services. The resources aspect of the organization has been largely downplayed at the expense of the testing.

Recommendations

The recommendations are primarily directed at MACRO and NAC. NAC is a state institution charged with the mandate to coordinate HIV activities in Malawi.

Women's rights non-governmental organizations can use the findings to mount awareness campaigns on women's rights in general and on access voluntary counselling and testing in particular. The legislative arm of government, especially the women's parliamentary caucus, can use the findings to inform debates on laws relating to HIV and women's right to be protected from violence, stigma and discrimination.

It is being recommended that duty bearers, in this case the state through NAC and MACRO, make a deliberate effort to come up with women-centred programmes aimed at addressing the above issues. McFadden (1992) opines that women must occupy a central position in whatever strategies and solutions are formulated in order for us to respond effectively to this challenge. Women's voices must be heard in the planning of these services.

To deal with issues of culture which are so deep rooted and protected, chiefs who are custodians of culture should be engaged into open and liberating discussions on women's rights, culture and the challenges women face. The training should aim at deconstructing the notion that women are subordinate and should lead to empowerment to show that, in line with the Malawi constitution, chiefs, marriage counsellors, men and women are working together to promote and protect the family as a fundamental unit where both men and women are equal partners.

Men are another entity that should be targeted with specific gender equality messages touching on gender-based violence, women's rights and the gender aspects of HIV/AIDS. The training with men should provoke thoughts on the need for fidelity to make sure both men and women are faithful to one partner. These men should include marriage counsellors as well, based on the role they play in marriages. Men are crucial because of the role they play in consent, violence following a positive result, blaming the wife and the issue of risky lifestyles.

Women will need to form pre and post test clubs where they can share challenges and how to deal with them. The NAPHAM women-only meetings could be used as a learning point.

The HIV/AIDS policy should be simplified and disseminated to make sure both men and women are making informed decisions without hindrances. It is a recommendation of this study that formulation of clear laws that would assist women in realizing their rights, such as the Domestic Violence Bill and the much talked about proposed legislation on HIV, stigma and discrimination, and consideration should be given to making testing compulsory for new couples before marriage. This recommendation is in line with the findings of Malawi's 2000 demographic and health survey where 91 per cent women and 94 per cent men agreed with the idea of premarital HIV testing.

MACRO should offer a diversity of services on top of voluntary counselling and testing as a way of reducing stigma. MACRO should also plan specific women-centred programmes to deal with challenges faced by women in their quest to realize their right to access voluntary counselling and testing services. MACRO can strengthen its link with NAPHAM and use NAPHAM members during awareness creation campaigns to bring a human face to positive living. The study revealed incidences where women first went to join NAPHAM to learn how to disclose a positive result to a difficult husband. MACRO can exploit this partner and make the organization a 'one-stop shop'. This can also help to deal with the pronounced stigma and discrimination.

With the current scenario where more men than women are accessing voluntary counselling and testing services, there is need for MACRO, under the leadership of NAC as the coordinator of HIV/AIDS initiatives in Malawi, to call for a stakeholders' meeting to learn how best to deal with this situation so that women can equally benefit from MACRO services rather than continue to lament over the figures which persistently show more men than women accessing the services at MACRO.

Unless the above recommendations are implemented, over half of the Malawi population will continue to be neglected, increasingly get infected and die, as in the words of Martha, one of the NAPHAM respondents:

> 'We die twice, those of us who are HIV positive and are women, we die twice. First from the virus, then from the violence, stigma and blame we suffer at the hands of our very closest family members.'

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ANNEX 1 RESEARCH GUIDES

Research question 1: Does knowledge of existence of VCT services affect women's access to VCT services?

Sub questions

Have you heard about VCT services?

How did you come to know about these services?

Do you know where you can get these services?

How far is the nearest VCT centre?

What is your impression of such services?

Respondents	Specific Questions
Women and men at VCT centres, In community At church gathering Random interviews	• Have you heard about VCT services? • What did you hear about these centres? • How did you hear about these services? • Where did you get the information from? • Have you made attempts to go for a test? • Why or why not?
Young people (Girls and boys)	• Have you heard about VCT services? • What did you hear about these centres? • How did you hear about these services? • Where did you get the information from? • Have you made attempts to go for a test? • Why or why not?
MACRO and NAPHAM	• Are men and women equally accessing VCT services? • If not what could be the reasons? • How do you disseminate information about the existence of your services? • What specific measures do you take to target women? • What specific measures do you take to target men? • Do you conduct services in rural areas as well? • If not how do you reach out to these areas?
NAC VCT Coordinator	• What is the coverage of VCT services? • Rural versus urban? • Are there specific initiatives to target women? • Are there specific initiatives to target men? • Are men and women equally accessing VCT services? • If not, why?

Research question 2: Do women require consent from a husband or male guardian to access VCT services?

Sub questions

Are you married?

Did you require consent from your husband to access VCT services

If yes, in what form?

If not, why not?

Do you always require consent to seek health services?

