THE ROLE OF GENDER RELATIONS IN DECISION-MAKING FOR ACCESS TO ANTIRETROVIRALS. A STUDY OF THE AIDS SUPPORT ORGANISATION (TASO) CLIENTS, KAMPALA DISTRICT, UGANDA

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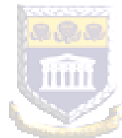
A mini-thesis submitted in partial fulfilment of the requirements for the degree of Masters of Public Health in the Faculty of Community Sciences, University of The Western Cape.



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September 2005

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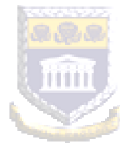


KEY WORDS

Access - Going to a service, getting it and utilising the service.

Decision-making – The resolve to change or improve a situation usually influenced by interaction with other people or information received by a person.

Families - People not necessarily living in the same household but are related by blood or marriage.

Gender - The social and cultural construct of the roles, responsibilities, attributes, opportunities, privileges, status, access to and control over resources and benefits between boys and girls in a given society (Uganda's Ministry of Gender Labour and Social Development (MGLSD)).

Gender roles – The relationship and responsibilities of men and women based on expectations regarding their rights and duties in society.

Households - Used interchangeably with families and homes.

Inequality - Discrimination in resource allocation, power, opportunity, benefits or access to services on the grounds of a person's status including gender (MGLSD).

Partners - Sexual partners not necessarily living in the same household.

Power relations - The ability to exercise control over the sources of power and how being male or female may influence this.

ABBREVIATIONS AND ACRONYMS

AIDS – Acquired Immune Deficiency Syndrome

ARVs - Antiretrovirals

ART - Antiretroviral Therapy

FGDs - Focus Group Discussions

HIV – Human Immunedeficiency Virus

MGLSD – Ministry of Gender, Labour and Social Development- Uganda

MTCT - Mother-To-Child-Transmission

PMTCT – Prevention of Mother-To-Child Transmission

PLWHA - People Living With HIV/AIDS

TASO - The AIDS Support Organisation

VCT - Voluntary Counselling and Testing

ABSTRACT

The way gender relations influence access to care and treatment particularly access to antiretroviral (ARV) medicines is a challenge to HIV/AIDS programmes and to the individuals and families with HIV. Gender norms that push women and men to adhere to dominant ideals of femininity and masculinity may restrict women's access to economic resources, health care and fuel the spread of HIV.

Aim: To determine the role of gender relations in influencing decision-making for access to ARVs between partners and in the family.

Design: Qualitative study- Six FGDs with both genders separately.

Setting: TASO Mulago clients were studied. TASO is one of the biggest indigenous HIV/AIDS centres in the East African Region providing free ARVs to clients.

Respondents: Respondents were those with a non-regular sexual partner described as having had a sexual partner in the last 12 months at the time of starting ARVs. These are poor clients doing odd jobs, with family responsibilities and are motivated to be open about their HIV status.

Results: In this study decisions made by PLWHA to access ARVs were influenced by the need to avert the stigma associated with AIDS, fear of death, the desire to have children and effect of ARVs on other people. All respondents made decisions to access ARVs first with their counsellors and preferred to involve in the decision-making process, family and friends rather than their partners.

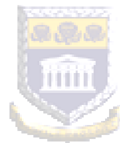
Conclusion: Gender relations play a vital role in partners' and families' decision-making to access ARVs. Gender issues must be incorporated into HIV programmes.

DECLARATION

I declare that The Role of Gender Relations in Decision-making for Access to Antiretrovirals. A Case Study of The AIDS Support Organisation is my own work, that it has not been submitted for any degree or examination in any university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Barbara Kagoro Bitangaro September 2005

Signed…………………………



ACKNOWLEDGEMENTS

I dedicate this mini-thesis to the memory of my father, the late Victor Kagoro who made it possible for me to be educated. May his soul rest in eternal peace.

I acknowledge the invaluable support received from my loving husband, Sam.

To my lecturer Dr Mickey Chopra who read through every bit of this research, I say thank you.

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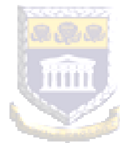

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CHAPTER ONE

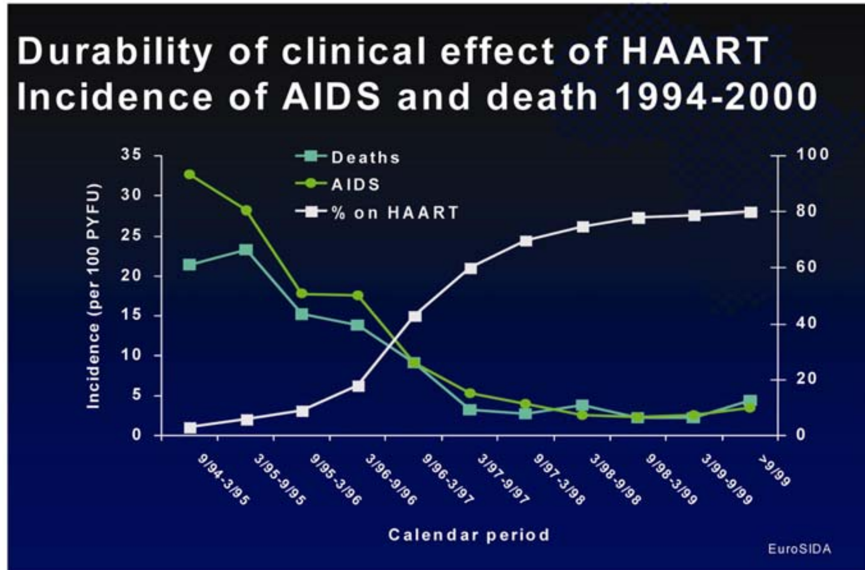
1.0 Introduction

HIV/AIDS threatens human welfare, socio-economic advances, productivity and social cohesion. The disease disproportionately affects vulnerable individuals and communities with 90% of the estimated 36.1 million living in developing nations.[1]

Several management strategies in terms of prevention and support and more recently the use of highly active antiretroviral therapy (HAART) have been carried out to curb the epidemic as research into a vaccine continues. The efforts include support and care, voluntary counselling and testing, treatment of opportunistic infections, messages and information as well as behavioural surveillance.

Since 1996, the use of antiretroviral medicines has dramatically reduced AIDS-related illnesses and death in countries where these drugs are widely accessible. People living with HIV/AIDS (PLWHA) can now lead a normal and productive life if they have access to ARV therapy (Table 1). However, of the 25.4 million HIV infected people in sub-Saharan Africa, about a third need treatment, and yet less than 100,000 are on ARV therapy.[2]

Table:1 Substantial reduction in HIV related morbidity and mortality coincident with introduction of HAART in the EuroSIDA cohort



Although prevention of mother-to-child transmission has been successful in the United States and Europe, in Africa, less than 5% of pregnant women at risk of HIV infection have access to preventive treatment with anti-retroviral drugs in Africa.[3]

The situation becomes worse in resource-poor settings where gender roles in families, specifically those played out by women, may hinder access to these drugs. Knowledge on the way gender influences decisions in the family in relation to people's health-seeking behaviour is limited.

Gender disparities in power and command over resources contribute to the spread of HIV worldwide. The gender differences in the causes of illness and death produced by a combination of biological, social and cultural factors imply that

improving the health of females and males requires an awareness not only of biological aspects of diagnosis and treatment, but also of the social factors that promote or reduce good health.[4]

1.1 The AIDS Support Organisation (TASO)

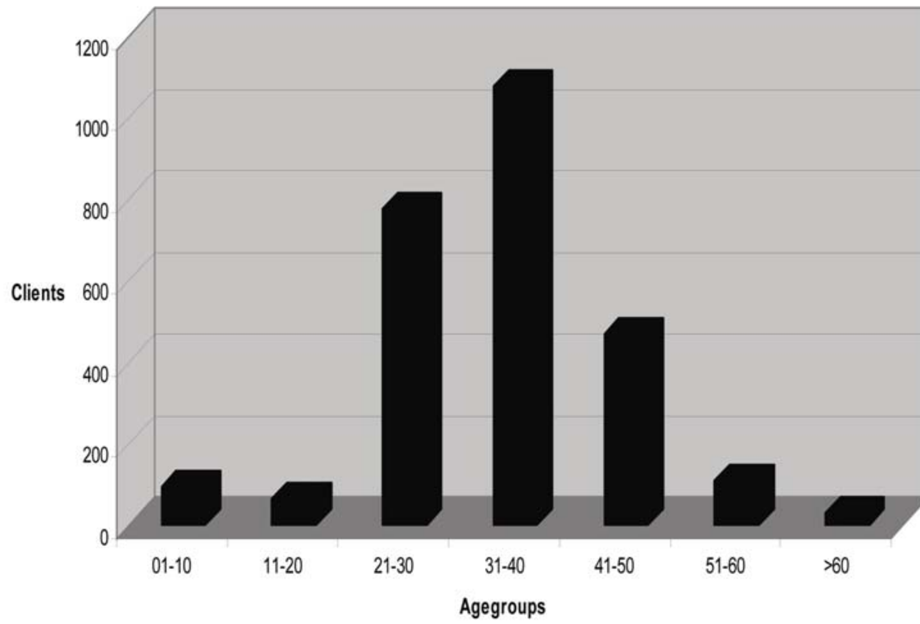
This study was conducted on clients of The AIDS Support Organisation (TASO) who are on antiretrovirals. TASO is the largest indigenous HIV/AIDS agency serving Uganda and the Great Lakes Region. People diagnosed with HIV by various voluntary counselling and testing (VCT) providers are referred to TASO to get registered as TASO clients. It operates in eight districts and over 83,000 PLWHAs have been registered and 22,000 directly receive care and support.

Kampala District is home to over 50% of the clients, Wakiso has over 26%, Mukono 16% and the rest of the other districts only 6.3%. The majority of clients (90.6%) live with their families. Only 9.4% report not living with their families.

At TASO Mulago, the majority of patients fall within the age group 31 – 40 (Table 2). Seventy percent (70%) of the clients at TASO are women, showing a marked difference in the way different genders access health care. In 2003, there were 650 new female clients in the agegroup 21 – 30 years compared to 150 males. In age group 31 – 40 years there were 740 new female clients compared to 350 new male clients. (Table 3) This pattern has persisted over time and TASO believes that the major reason is the traditional phenomenon of men usually delaying to seek healthcare.[5]

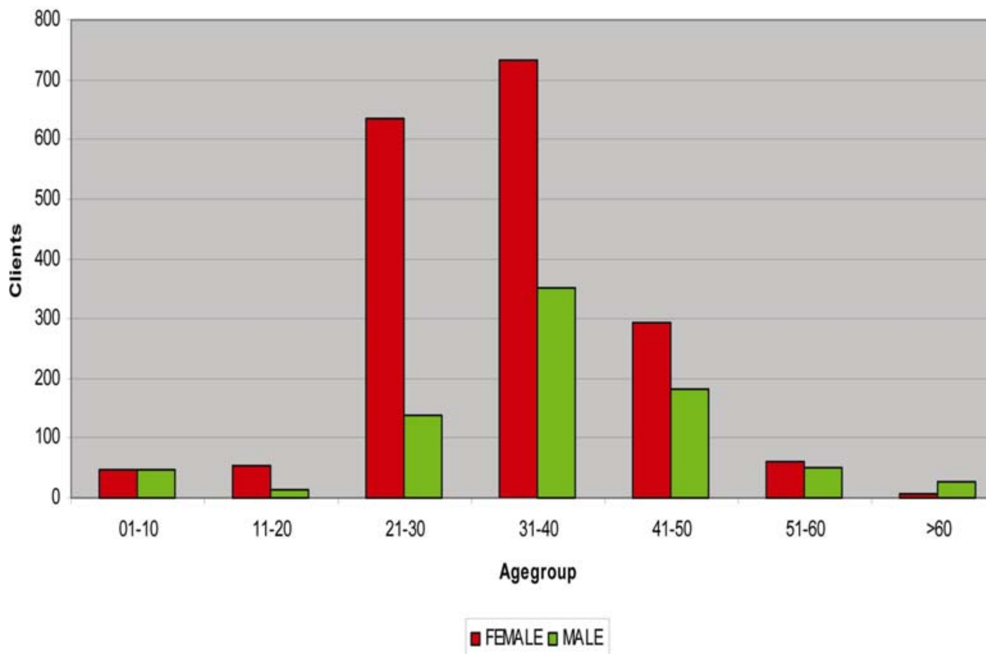
TASO Mulago: New Clients by Agegroup (Jan-Dec 2003)

Table 2



TASO Mulago: New Clients by Agegroup by Sex (Jan-Dec 2003)

Table 3



TASO provides counselling, support and treatment for patients. Clients at TASO represent the poor - living below the poverty line or less than US$300 income per year and are motivated to come out openly about their status. TASO clients have started accessing ARVs on a non-paying scheme.

TASO Anti Retroviral Therapy (ART) programme is a subcomponent of the National ART Scale-up Plan, which aims at providing ART to 60,000 PLWHAs by 2005 as a contribution to the WHO 3 times 5 Initiative on global scale-up of access to ART. ART is an emergency for the 10,000 who will die without it in the next 2 years.[6] By October 2004, 217 clients were accessing ARVs at TASO Mulago and stratified by gender there were 43 men and 174 women. A total of 615 clients had been screened for therapy of whom 117 were men, showing a gap between men and women's health-seeking behaviour.

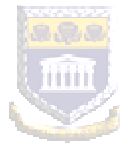
TASO clients are poor people who have undergone counselling on HIV and adherence to ARV therapy. They are given ARVs on the basis that they reveal to their partners or any other family member their HIV serostatus and that they are taking ARV medicines. This is meant to encourage support and adherence to therapy. Free ARVs in TASO are given out based on how long one has been a client of TASO.

1.2 Aim and Objectives of the Study

The aim of this study was to determine the role of gender relations in decision-making for access to antiretrovirals.

The objectives were to:

1. Identify TASO clients accessing ARVs stratified by gender.
2. Describe the decision-making process taken for access to ARVs by men and women.
3. Determine key persons involved in influencing decision-making for access to ARVs.
4. Determine key factors related to gender that influence decision-making for access to ARVs.
5. Identify recommendations for improving access to ARVs especially for women.



CHAPTER TWO

2.0 Literature Review

2.1 The status of HIV/AIDS in Sub-Saharan Africa and around the Globe

As of the end of 2003, an estimated 40 million people worldwide - 37 million adults and 2.5 million children younger than 15 years - were living with HIV/AIDS. Approximately two-thirds of these people (26.6 million) live in Sub-Saharan Africa; another 18 percent (7.4 million) live in Asia and the Pacific. According to the latest UNAIDS estimates, the cumulative number of people that have been infected with HIV in Uganda is about 2 million and its estimated that approximately 1.4 million are still alive.[7]

2.2 Gender Differences in Infection

Globally, the incidence of HIV/AIDS among women has risen at a shocking rate. In 1997, 41 per cent of HIV infected adults were women and this figure rose to 49.8 per cent in 2001. Today, women constitute 58% of infected people in sub-Saharan Africa. This is worsened by the fact that in Africa where HIV/AIDS is the leading cause of death, 68% of all young persons infected are female.[8] In almost every country in the region, prevalence rates are higher among women than men.

The social and cultural determinants of HIV infection in women are very different from those for men because they relate to the role of women within relationships, families, communities that in turn, determines the nature and patterns of sexual activity and other factors that place women at risk of HIV infection.[9] Their gender

positioning and economic status in society, particularly in the home, limits their negotiating power in decisions related to having safe sex and accessing health care.

The special vulnerability of women and girls is well documented. For example, in sub-Saharan Africa overall, women are 30% more likely to be infected with HIV than men. Among young people, the gender disparity in infection rates is particularly pronounced. In household surveys in seven countries in sub-Saharan Africa, 15–24-year-old women were found to be 2.7 times more likely to be HIV-infected than their male counterparts (WHO, 2002a) despite the fact that they were far less likely to report having non-marital, non-cohabiting partners in the previous 12 months.[10]

In Uganda, the gender differences in infection are marked. Of a cumulative total of 56,451 adult cases presented in the STD/AIDS Control Programme for 2003, 44.8% were male while 30,347 (55.2%) were female. The male-to-female ratio in the 15–19 year agegroup was 1:5 with girls still disproportionately affected by the epidemic in that agegroup.[11]

In this era, what is of vital importance is how men and women already infected with the virus will protect themselves from re-infection and also have access to the life-saving medicines that are now available in the resource-rich countries.

2.3 Benefits and Limitations of Antiretroviral Therapy

Antiretroviral therapy as disease modifying therapy for established HIV infection has produced dramatic effects on morbidity and mortality among HIV-infected patients in industrialised countries. But in developing countries, where 90 percent of AIDS cases occur, these drugs are not widely available because of the high costs and technical infrastructure required.[12]

Antiretroviral therapy changes the natural history of HIV infection. Results from medical studies on triple combination therapy have been extremely impressive, especially among patients who have never been exposed to an ARV. Studies of triple combination therapy have shown that viral loads can be reduced by 99 percent and mortality can be reduced by as much as half.[13]

Despite the general success of ARVs there are limitations. These are development of resistance, limiting future options and risking dissemination of drug-resistant virus. There are also known and unknown toxicities as well as an unknown duration of benefit.

However ARVs remain the only option at a time when there is no vaccine or drugs that can completely eliminate the virus. The process of accessing ART must however be viewed in light of how gender influences access to these drugs.

The usefulness of treatment for HIV infection is also limited by the emergence of virus strains that resist antiretroviral therapy. This means that mutations in the

virus genome allow HIV to reproduce even in the presence of therapeutic concentrations of drugs (concentrations that usually stop viral reproduction).[14]

The most glaring of these limitations is, of course, access. Antiretrovirals are only useful for patients who can access them either through insurance, government subsidy, or some other means. This leaves out a vast majority of the world's HIV-infected population.[15]

2.4 Access to ARVs

As the effectiveness of ARVs has become established, many developing countries are trying to look for ways of helping their poor people gain access to these life saving medicines which seem to be out of reach for the majority of sick people. Presently, 93% of the people infected with HIV who live in developing countries cannot obtain ARVs.[16]

Currently 100,000 people are living with HIV/AIDS in Uganda according to the 2004 Report of the Global AIDS Epidemic published by UNAIDS. Although

ART has been available in Uganda since 1998, only an estimated 10,000 AIDS patients are currently using ARVs or antiretroviral drugs.[17]

Most Ugandans taking ARVs buy them from private outlets and The Joint Clinical Research Centre (JCRC), a government-owned HIV/AIDS Research Centre.

In 2003, only 5% of all HIV-infected pregnant women in Uganda received Nevirapine, an antiretroviral that prevents transmission of HIV from mother to child. This is despite the fact that Uganda has the most successful HIV prevention programme in Sub-Saharan Africa.[18] Stigma and discrimination can deter people from getting tested, contribute to them infecting others and prevent people who are infected from receiving adequate care and treatment.[19]According to UNAIDS, while affordability is probably the single most important reason that people cannot obtain the drugs they need, access to these drugs is hindered by legal, infrastructural and cultural factors. In all these factors lies the issue of gender.