Respondents	Specific questions
Women	• Are you married? • Did you require consent from your husband to access VCT services • If yes, in what form? • If not, why not? • Do you always require consent to seek health services?
Young people	• Would you require consent to access VCT services? • From who? • Why or why not? • Have you accessed VCT services? • If not why? • Do you consider yourself at risk of contracting HIV/AIDS?
Men	• Are you married? • Would your wife require consent from you to access VCT services? • Would you require consent from your wife to access VCT services? • If yes, in what form? • If not, why not? • Does she always require consent to seek health services? • What would happen if she went without the consent?
Chiefs	• What do you know about VCT services? • Do men and women have equal access to the services? If not why? • Do women need consent to access the services? • If yes why?
Single women (Unmarried teenage girls, widows, divorced)	• Are you married? • Would you require consent from a male guardian to access VCT services • If yes, in what form? • If not, why not? • Do you always require consent to seek health services? • If not already tested, then what stops you from accessing VCT services?
NAC, MACRO and NAPHAM officials	• Do women require consent to access VCT services? • Would this affect women's access to VCT services? • Are women aware that the VCT service policy provides for access without consent?

Research question 3: What are the major factors that impede women from accessing VCT services?

Sub questions

Have you tried to access VCT services before? If yes follow up with

What factors prevented you from accessing the services?

How far is the nearest VCT facility?

How do you get there?

Respondents	Specific questions
Women	• Have you tried to access VCT services before? If yes follow up with • What factors prevented you from accessing the services? • How far is the nearest VCT facility? • How do you get there?
Men	• What factors prevent women from accessing the services? • How far is the nearest VCT facility? • How do they get there?
MACRO, NAPHAM and NAC Directors	• What factors prevent women from accessing the services? • How far is the nearest VCT facility? • Follow up depending on response
Members of parliament Lilongwe city and rural	• What factors prevent women from accessing the services? • How far is the nearest VCT facility? • How do they get there?
Chiefs	• What factors prevent women from accessing the services? • How far is the nearest VCT facility? • How do they get there?

Research question 4: Does fear of being blamed for bringing the infection in the family prevent women from accessing VCT services?

What fears do you think women have regarding HIV testing

Could you explain the problems women face when they test HIV positive?

Respondents	Specific questions
Women and men	• What fears do you think women have regarding HIV testing • Could you explain the problems women face when they test HIV positive?
Young people(Girls and boys)	• What fears do you think women have regarding HIV testing • Could you explain the problems women face when they test HIV positive? • Do men face the same problems? • Why or why not? • Does this apply to you as young people?
Chiefs	• What fears do you think women have regarding HIV testing • Could you explain the problems women face when they test HIV positive? • Why do they face such problems • Do men face similar problems? • If not why?
NAC Director and UNAIDS	• What fears do you think women have regarding HIV testing • Could you explain the problems women face when they test HIV positive? • Why do you think this is the case? • Do men go through similar problems? Why?
VCT centre staff	• What fears do you think women have regarding HIV testing • Could you explain the problems women face when they test HIV positive? • Do men face the same challenges? • If not why? • How have you dealt with such challenges? • Why do you think this happens to women more than men?

Research question 5: Do women in monogamous heterosexual relationships consider themselves not at risk of contracting HIV/AIDS?

Are married women in monogamous marriages at risk of HIV/AIDS?

How about widows?

Single women such as unmarried, widows, divorced?

How would you compare the risk for rural and urban women

How about those who have mobile husbands who seek work in town versus those who stay together always?

Would you consider going for a test? If not why and if yes why?

Respondents	Specific questions
Men and women	• Are married women in monogamous relationships at risk of contracting HIV/AIDS? • How about widows? • Single women such as unmarried, widows, divorced? • How would you compare the risk for rural and urban women • How about those who have mobile husbands who seek work in town versus those who stay together always? • Would you consider going for a test? If not why and if yes why?
Girls and boys	• Are married women in monogamous relationships at risk of contracting HIV/AIDS? • How about widows? • Single women such as unmarried, widows, divorced? • How would you compare the risk for rural and urban women • How about those who have mobile husbands who seek work in town versus those who stay together always? • Would you consider going for a test? If not why and if yes why?
Staff at VCT centres	• Do women in monogamous relationships consider themselves at risk of contracting HIV/AIDS? • Which category of women frequently comes for testing? • Why? • Which categories are most at risk?

Research question 6: Will enactment of laws providing for equal access to VCT services for men and women improve women's access to VCT services?

Are there any laws on VCT?

Is there any need for a law?

Does knowledge of one's sero-status make a difference?

Would a law make a difference?

What would be its key contents?

What would be the advantages or disadvantages of such a law?

Should testing continue to be voluntary even with the increase in number of HIV cases?

Respondents	Specific questions
Traditional chiefs (Male and female)	• Have you heard of VCT? • Are men and women equally accessing these services? • Why or why not? • Would a law making testing compulsory make a difference? • What would be the advantages/ disadvantages of such a law? • Does knowledge of ones status make a difference in controlling HIV?
NAC policy officer and UNAIDS	• Are there any laws on VCT? • Is there any need for a law? • Does knowledge of one's sero-status make a difference? • Would a law make a difference? • What would be the advantages or disadvantages of such a law? • Should testing continue to be voluntary even with the increase in number of HIV cases?
PS HIV/AIDS	• Are there any laws on VCT? • Is there any need for a law? • Does knowledge of one's sero-status make a difference? • Would a law make a difference? • What would be the advantages or disadvantages of such a law? • Should testing continue to be voluntary even with the increase in number of HIV cases?