International Centre for Research on Women highlights greater discrimination and stigmatisation of women when accessing HIV/AIDS care and support. This is because HIV infection is largely attributed to pre-marital, extramarital and multiple heterosexual relations[20] and it is considered inappropriate in traditional societies for an elderly women to be promiscuous.

Studies continue to reflect that men have the decision-making power, not only as breadwinners, but regarding sexual issues and family planning.[21] For example, a key reason for resistance to family planning programmes in the third world is male control over women's fertility.[22] Women are often forced to ask for permission from their husbands or other family member to access services. Often women will choose not to ask or will be denied to use services.

Some women will even have to consult their spouses or other male household members as to whether to accept a service provider's advice, thereby hindering successful care and treatment. Yet women bear the burden of caring for the sick, of holding the family unit together in the face of sickness and death and of coping with the emotional trauma of dying.[23] In short, they are the backbone of any family.

2.5 Importance of Gender when planning ARV programmes

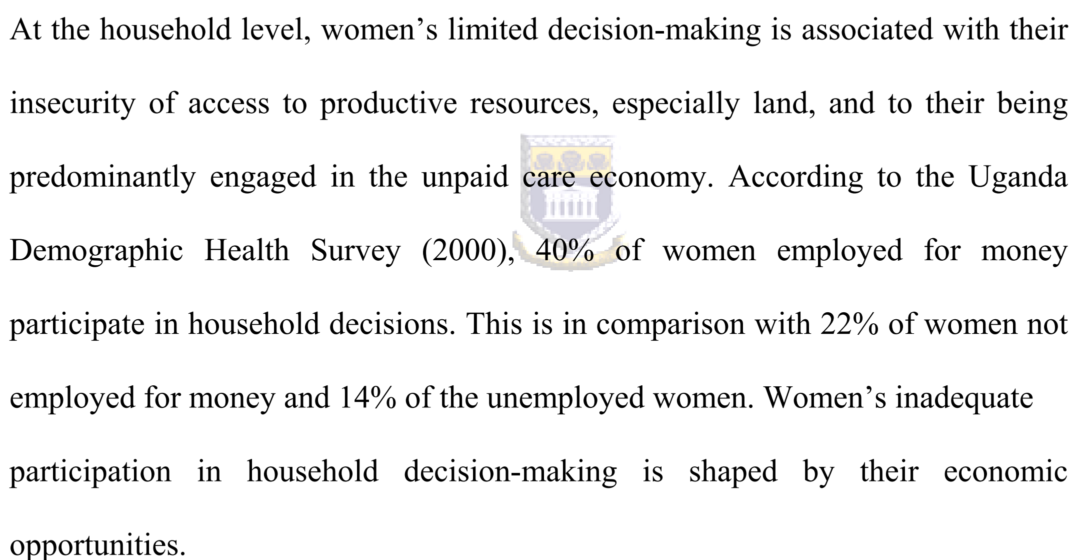
Gender directly affects health-seeking behaviour and more so when it comes to HIV/AIDS. For example when a woman is sick she can only access ARVs if she has money or is not stopped from doing so by her spouse. However the majority of women in Africa are not economically empowered or well placed, making them more dependable on men and unable to make major decisions regarding their health.[24]

Still because of these power relations, women may find it hard to inform partners about their HIV status and when they do, women have to bear the brunt of being disowned, which many times comes with violence and worse still murder, being meted upon them.[25] Yet partner notification is vital in terms of adherence to ARVs. Because taking these medicines is a lifetime decision, PLWHA need to be supported and encouraged to take these medicines and to protect themselves and their partners from further re-infection by using condoms.

Women are also discriminated against when trying to access care and support when they are HIV-positive. In many countries, men are more likely than women to be admitted to health facilities. Family resources are more likely to be devoted to buying medication and arranging care for ill males than females.[26]

Decisions within households about the allocation of time and other decisions can intensify or lessen gender disparities.[27] In fact the evidence suggests that they can do both. While households are generally assumed to pool their financial resources for consumption, production and healthcare, this may not be the case.

At the household level, women's limited decision-making is associated with their insecurity of access to productive resources, especially land, and to their being predominantly engaged in the unpaid care economy. According to the Uganda Demographic Health Survey (2000), 40% of women employed for money participate in household decisions. This is in comparison with 22% of women not employed for money and 14% of the unemployed women. Women's inadequate participation in household decision-making is shaped by their economic opportunities.



Yet for an HIV programme delivering ART to be successful, it must be designed to encourage women to attend therapy with their spouses so as to encourage support, adherence and to avoid re-infection and drug resistant strains. The development of services to support care in the community must respond to the disproportionate role or care burden that falls on women.

2.6 Gender roles and decision-making

Gender role is defined here as the patterned interactive relationship and responsibilities of men compared to women, specifically what an individual does in his/her relationship with others…. Roles can further be defined as expectations regarding the skills, rights and duties of individuals and this functions as prescriptions for interpersonal behaviours that are associated with particular, socially recognised categories of people.[28]

Important to note is that, these gender roles tend to discriminate against women limiting their decision-making abilities, at home, in business, politics, health and all spheres of life. In Africa, girls are brought up to be submissive to boys, which in womanhood, translates into dependency on men. Women are conditioned to become a weaker sex whose role is to give birth, tend the home and be the caregiver.

As a result of these roles assigned to men, many women find it difficult to take control of situations and to make decisions on their own. In Africa, despite the many gender movements aimed at involving women in positions of power and decision-making and increasing their income levels as opposed to men, women have continued to lag behind. And although women produce over 80% of the subsistence farming, it is the men who earn high incomes from cash crop farming. It is obvious that women who are not economically empowered in their work have limited decision-making power, within the family and within society.

2.7 Gender context in Uganda

In Uganda, men dominate decision-making at household level and within the public sphere. Men tend to make decisions with respect to agricultural production, labour allocation, consumption and participation in the labour force.[29] The dominance of men in decision-making in Ugandan households undermines women's health-seeking behaviour. Women will often depend on their partners in order to access health services.

Even if conditions within the household are conducive to females seeking health care, this is undermined if there is no way of reaching the health unit. Thus at the access stage, the most obvious hindrances to women receiving health care include lack of transport, road communication and money for fares.[30]

Soft loans for women often improve their economic power and therefore their power to make decisions with their partners can avert their unfair gender positioning. When the poorest especially women, receive credit, they become economic actors with power. Power to improve not only their own lives, but, in a widening circle of impact, the lives of their families, their communities and their actions.[31]

2.8 Gaps in research on role of gender in accessing ARVs

Many countries are at a stage of introducing, and in some cases, expanding access to ARVs. Uganda, in common with many other countries, has not yet taken account of gender issues in the entire health sector.[32] Yet experience shows that

controlling the epidemic depends in large measure on communities and families' abilities to confront the gender-driven behaviour that increases the chances of infection for girls and boys, men and women.

Several efforts have been taken to reduce costs and address PLWHA who have no means to access these medicines. Given the decreasing costs however, not many studies have been done to understand how gender influences access to ARVs. This study is a first attempt to analyse and document the gender related decision-making patterns of men and women in accessing ARVs in Uganda.

Few health services have put gender issues on their agenda when dealing with men and women.

The impact of male involvement in reproductive health programmes has not been fully studied and yet men appear to be receptive to using information that will improve their health. A programme in India that sent male outreach workers to talk with husbands of pregnant women found that men's understanding of the services involved in antenatal care and their importance increased as a result of the programme. [33]

CHAPTER THREE

3.0 Research Design and Methodology

3.1 Introduction

In determining the role of gender relations in decision-making for access to ARVs qualitative descriptive study with TASO clients was carried out in Kampala District between September and October 2004.

This chapter describes the study design and methods used to collect and analyse data. The chapter further describes the sampling approach for the study population.

3.2 Sampling

3.2.1 Sampling Technique

In choosing the respondents for FGDs, a random selection based on the clinic days was done with exclusion criteria being clients who are not in a long-term relationship – defined as those with a regular sexual partner (a relationship that has lasted for more than 12 months) by the time ARVs were started. This was meant to examine decisions between partners and within relationships in families.

3.2.2 Sample Size

The study sample was made up of 21 females and 19 males who took part in the discussions at TASO-Mulago on September 20th, 22nd and 27th. In total, the sample comprised of 40 respondents. Six FGDs were conducted, three for each gender. The first, second and third FGDs for men had 7, 6 and 6 respondents

respectively. In the women's FGDs, there were 8, 6 and 7 respondents in each of the three groups. Respondents represented age groups in their twenties, thirties, forties, and fifties. The number of FGDs was based on the assumption that at the end of the discussions data would be saturated.

3.3 Data Collection

3.3.1 Focus Group Discussions

The main tool for data collection was a Focus Group Discussion (FGD) Topic Guide (See Appendix C) which was used to stimulate discussion on decision-making for access to ARVs among groups of men and women separately. A Research Assistant, who understands *Luganda,* a local dialect widely spoken in Kampala, used audiotape and recordings in a diary to capture responses. Additional information included age, when respondents knew their HIV-positive status, what motivated them to take an HIV test, to start ARVs and when ARVs were started.

Similar questions were asked for both men and women about their involvement in decision-making in relationships and families and the ability to initiate and to make joint decisions regarding ARV therapy, plus factors that motivate or hinder men and women to decide to access ARVs with their partners.

During FGDs, saturated and unproductive questions were eliminated and tapped new leads that were not anticipated were followed. Emerging issues were probed in detail and field notes captured within 24 hours for each FGD, to minimise the

risk of information loss. Audio-taped data was continuously transcribed to identify areas that needed further investigation. When the themes and coded categories were not confirmed, new ones were formulated.

Focus group discussions (FGDs) probed decision-making for access to antiretrovirals (ARVs). The FGDs proved to be an excellent technique to use for examining group or community consensus about the study subject.

There were two separate FGDs for men and women on each of the days at 11.00pm and 12.30pm. The FGDs were held on Mondays and Wednesdays, which were days when clients picked their ARVs. Discussions were one hour and 15 minutes; the 15 minutes were for settling in and introductions.

Separating of women from men during the FGDs enhanced the interaction of respondents and encouraged deeper, open and honest discussions about gender relations and HIV/AIDS.

To gain participants' trust, an overview on rules and procedures of the research was given to them. The research went by the set standards of informed consent and confidentiality and numbers, instead of names, were used during the discussions. (Appendix D).

3.3.2 Document Reviews

In addition to FGDs, various documents on gender and HIV/AIDS were reviewed for data collection.

There was a physical random search for publications on gender and HIV/AIDS in libraries/resource centres of key health organisation for instance The World Health Organisation, Ministries of Health and Gender. Unpublished documents from informal contacts also provided insight into roles within households and how they impact on decision-making for ARVs between partners and other persons.

An internet-based search engine (google) was used to identify literature on gender and HIV/AIDS. Articles published from as early as 1990 to 2004, dealing with gender relations specifically in households and how they impact on decision-making for healthcare, particularly for HIV/AIDS services, were selected for review. This was to establish the trend of gender relations regarding decision-making for access to HIV/AIDS care over time and how the epidemic has impacted on who makes these decisions and with whom they are made.

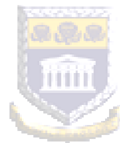
A total of 24 websites with literature on the HIV/AIDS trend, access to antiretroviral therapy and decisions made in households to access these life-saving drugs were reviewed. Key words used in the search were decision-making, access, gender, antiretrovirals and HIV/AIDS. Journals that dealt with gender and power relations, women's autonomy and decision-making for health care in households were examined.

3.4 Data Analysis

3.4.1 Data coding

Information recorded on data capture sheets was broken down into different themes based on the study objectives. Themes regarding decision-making for ARVs, key persons involved and factors influencing access to ARVs were identified and re-examined using transcribed audiotapes. Data was coded and retrieved both manually and on computer. Data was taken back to six participants who are counsellors and also clients of TASO to confirm interpretation.

The researcher compared and contrasted the way men and women made decisions regarding access to and utilisation of ARVs. Sub-themes for analysing access to ARVs included cost, fears, adherence, stigma, discrimination and influence of others.



3.5 Validity

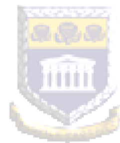
Triangulation of data sources was carried out to ensure validity of information collected. This was done through comparing and contrasting the information generated from textbooks and internet articles describing gender roles and relations especially with respect to health-seeking behaviour. The findings from literature sources were compared and contrasted with the outcomes of the FGDs.

3.6 Generalisability of findings

Respondents in this study comprised of poor people with HIV and the majority of TASO clients fall in the age group 21-50 years, therefore the sample was

representative of a big majority of the community at TASO. The levels of literacy were also representative of the general population. Respondents were able to bring out the norm in the communities they live in. Separating the genders encouraged open dialogue between members of the same sex and enabled the researches analyse gender relations as they arose.

However, by random sampling to recruit men and women who had been motivated by TASO to access ARVs, these findings may not be generalisable to men and women in similar circumstances that have not undergone counselling.



CHAPTER FOUR

4.0 Results: Presentation and Discussion

4.1 Introduction

This chapter presents the main results of the study, drawn from the literature reviewed and focus group discussions held as highlighted in the preceding chapters (two and three) of the thesis. As pointed out in chapter three, the study involved a randomly selected sample of forty (40) TASO clients in Mulago, of whom 21 were female and 19 male. A total of 45 documents, publications and websites were reviewed as secondary data sources for the thesis.

It is evident from the above sex disaggregation of the study population that the higher number (21) was female. This is contrary to the assumptions highlighted in the literature reviewed (Chapter two), indicating that gender roles restrict women's access to information and health care in comparison to men. This unexpected finding may be explained by the thesis findings to the effect that when women learn about their HIV-positive status, they come out of denial faster than men and are more open to seeking treatment and to take up their role as healthcare providers in the home. The other possible explanation is that since TASO offers free ARVs, women are more likely to be attracted to such a service, especially through the auxiliary PMTCT and other reproductive health services provided within Mulago Hospital, where TASO is situated.

It is important to note however that the larger number of females accessing treatment at TASO does not necessarily infer that women have greater access to

ARVs than men in general. Other factors such as cost and unequal power relations between men and women in the home restrict women's access to ARVs.

The chapter is arranged in four main sections related to the study aim and objectives outlined in chapter one of this report. The sections are: Characteristics of clients accessing ARVs at TASO- Mulago, Decision making process for accessing ARVs, People involved in the decision making process to access ARVs, and Gender related influences on access to ARVs.

4.2 Results

4.2.1 Characteristics of Clients accessing ARVs at TASO- Mulago

A total of 40 people: 19 men and 21 women participated in the FGDs. All study participants were semi-illiterate or illiterate (See Table A for literacy status of respondents). Semi-literacy was determined by the ability of respondents to read sentences in at least one of the major Ugandan language newspapers i.e. *The New Vision, Bukedde, Orumuri,* while illiteracy involved inability to read sentences from any of the newspapers.

The level of literacy was important because the majority of patients in Africa are illiterate and no studies have been done in Uganda on how this category makes decisions to access these drugs (ARVs) even when they are free. Literacy was an important factor in determining ability to access information that will enable people to make correct decisions, which is critical if men and women are to make healthy reproductive health choices.

Table A: Literacy Status of Respondents by Sex

Literacy Status	Male	Female	Total
Semi-illiterate	18	14	32
Illiterate	1	7	8

From the above table, it is evident that none of the respondents was fully literate and that the majority of the semi-literates were male (18 out of 32). It is also clear that the majority of the respondents who were illiterate were female (7 out of 8).

In the study, participants' ages ranged from 27 to 50 years for females and 28 to 64 years for males. The mean age for females was 35.5 years while for males it was 41 years (Table B). The sample was representative of clients in TASO who were receiving treatment but were not respondents in the study. The majority of new female clients at TASO fall in the age group 21 to 40 years while for males it is 31 to 50 years.

Table B: Age Distribution of Respondents by Sex

Age (years)	Male	Female	Total
21- 30	1	2	3
31 – 40	11	14	25
41 – 50	4	5	9
51 – 60	2	0	2
61 – 70	1	0	1
Total	**19**	**21**	**40**

There was not a single woman of over 50 years who was accessing ARVs. Older women tend to be less likely to access care and treatment services due not only to the lack of money for transport and other associated costs, but also the greater social stigma and neglect they suffer as a consequence of being infected with HIV. The quotations below show this:

My fear was that what would people think of me, an old woman going to TASO- 50 year-old woman.

> *Many of the women in TASO have lost their husbands. It is also difficult for an old woman to find ways of coming to TASO. Many times there is no money and even when there is money, people think: How can an old woman get AIDS?* - 39 year-old woman.

Most of the respondents lived in and on the outskirts of Kampala, the capital city of Uganda and can be referred to as semi-urban dwellers. Only two of them, one male and the other female lived in Kasese town, 420 kilometres to the west of Kampala. These two can also be described as semi-urban dwellers as they live in conditions similar to those of the Kampala-based respondents.

4.2.1.1 Participation

During the study, female participants in FGDs were more open and shared their experiences more freely than men. Discussions in all FGDs indicated that men were reluctant to seek care and treatment for HIV/AIDS. This in part explains their apparent reluctance to discuss issues about their health. The quotation from one of the male respondents in the FGDs illustrates the point vividly:

> *"It is not easy to get up and come to TASO when everybody is looking at you. It took me over a year to decide to come here,"*- 45-year-old man.

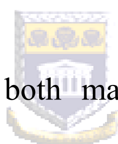
A female respondent reinforced that view below:

> *Men discuss illnesses especially these sexually transmitted diseases with their doctors and not their partners. So how do you start involving them?*- 42-year-old woman.

All the women contributed without being urged but some of them were shy when it came to discussing decisions made by partners regarding pregnancy. This was probably because women in Uganda are socialised not to discuss issues of sexuality, and that doing so implies in many societies that the woman "knows too much" and may be promiscuous.

4.2.2 Decision-making process for accessing ARVs

The study revealed that the decision to access ARVs was made after confirmation of a positive HIV test and a low CD4 cell count for all respondents.



The decision to access ARVs for both male and female respondents was influenced by the need to avert the stigma associated with AIDS, TASO campaigns, and sensitisation, the desire to have children, the positive effect of ARVs on other users, and the fear of death. For instance, one of the respondents remarked, *"I was scared that I might not live to see my children grow (sic). I did not want to die. I was determined to get the drugs"* – 38-year-old woman.

However, the desire to have children as a driving force for making decisions to access ARVs brought out gender differences. Whereas the men had no reservations about the possibility of HIV-positive people getting children, women were concerned about having children when they were HIV-positive. The effect of pregnancy on women's health worried women respondents.