Men and women	• Are there any laws on VCT? • Is there any need for a law? • Does knowledge of one's sero-status make a difference? • Would a law make a difference? • What would be the advantages or disadvantages of such a law? • Should testing continue to be voluntary even with the increase in number of HIV cases?

ANNEX 2

QUESTION GUIDE FOR FOCUS GROUP DISCUSSIONS (FGDS) AND FIELD INTERVIEWS

1 Knowledge of existence of VCT services

- Have you heard about VCT services?
- How did you come to know about these services?
- Do you know where you can get these services?
- How far is the nearest VCT centre?
- What is your impression of such services?
- Have you made attempts to go for a test?
- Why or why not?

2.Consent to access VCT

- Are you married?
- Did you require consent from your husband/ wife/partner to access VCT services
- If yes, in what form?
- If not, why not?
- Do you always require consent to seek health services?

3 Factors hindering access to VCT services

- What are the major factors that impede women and women from accessing VCT services?
- Have you tried to access VCT services before? If yes follow up with
- What factors prevented you from accessing the services?
- How far is the nearest VCT facility?
- How do you get there?

4 Fear of blame and violence

- What fears do you think women have regarding HIV testing
- Could you explain the problems women face when they test HIV positive
- Do men face the same problems?
- Why or why not?
- Does this apply to you as young people?

5 Risk factor and access to VCT services

- Are married women in monogamous marriages at risk of HIV/AIDS?
- How about widows?
- Single women such as unmarried, widows, divorced?
- How would you compare the risk for rural and urban women
- How about those who have mobile husbands who seek work in town versus those who stay together always?
- Would you consider going for a test? If not why and if yes why?

6 Will enactment of laws providing for equal access to VCT services for men and women improve women's access to VCT services?

- Are there any laws on VCT?
- Is there any need for a law?
- Does knowledge of one's sero-status make a difference in controlling HIV?
- Would a law make a difference
- What would be its key contents?
- What would be the advantages or disadvantages of such a law?
- Should testing continue to be voluntary even with the increase in number of HIV cases?

ANNEX 3 – NEWSPAPER ARTICLES

Man kills wife after refusing sex

by Edwin Nyirongo

Police in Karonga have arrested a man for allegedly killing his wife after she refused to have sex with him.

Police spokesperson Enock Livason said the suspect, Boniface Simbeye from Eliya Thawathawa Village T/A Kilupula in Karonga quarrelled with his wife on the night of January 7.

"Simbeye wanted to have sex with his wife, Leah Nyahunga at around 8 o'clock in the evening but she refused, saying they could not do that since they are HIV positive. Her refusal angered the man who beat her," he alleged.

Livason said the woman fell unconscious and some relatives took her to hospital where she was pronounced dead on arrival.

He said the post-mortem carried out at Karonga District Hospital revealed that Nyahunga died of internal bleeding which resulted in blood clotting. It also showed that the accused was one month-pregnant.

Simbeye has been charged with murder and is kept on full remand. He has two other wives apart from the deceased.

paign for treated nets underway.—File photo

Blantyre rural people desperate for VCT centre

BY FRANCIS MACHADO

PEOPLE from Blantyre rural west Friday said they urgently need a Voluntary Counseling and Testing (VCT) centre to meaningfully take part in the fight against HIV/Aids.

The people that included religious leaders, teachers, political leaders, members of HIV/Aids clubs, and community members, made the call at Chikuli Primary School where Health Minister Hetherwick Ntaba on December 1 led the country in activities to mark World Aids Day.

The call was made during a discussion forum that Malawi Network of Aids Service Organisations (Manaso) organised as a follow up to World Aids Day activities to assess needs of people and what they think government and NGOs should do in the Aids fight.

Lucius Kagwa, a catechist at Kadikira Catholic Parish said they encourage people to undergo VCT and care for the sick by engaging in home based care and health support groups.

"There is plenty of goodwill from many people but we don't have enough resources, and the nearest VCT is about 11 kilometers away," Kagwa observed.

Bantu Buleki, another participant at the discussion, observed that many people only hear messages on radios but NGOs and government were not in direct contact with people on the ground.

He said clubs and groups that were formed at village level need finances and guide on how to fight the pandemic.

Lovemore Mkwezalamba of Chikuli Youth Club, an Aids organisation, said most groups lack knowledge on how to write good proposals to get funding from the National Aids Commission (Nac).

The group said poverty and lack of proper knowledge worsened the Aids pandemic.

Manaso organised the discussion to get people's views on what they think government, civil societies, NGOs, donors and themselves could do to fight HIV/Aids.

During World Aids Day celebrations, people rushed for VCT at Chikuli that was provided by Macro, Goal Malawi and Word Alive.

ANNEX 4 – TAKING NOTES AT FOCUS GROUP DISCUSSION WITH YOUNG GIRLS