This concern is nevertheless undermined by the lack of control over their sexuality and reproductive health. The following quotations illustrate this point:

> *What do you do if your husband wants a child and yet you know that you are both sick? Your husband is also convinced that you can use Nevirapine! If you say no, then the man will tell you to leave-* 35-year-old woman.

> *You cannot talk about not having a child when you do not have any, even when you are HIV positive. For a man to be respected, he must have a child. By the way not only one, he must have many. One also needs an heir-* 48-year-old man

All respondents discussed access to ARVs first with their counsellors. In helping them decide whether to access ARVs or not, the majority of respondents preferred to do so with family and friends as opposed to their partners. This scenario can be explained by two important factors: concealment of status from partners for both genders, and denial of HIV infection, especially among men. The quotations below illustrate:

> *I had a lot of regrets and for long I thought I might have been better off not knowing I was HIV-positive. It took me several months for my wife to know the problem-* 54-year-old man.
> *As you know, men usually stay in denial even when HIV signs are showing. I told my partner that I was HIV-positive and that he too might be infected and he continued to deny it until the day he fell sick-* 35-year-old woman.

> *Some women know that their partners have been accessing drugs after the partner has died. But even women hide drugs from men-*34-year-old man.

> *You cannot tell a woman that you are HIV-positive so it is also difficult to discuss about the drugs. She will run away-* 48-year-old man.

I am still trying to get my husband to come for testing and if positive, to start ARVs. He has still refused but I think he will come- 48-year-old woman.

Concealment of information on HIV status, coupled with denial were critical factors in determining whether or not the decision to access ARVs was shared among partners. Among the 19 men involved in FGDs, only three men knew whether their partners were taking ARVs or not. One of these men was in a discordant relationship so his partner was not on therapy, the second had a partner who was a client of TASO while the third found it difficult to take his drugs secretly and decided to inform his partner. The majority of the men (13) came out strongly against disclosing to one's partner access to ARV therapy because they considered it a private matter.

Only four of the women knew whether their partners were taking ARVs or not. Of these, two of their partners had died in denial while the partners of the other two were in denial despite knowing that their female partners were accessing ARVs.

Respondents revealed that it was easier for women and men who had disclosed their HIV statuses to their partners to take joint decisions on accessing ARVs than those who had not done so. The quotations below demonstrate:

If you started at TASO together then you can talk about ARVs together- 42-year-old man.

If you revealed your status earlier, it becomes easier for you to discuss ARVs with your partner- 32-year-old woman.

Some of us used to hide drugs from our partners before we joined TASO but if you revealed your status earlier, then it becomes easy to discuss ARVs- 39-year old man.

We both fell sick at the same time so we had to decide together about ARVs– 45-year-old man.

Respondents who discussed access to ARVs with their partners were influenced by suspicion of each other's serostatus or the belief that their partners would be receptive based on a stable relationship. Three of the men discussed ARV therapy with their partners. This was because their partners knew their (men's) status. One of them was advised by his mother to tell the partner.

The reasons for women discussing access to ARVs with their partners included- the partner being a TASO client, joint attendance of antenatal care, death of the partners' child, financial dependence on men, and suspicion that the partner was HIV-positive.

4.2.2.1 Factors influencing decision making for accessing ARVs

The study showed that accessing ARVs by both men and women was significantly motivated by the effect the drugs had had on other clients/users known to them. TASO also runs a drama group, which acts out HIV/AIDS plays with messages on ARVs. These plays were also found to be effective in giving hope to persons infected with HIV. The quotations below demonstrate:

I saw them acting at one of their centres. They looked very healthy and I was told that they were on drugs. I hoped my turn to access drugs would come – 32-year-old woman.

The drama group through their messages has been very instrumental in encouraging us to access drugs. They (people in the community) had scared us that the drugs were dangerous and one was better off not taking them – 40-year-old man.

The fear of dying, the need to ward off AIDS symptoms and the duty to care for children were also found to be key factors in determining access and utilisation of ARVs among TASO clients. This is evidenced by the views expressed by respondents below:

> *By staying alive I am protecting my children. The drugs have made me stronger and I often bring my children to TASO to see what can happen to them if they are not careful* – 45-year-old man.

> *I looked after my brother and sister when they were dying. I do not want to die like them. When you have drugs you die decently by reducing on the suffering* – 35-year-old woman.

The other key factor for both men and women making decisions to access ARVs was the need to stay healthy so as to avoid being discriminated against at their workplaces:

> *My boss wanted to sack me because I was falling sick so often. He would get hold of my arm and tell the other workers how I looked like I was about to die. But when I started drugs, he was surprised at the way I looked. He no longer threatens me-* 33-year-old woman.

> *I make passion fruit juice. You all know the rumour that we put blood in these drinks so that other people can get AIDS. If people knew I was positive, they would shun me. No one knows because the drugs have made me healthy- 37-year-old woman.*

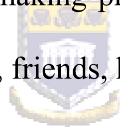
All respondents noted that stigma against persons living with HIV/AIDS was high in their communities and to avert this, it was important to take drugs that would delay progression of AIDS. In addition to stigma, the effect of disclosure on relatives and close associates were cited as contributing to unilateral decision-making as argued by two respondents. The quotations below illustrate:

Men usually decide to access drugs independently because they fear the stigma associated with revelation of a positive status. Many times they do not tell their wives. They treat themselves without the women knowing and when the women fall sick they take them to their own (men's) doctors and the secrecy continues - 34-year-old man.

I feared telling my father because I am the only surviving boy in my family. The rest have died of the disease and so I feel I have to face it alone – 48-year-old man.

4.2.3 People involved in the decision-making process for accessing ARVs

The study shows that in deciding to access ARVs, clients involved a cross section of people. In the preceding section (4.2.2), the decision-making process to access ARVs has been discussed and some key participants identified. The section also discusses in depth, interaction between partners (men and women) in comparison with other persons. This section (4.2.3) elaborates the involvement of other actors (other than partners) in the decision making process for accessing ARVs. These included counsellors, family members, friends, health practitioners and children.



4.2.3.1 Counsellors

All respondents agreed that counsellors were always the first point of call for any decision regarding HIV. This is largely dictated by the HIV/AIDS care system in Uganda generally and TASO in particular, where counselling is integrated into all services and is usually the first level of interaction between service providers and clients. This is evidenced in the views below expressed by respondents:

I first knew about these new drugs for AIDS from my counsellor. We men usually trust our counsellors. In fact I call my counsellor mama and tell her everything about myself - 45-year-old man.

The counsellor here told me about these drugs and how I could access them. This is an important person to us- 39-year-old woman.

4.2.3.2 Family members and Friends

Generally, in making decisions to access therapy respondents preferred to discuss the decision with a family member other than a sexual partner. Family included parents, grandparents, siblings and in-laws. Fifteen men discussed ARVs with family and friends and only three discussed it with their partners. This trend is attributed to the confidence and trust that both men and women have in their families and the belief that blood relations are more receptive and dependable in times of hardship than anyone else. Two respondents elaborate:

> *Discussing ARVs with other people depends on whether you will not burden others with your problem. But this is your family – 42-year-old man.*

> *You do not just tell anyone that you are taking drugs. You have to find out how useful it will be to you to confide in someone even if it is your partner. I told my grandmother because she is the only one who treated me like a human being when she discovered I had HIV* – 32-year-old man.

For the 16 women who discussed ARVs with family members and not their partners, the decision was influenced by negative responses of male partners in their communities upon the revelation that their partners were visiting VCT centres.

> *Men usually decide whether the woman should take the medicine or not and with the many bad rumours about these drugs men refuse their wives to come to TASO. This is what I feared. I discussed it with my children because they are understanding*- 32-year-old woman.

> *Some women return to TASO saying their partners have stopped them from taking the drugs. So why risk involving your partner*- 33-year-old woman.

From the above, it is evident that the family plays a major role in influencing decisions made by individuals to access ARVs.

4.2.3.3 Health practitioners

Health practitioners (doctors, antenatal attendees) were a key influencing factor for men and women in making decisions to access ARVs. This can be attributed to the fact that most clients, especially women, visited health workers when their health declined or when pregnant as they sought antenatal care. The quotations below explain this scenario:

> *I was very sick and my doctor advised me to start on ARVs. Friends advised me not to take the drugs, as I would not be able to afford them. I went back to my doctor who weighed the benefits and disadvantages for me. I chose to join TASO so that they could give me the drugs* - 35-year-old woman.

> *I was pregnant and when I visited antenatal my blood was checked (sic). I was HIV-positive. They told me to take my partner with me on the next visit and they told us we had the virus and advised that we join TASO for care. But my partner refused to come for drugs and died* – 30-year-old woman.

From the above, it is clear that women usually obtain information about ARVs from places where they seek healthcare. It is also evident that the involvement of men in women's reproductive health, particularly during antenatal care, provides entry points to reach men for VCT and subsequently, ARVs.

4.2.3.4 Children

The involvement of children in decision-making for ARVs in households came out frequently for all respondents, men and women. Children were however

involved at a later stage after discussing therapy with other key persons such as counsellors and friends. Both men and women found it easier to discuss access to ARVs with older children than with their partners. While women said children are understanding and are able to remind them to take their drugs, the men looked at children as caretakers of families in the event that their parents were not around and argued that the earlier they (children) knew about the pending responsibility, the better for them. All respondents believed that revealing one's status allowed them (children) to protect themselves against the virus. The quotations below illustrate:

> *I was badly off. So when I got money I knew I had to tell someone about my status and so I decided to tell my children in case something happened to me after taking the drugs* – 33-year-old woman.
>
> *By telling the children that you are sick you are helping them. I have brought my children many times to TASO so that they can see what HIV does to people. In this way they can protect themselves – 54-year-old man.*

From the above, it is evident that children play an important role in decisions made by their parents and can act as a link between partners when deciding to access ARVs.

4.2.4 Gender-related influences in access to ARVs

Drawing from the preceding sections of this chapter, it is obvious from the study that gender plays an important role in decision making for access to ARVs by men and women. The study brings out gender issues related to finances, reproductive health and power relations.

4.2.4.1 Gender and finance in access to ARVs

The study reveals that women have limited or no funds for accessing ARVs, even when they are free. Factors such as transport and the need for appropriate diet inhibit their full access to and utilisation of ARVs. The quotation below illustrates:

> *I have no money. My family is poor so I had to find ways of getting money to go to the clinic*-31-year-old woman.

Women's financial incapacity (poverty) is determined by several factors, ranging from inadequacy in employable and income generating skills arising from higher illiteracy as seen in section 4.1 above. The higher illiteracy among women may be explained by the social cultural discrimination against girls in education due to boy preference in patriarchal communities, which are typical of the study population. Women's poverty is further exacerbated by oppressive customs such as property grabbing by relatives in the event of severe illness or death of their partner. The quotation below illustrates:

> *When I fell sick my family took away everything from my wife. They did not even leave the carpet for her (sic)* - 34 year-old man.

The above scenario explains why women depend on their partners to finance their access ARVs. This factor is confirmed in section 4.2 where women's financial dependence on men was a key factor for discussing access to ARVs with their partners.

4.2.4.2 Gender and reproductive health in access to ARVs

The desire to have children, especially sons, was a significant factor in determining access to ARVs. All 21 women and 18 men agreed that this desire was an important reason for people who are HIV-positive to access ARVs. Only one man was of the view that pregnancy should be forgotten by PLWHA. The main reason advanced by men was the need to have an heir and under patriarchal society these are boys (heirs). Boy preference is illustrated in the quotation below:

> *My wife convinced me to get another child using Nevirapine. I wanted a boy but it also ended up being a girl like my other children* – 54-year-old man.

While men believed that with the prevention of mother-to-child transmission programmes it was safe for women to get pregnant, the women were more concerned about the risk of transmission of HIV to their babies and were worried that pregnancy may weaken them, making it difficult for them to care for the older children. Despite their concern, the women were usually forced to conceive in order to fulfil socio-cultural obligations, which require them to submit to their partners' demands. This is illustrated in the quotation below:

> *What do you do if your husband wants a child and yet you know that you are both sick? Your husband is also convinced that you can use Nevirapine! If you say no, the man will tell you to leave the home,-* 35-year-old woman.

4.2.4.3 Gendered power relations and access to ARVs

Under patriarchal society, power to make decisions on matters in households and community is a male preserve; therefore their partners must sanction women's decisions. The study reveals that women had to seek permission from their

partners in order to visit a health facility. This scenario is reinforced by the women's weaker financial capacity as seen in section 4.4.1 above and reaffirmed below:

> *If you do not ask for permission, where will you get the money to go to hospital?* – 42-year-old woman.

Men's control of women's movement was caused by the stereotype that when women move out of the home without their partners or relatives, they are bound to become promiscuous. The quotation below proves this:

> *It is hard for some women to visit TASO because when you walk out of the house, the man thinks you are going to see other men* – 32-year-old woman.

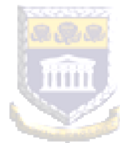
The study also revealed that men's control over women extended to deciding for them whether or not to take the drugs (ARVs) or continue visiting service providers. This is evidenced in the quotations below:

> *Men usually decide whether the woman should take the medicine or not and with the many bad rumours about these drugs, men refuse their wives to come to TASO* – 32-year-old woman.

> *Some women return to TASO saying their partners have stopped them from taking drugs* – 33-year-old woman.

It was highlighted in section 4.2.2 that women were quick to realise the consequences of being HIV-positive and sought medical help, while men stayed in denial for a long period of time. The socialisation of men and women plays a key role in this trend. Whereas men are taught to persevere in times of hardship, women are expected to seek help from others. The effect of this is the evident poorer health seeking behaviour among men compared to women. In addition, women's pro-active health seeking behaviour is in part dictated by their gender

roles, which include caring for children. This role brings women into closer and regular contact with health workers and therefore provides a greater opportunity to attend to their own health. They were also able to open up during discussion probably because while women are socialised to talk about their problems, men are expected to be macho and tackle problems individually.



CHAPTER FIVE

5.0 Conclusions and Recommendations

5.1 Introduction

5.1.1 Assumptions and Limitations

Respondents in the study comprised of only clients accessing ARVs at TASO so they are not generalisable because it is not a community-based study. The assumption is that by 12 months a sexual partner has become regular and therefore the two are in position to make decisions regarding their sexuality together.

It was difficult at first to get participants together to take part in the discussions as seen by the spacing of FGDs because timing coincided with TASO clients' picking up of ARVs and meeting of counsellors. TASO clients have been respondents in many other HIV-related studies and the men seemed reluctant to take part at the start of the study. However, after explaining to them how the study will benefit them, they agreed to take part in discussions. Recruitment was also based on a person's likelihood to be open and vocal during discussions.

This chapter presents a summary of key emerging issues from this study and makes recommendations for improving access to ARVs for both men and women. The recommendations are specifically targeted at TASO, government policymakers and implementers, persons infected or affected by HIV/AIDS, civil society organisations working in the area of HIV/AIDS, and researchers.

The study demonstrates the importance of paying attention to gender relations in the design and delivery of ARVs in particular, and HIV/AIDS programmes in general.

5.1.2 Strengths of the study

There are no studies that have looked at gender relations in decision-making for ARVs in families. Most studies in Africa have focused on access to ARV therapy at the service provider level; the emphasis being the type of service being offered and how it is offered to men or women who attend that service. Yet in Africa, households constitute a major point for decision-making. African households have stood out for centuries using the family unit to ward off wars, famine, drought and the latest AIDS epidemic.

5.2 Overview of emerging issues and recommendations

5.2.1 Characteristics of TASO clients

It is evident from the study that TASO clients can be described as typically illiterate or semi-literate, with women representing a higher proportion of the illiterate. Matched with the revelation in the literature review, which indicated a higher prevalence of HIV infection among females (55.2%) in Uganda, these findings suggest a positive correlation between high illiteracy among women and their greater vulnerability to HIV/AIDS infection than men. It can therefore be deduced that illiteracy is a key factor in increasing women's vulnerability to HIV/AIDS and by extension, access to care and treatment services including ARVs.

Investing in the education of women and girls, as well as men can therefore be a strategic intervention in reducing this vulnerability and improving both men and women's access to care in general, and ARVs in particular. It is therefore important that government and other stakeholders in education do not only upscale both formal and informal (adult literacy) education programmes, but also mainstream HIV/AIDS into educational and training curricular at all levels.

The clients were generally poor, semi-urban dwellers, and employed in the informal sector. There was not a single female client aged over 50 years. Whereas this finding may not be necessarily true for older women's access to ARVs, it is significant in underlining age as a key variable in accessing ARVs. Older women tend to be less likely to access care and treatment services due, not only to the lack of money for transport and other associated costs, but also the greater social stigma and neglect they suffer as a consequence of being infected with HIV/AIDS. The evidence below illustrates this:

> *My fear was that what would people think of me, an old woman, going to TASO* -50 year-old woman.

ICRW supports the above finding on older women's higher susceptibility to HIV-related discrimination and stigmatisation.[34]

> *Many of the women in TASO have lost their partners. It is also difficult for an old woman to find ways of coming to TASO. Many times there is no money and even when there is money people think: How can an old woman get AIDS?* - 39-year-old woman.

This finding confirms that poverty is a key variable in HIV/AIDS. The cost of accessing ARVs can therefore inhibit the greater number of the poor from

benefiting from HIV/AIDS programmes even when free ARVs are provided. It is therefore clear that care and treatment services need to be accessible to the poor.

The design and implementation of home-based care and management of HIV/AIDS programmes is recommended by this study as a key strategy for increasing access to ARVs for the poor. Further research will certainly be required to investigate why older women do not access ARVs as revealed in this study.

5.2.2 Decision making process in accessing ARVs

The study has pointed out that both men and women find difficulties in discussing access to ARVs with their partners and prefer to do so with other people such as counsellors and family members. Concealment of status from partners due to stigma, and living in denial especially among men were critical factors that contributed to this scenario. This finding is supported by a report on HIV/AIDS Treatment and Care in Resource Poor Countries.[35] Men's limited access to ARVs due to concealment of their HIV status and living in denial as suggested in this study, challenges the widely held notion that since men control money, they definitely access healthcare in general and ARVs in particular. It was also revealed that whereas men were reluctant to seek care and treatment, women did so without much hesitation. Despite this, however, UNAIDS reveals that family resources are more likely to be allocated to men's health.[36]

Many women were however forced to open up to discussions on access to ARVs with their partners particularly because of the need to get not only financial assistance say transport, but also permission to leave the home. A Danish Embassy Uganda-Poverty and Gender Assessment Report confirms the authority of men's control over women's choices and access to services.[37]

To reverse this state of affairs, it is recommended that TASO, other NGOs, and Local Government Community Development Workers design and implement outreach programmes for counselling households, targeting especially men.

5.2.3 Key persons involved in the decision making process

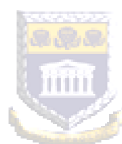
This study has indicated that the family, counsellors and health practitioners are key players in decision-making to access ARVs for both men and women. Whereas it is easier to reach counsellors and health practitioners in HIV/AIDS programmes, targeting families remains a grey area. ARVs are still supply-driven and therefore government investment in community mobilisation and empowerment programmes as a response to HIV/AIDS is therefore necessary and expedient for improving access to HIV/AIDS care and treatment in general, and ARVs in particular.

5.2.4 Gender-related influences in accessing ARVs

The study has underlined gender differences between men and women as a key denominator in access to ARVs. Patriarchal norms that emphasise male supremacy and control over women mean that women's access to ARVs does not

only require sanctioning by their partners, but also restricts women's control over money, other assets such as transportation, skills and even their own sexuality. This is reaffirmed by Vallaeys [38] and, Brydon and Chant[39] in their publications on HIV/AIDS in the third world.

These norms also affect men's access to ARVs. Men in the study were mostly affected by stigma because they wanted to safeguard their supreme position and cannot therefore be seen to access services and being thought of as vulnerable. This therefore calls for not only up-scaling government and NGO gender sensitisation programmes using various media to reach the grassroots (villages), but also investing in income generating programmes targeting women. Another crucial area for action is promotion of the reproductive and sexual health and rights of women and men.



Studies can also be done to determine whether there are more women accessing ARVs when they are paid for. Women's vulnerability is more likely to become overt when services are paid for.

5.3 Overall Conclusion

This study has reaffirmed the centrality of gender issues regarding HIV/AIDS particularly decision-making for access to ARVs. It has deepened the analysis of gender dimensions and provided new insights with specific reference t o accessing ARVs. Policy makers, implementers, TASO, HIV/AIDS activists, researchers and the academia will find this study useful.

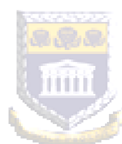
REFERENCES

[1] The World Bank Group, HIV/AIDS and Gender Equality: Gender and Development Briefing Notes, 2003, accessed online at http://www.worldbank.org/gender.html, March 2004.
[2] UNAIDS/WHO, AIDS Epidemic Update, December 2001, accessed online at http://www.unaids.org, April 2004.
[3] Mukherjee, J.S. Farmer P.E. Niyizonkiza D. McCorkle L. Vanderwarker C. Texeira P. Kim J.Y. Tackling HIV in Resource Poor Countries, British Medical Journal 327:1059-1116, November 8, 2003.
[4] The World Bank, A World Bank Policy and Research Report, Engendering Development through Gender Equality and Rights Resources and Vice, Oxford University Press, New York, 2001, p50-51.
[5] The AIDS Support Organisation, TASO Newsletter, 12 (1), Graphics Systems (U) Ltd, Kampala, January - June 2004, p2.
[6] ibid, p2.
[7] UNAIDS/WHO, AIDS Epidemic Update, December 2003, accessed online at http://unaids.org/UNAIDS/EN/Resources?Publication/Corporate+publications/AIDS+epidemc+update, December 2003.
[8] UNAIDS/WHO, Report on the Global HIV/AIDS Epidemic, 2002, accessed online at http://www.journ-aids.org/HIV-AIDS%20stats1.htm, March 2004.
[9] Hamblin J, Reid E, HIV and Development Programme, Women, the HIV Epidemic and Human Rights: A tragic Imperative, Issues Paper 8, UNDP, New York,1995, p2.

[10] UNAIDS, Report on the Global HIV/AIDS Epidemic, 2004, accessed online at http://www.journ-aids/HIV-AIDS%20stats1.htm, October 2004.
[11] Ministry of Health, STD/AIDS Control Programme, HIV/AIDS Surveillance Report, Kampala, June 2003, p16.
[12] AIDS in Developing Countries, Essays and Enotes, 2000 - 2004, accessed online at http://www.enotes.com/aids-developing/, December 2004.
[13] Steven Forsythe, The Affordability of Antiretroviral Therapy in Developing Countries: What Policymakers Need to Know, 2004, p 3 of 14, accessed online at http://www.worldbank.org/aids-econ/arv/background/aidconc.htm, October 12, 2004.
[14] William O'Brien, Resistance to Antiretroviral Drugs, Bulletin of Experimental Treatment for AIDS, January 1998, p1 of 12, accessed online at http://www.sfaf.org/treatment/beta/b35/b35/resist.html, October 29, 2004.
[15] Martinez J, Novel Targets: The need for novel targets and approaches to HIV therapy, Research Initiative Treatment Action, 8(1), 2002, p 1 of 4, accessed online at http://www.centerforaids.org/rita/0702/novel.htm, October 23, 2004.
[16] ibid. No 13.
[17] Ministry of Health, Antiretroviral Treatment Policy for Uganda, Kampala, June 2003, p4.
[18] Ministry of Health, Sexually Transmitted Diseases/AIDS Control Programme Performance Evaluation Report for the HIV Antiretroviral Drug Access in the Private Sector in Uganda, Kampala, 2000, p1.
[19] HIV/AIDS Treatment and Care in Resource Poor Countries, July 26, 2005, accessed online at http://www.avert.org/hivcare.htm, August 3, 2005
[20] ICRW Research Update, Understanding HIV-Related Stigma and Resulting Discrimination In Sub-Saharan Africa, June 2002
[21] op.cit. No. 4.

[22] Brydon L, Chant S, Women in the Third World, Gender Issues in Rural and Urban Areas, Edward Edgar Publishing Ltd, Aldershoft, 1989, p194
[23] op.cit. No. 9.
[24] Vallaeys C, Awareness is not enough: Gender in the HIV/AIDS Epidemic in the HIV/AIDS Pandemic in Africa, Markkula Center for Applied Ethics, 2004, accessed online at http://www.scu.edu/ethics/publications/submitted/vallaeys/gender.html, November 2004.

[25] Van Dyk, Alta and Van Dyk, Peet, What is the point of knowing? Psychosocial barriers to HIV/AIDS Voluntary Counselling and Testing Programmes in South Africa. South African Journal of Psychology, 2003:33(2), p118, accessed online at http://www.heaids.org.za/information, July 2004.
[26] UNAIDS, Gender and HIV/AIDS, June 21, 2001, accessed online at http://www.aegis.com/news/unaids/2001/UN010624.html, July 21, 2004.
[27] Power Resources and Incentives in Households, February 20, 2003, accessed online at http://home.sandiego.edu/~baber/gender/Class_Notes_Feb_20.pdf, July 2004.
[28] Stromquist Nelly, Women in the Third World, An Encyclopaedia of Contemporary Issues, Garland Publishing Inc, New York, 1998, p3,4.
[29] The Royal Danish Embassy, Uganda-Poverty and Gender Assessment: Strengthening Linkages between Poverty and Gender Analysis in Uganda, Kampala, June 2004, p1.
[30] ibid, p6
[31] Kanas Liu, B, Global Women's Media Team, Micro-credit Scheme Helps Poor Women: Clinton Supports, accessed online at http://www.women.action.org/ungass/bpfa/micro.credit.html, December 2004.
[32] Keller Bonnie, Engendering Uganda's Poverty Eradication Initiatives: A Desk Review on Gender and Poverty, Kampala, 2002, p52,53.
[33] Blanc A.K, The Effect of Power in Sexual Relationships on Sexual and Reproductive Health: An Examination of the Evidence, Studies in Family Planning 2001: 32(3): p190.
34 op cit No. 20
35 Op.cit No. 19
36. Op.cit No. 26
37 Op.cit No. 29
38 Op.cit No. 24
39 Op.cit No. 22



BIBLIOGRAPHY

Adirieje U, 13th ICASA: We want more access to care but what? 28 July, 2004. http://archiveshealthdev.net/af-aids/msg01061.html, Sept. 2004.

AIDS in Developing Countries, Essays and Enotes, 2000 - 2004, http://www.enotes.com/aids-developing/, December 2004.

Bawah A. Spousal Communication and Family Planning Behavior in Navrongo: A longitudinal Assessment. Studies in Family Planning 2002: 33 (2): 185-193.

Blanc A.K, The Effect of Power in Sexual Relationships on Sexual and Reproductive Health: An Examination of the Evidence, Studies in Family Planning 2001: 32(3): p189 - 213.

Dilley J.W, Pies C, Helquist M, Face to Face: A Guide to AIDS Counseling. Aids Health Project Book Excerpts, 1993, http://www.ucsf-ahp.org/HTML/fac2fac1.htm, 15 Oct. 2004.

Eckman A, Huntly B, Bhuyan A. How to integrate Gender into HIV/AIDS Programs: Using Lessons Learned from USAID and Partner Organisations. Interagency Gender Working Group, May 2004. http://www.prb.org/pd04/HowToIntegrGendrHIV.pdf, 12 August 2004.

Foreman M, AIDS and Men: Taking Ri aking Responsibility? London, PANOS/Zed Books Ltd, 1999.

Foreman M, PANOS Dossier: Triple Jeopardy, Women and AIDS, London, Panos Publications Ltd, 1990.

Gulick, R. Assessing the Benefits of Antiretroviral Therapy. Annals of Internal Medicine, 2000:133 (6): 471-473.

Gupta G.R, Whelan D, Allendorf K, Integrating Gender into HIV/AIDS Programmes, International Center for Research on Women, 2003, http://www.unaids.org/publications/documents, Oct. 2004.

Hamblin J, Reid E, HIV and Development Programme, Women, the HIV Epidemic and Human Rights: A tragic Imperative, Issues Paper 8, UNDP, New York,1995, p2.

Jejeebhoy, S. Convergence and Divergence in Spouses' Perspectives on Women's Autonomy in Rural India. Studies in Family Planning 2002: 33 (4): 299-308.

Kanas Liu, B, Micro-credit Scheme Helps Poor Women: Clinton Supports, Global Women's Media Team, 2000, http://www.women.action.org/ungass/bpfa/micro.credit.html, 16, Dec. 2004.

Keller Bonnie, Engendering Uganda's Poverty Eradication Initiatives: A Desk Review on Gender and Poverty, In Pillar 4: Actions which Directly Improve the Quality of Life of the Poor, Kampala, 2002, p52 - 56.

Kuyoh M, Best K, HIV-positive Women Have Different Needs, FHI's Quarterly Health Bulletin Network, 2001: 20 (4), http://www.reproline.jhu.edu/english/6read/6issues/6network/v20-4/nt2042.html, 26 Oct. 2004.

Martinez J, Novel Targets: The need for novel targets and approaches to HIV therapy, Research Initiative Treatment Action, 8(1), 2002, p 1 of 4, http://www.centerforaids.org/rita/0702/novel.htm, October 23, 2004.

Ministry of Health, Antiretroviral Treatment Policy for Uganda, Kampala, June 2003, p 4-13.

Ministry of Health, Sexually Transmitted Diseases/AIDS Control Programme, Performance Evaluation Report for the HIV Antiretroviral Drug Access in the Private Sector in Uganda, Kampala, 2000, p1.

Ministry of Health, STD/AIDS Control Programme, HIV/AIDS Surveillance Report, Kampala, June 2003, p 1-16.

Mukherjee, J. S. Farmer P.E. Niyizonki[illegible] McCorkle L. Vanderwarker C. Teixeira P. Kim J.Y. Tackling HIV in re[illegible] poor countries, British Medical Journal 2003: 327:1059-1116.

Painter T, Kassamba L, Matia D, Lin L, Sibailly T, Kouassi M, Ekpini E, Roels T, Wiktor S. Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study. British Medical 2004: 329.

Power Resources and Incentives in Households, February 20, 2003, http://home.sandiego.edu/~baber/gender/Class_Notes_Feb_20.pdf, July 2004.

Steven Forsythe, The Affordability of Antiretroviral Therapy in Developing Countries: What Policymakers Need to Know, 2004, p 3 of 14, accessed online at http://www.worldbank.org/aids-econ/arv/background/aidconc.htm, October 12, 2004.

Stromquist Nelly, Women in the Third World, An Encyclopaedia of Contemporary Issues, New York, Garland Publishing Inc, 1998.
The AIDS Support Organisation, TASO Newsletter, Kampala: Graphics Systems: 2004: 12(1).

The Royal Danish Embassy, Uganda-Poverty and Gender Assessment: Strengthening Linkages between Poverty and Gender Analysis in Uganda, June 2004, p1.

The World Bank, A World Bank Policy and Research Report, Engendering Development through Gender Equality and Rights Resources and Vice, New York, Oxford University Press, 2001, p 31-72.

The World Bank. HIV/AIDS and Gender Equality, Gender and Development Briefing Notes, July 2003. http://www.worldbank.org/gender.html, 12 March 2004.

Thornton C.A, Romanelli F, Collins J. D, Reproduction Decision Making for Couples Affected by HIV: A Review of the Literature, Review May/June 2004: 12(2).

UNAIDS, Gender and HIV/AIDS, June 21, 2001, http://www.aegis.com/news/unaids/2001/UN010624.html, July 21, 2004.

UNAIDS, Report on the Global HIV/AIDS Epidemic, 2004, http://www.journ-aids/HIV-AIDS%20stats1.htm, October 2004.

UNAIDS, The Impact of Voluntary Counselling and Testing- A Global review of the benefits and challenges, 2001, http://www.unaids.org, 2004.

UNAIDS/WHO, AIDS Epidemic Update, December 2003, http://unaids.org/UNAIDS/EN/Resources?Publication/Corporate+publications/AIDS+epidemc+update, December 2003.

UNAIDS/WHO, Report on the Global HIV/AIDS Epidemic, 2002, http://www.journ-aids.org/HIV-AIDS%20stats1.htm, March 2004.

UNAIDS/WHO. AIDS Epidemic Update. Geneva. 2001
Vallaeys C, Awareness is not enough: Gender in the HIV/AIDS Epidemic in the HIV/AIDS Pandemic in Africa, Markkula Center for Applied Ethics, 2004, http://www.scu.edu/ethics/publications/submitted/vallaeys/gender.html.

Van Dyk, Alta and Van Dyk, Peet, What is the point of knowing? Psychosocial barriers to HIV/AIDS Voluntary Counselling and Testing Programmes in South Africa, South African Journal of Psychology, 2003:33(2), p118, July 2004.

Were B, Positive Living: the situation of women living with HIV/AIDS in Uganda, Expert Group Meeting on The HIV/AIDS Pandemic and its Gender Implications, 2000, http://www.un.org/womenwatch/daw/csw/hivaids/Were.htm, 26 Aug. 2004.

WHO, Gender and HIV/AIDS, 2003, http://www.who.int/entity/gender/documents/en/Gender_factsheet.pdf.

William O'Brian, Resistance to Antiretroviral Drugs, Bulletin of Experimental Treatment for AIDS, January 1998, p1 of 12, http://www.sfaf.org/treatment/beta/b35/b35/resist.html, October 29, 2004.

APPENDIX 1: FOCUS GROUP GUIDE

A) INTRODUCTION

My name is Barbara Kagoro Bitangaro from the University of the Western Cape in Cape Town, South Africa. I am pursuing a Masters in Public Health. We are here today to discuss issues regarding ARVs. This research will contribute to improving strategies for bettering the lives of people living with HIV/AIDS (PLWHA). Please feel free to discuss your views and opinions, as there are no right and wrong answers. Remember all your views are contributory to this discussion. All information here will be confidential and to implement this, we will use numbers instead of names. Allow me to record all the responses to enable me remember everything after the discussion.

B) WARM UP

● Please tell me about yourself- (age, residence, HIV discovery, starting of ARVs).

C) PROBING ACCESS, DECISION MAKING

● You are all taking ARVs. How did you know that you needed ARVs?

● Who initiated the idea of starting ARVs?

● What are some of the factors that motivate men/women to start taking ARVs?

● What are gender-related factors that motivate men/women to start taking ARVs? (elaborate)

● Who do men/women) usually discuss their decisions to access ARVs with? Was this the case in your instance? Why do they feel the need to discuss it with that person(s)?

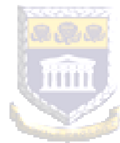
● Did any of you discuss ARV access with your partners? If yes/no, why?

● Do men/women discuss starting ARV with their partners? If so, why? What usually is their partner's response if they do? For those who don't, why don't they?

● Do men/women confide in anyone else in the family?

● If men/women want to do something like going to hospital, do they always consult someone or do they make decisions independently?

- Is your partner accessing ARVs? Do partners consult or inform their female partners about decision-making for ARVs? For those who were consulted, what was the response? Do men/women agree who should access first?
- Do men/women have any fears in starting ARV therapy?
- What obstacles do men/women face when accessing ARVs especially with partner/family? (time, distance, household chores, financial aid etc)
- How can men/women be helped to decide with their partners to access ARVs?



APPENDIX 2: ETHICS STATEMENT

PURPOSE

The study will examine the role of gender in making decisions to access antiretrovirals and the processes involved in decision-making for their access. Key persons influencing decision-making will be determined. Six focus group discussions (FGDs) involving both genders will be conducted. Participants will include those who have a regular sexual partner (a relationship that has lasted more than 12 months) and are accessing ARVs.
This research will lead to the award of a Master of Public Health.

PROCESS

Ethical research

I will abide by the set standards of ethical research, which revolve around informed consent and confidentiality.

Ethical research must be tailored to the specific needs of the communities under study and must be fully responsive to th mic, medical, and social contexts of those communities.[33]

Demands for the reform of the ethical review process during the 1980s are now starting to influence ethical review to include not only protecting research subjects from research risks, but also to ensure that the potential benefits of research should also be considered in deciding on the ethics of a proposal.[33]

I will strive to advance ethical standards by adhering to local regulatory standards concerning the ethical conduct of research. In case of any traumatic effect on the client, The AIDS Support Organisation (TASO) is close to where FGDs will be conducted. I will document the steps taken to ensure that none of my clients is unfairly burdened during the study. Discussions with people living with HIV/AIDS (PLWHAs) will be sensitive i.e. keeping appointments.

Confidentiality

When conducting this research, the highest standards of confidentiality will be observed. Only the researcher will keep the list of clients accessing ARVs given by TASO and will destroy it after analysing the data. Numbers instead of names of participants will be used for study. The research assistant will be sworn to confidentiality regarding any information he may come across in the course of his duties.

Informed consent

Informed consent will be obtained from clients after explaining to them the purpose and process of the research. The dignity of all participants will be paramount.

Benefits

This material will contribute to literature on HIV and how gender influences access to ARVs, which is a relatively new area of study. This research will include a meaningful process for client participation since it will come up with ways in which access to ARVs can be improved for partners/families. Service providers can use this information to improve their services in terms of access to care. Results of the research will be shared among participants, other PLWHAs, TASO staff, and other health care providers. It will also form a basis for further research into how families cope with the burden of HIV/AIDS and the role of gender.

This study will help change areas of perceptions regarding HIV care by health providers and come up with useful interventions.

The issue of policy will come up as a result of my study because the research will provide information that can be used for HIV/AIDS home care programmes and for policy makers to look at the role of gender in influencing health-seeking behaviours.

References

All documents used for reference will be cited.