

**QUALITY OF CARE OFFERED TO HIV POSITIVE PREGNANT WOMEN  
DURING ROUTINE OPT OUT HIV TESTING AND COUNSELLING IN  
DEDZA, MALAWI.**

**MSc (Midwifery) Thesis**

**ELLASY KHONJE MTUMBUKA**

**UNIVERSITY OF MALAWI**

**Kamuzu College Of Nursing**

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**By**

**Ellasy Khonje Mtumbuka**

BSc (Nursing)-KCN, University of Malawi.

A Thesis Submitted to the faculty of Nursing in Partial Fulfilment of The Requirements  
for the Masters Degree in Midwifery

**University of Malawi**

**Kamuzu College of Nursing**

**August, 201 2**

**DECLARATION**

I, Ellasy Khonje Mtumbuka, hereby declare that this thesis is my own original work which has not been submitted to any other institution for similar purposes. Where other people's work has been used acknowledgements have been made.

**Ellasy Khonje Mtumbuka**

.....

**Full Legal Name**

.....

**Signature**

.....

**Date**

**CERTIFICATE OF APPROVAL**

The undersigned certify that this thesis represents the student’s own work and effort and has been submitted with our approval.

Signature:..... Date.....

**Ursula Kafulafula, PhD** (Senior Lecturer)

**Main Supervisor**

Signature..... Date.....

**A. Maluwa, PhD** (Associate Professor)

**Co Supervisor**

## **DEDICATION**

I dedicate this work to my lovely daughter Esther who missed the motherly love and care that she was supposed to get if I were around.

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I am very grateful to Professor Kaye Bultemeier for the support and guidance during the process of the development of this thesis. Her constructive comments and suggestions which assisted me to come up with this document are greatly appreciated. She will always be remembered.

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## **ABSTRACT**

Following a joint policy statement by the WHO/UNAIDS in 2004 and also a policy statement in the National HIV/AIDS policy of 2003, HIV Counselling and Testing is offered routinely in antenatal clinics in Malawi, known as opt out HIV testing and counselling. The aim of this study was to describe the quality of the care offered to HIV positive pregnant women during routine HIV testing and counselling at the antenatal clinic.

The study utilized a descriptive exploratory design using qualitative phenomenological method and was guided by Donabedian quality conceptual framework. The study was conducted at the antenatal clinic of Dedza District hospital in the Central Region of Malawi. Twelve HIV positive antenatal women between the ages of 15-49 were purposively sampled and interviewed through in depth interviews using semi structured interview guide. In addition, a check list was also utilized to observe and examine the structure elements in HIV testing and counselling and health workers present at the time were also interviewed to verify the findings on structure attribute. Observation was also utilized to supplement the findings from the in depth interviews. Data was analyzed through thematic content analysis.

The findings revealed inadequate infrastructure, lack of some necessary resources and lack of adherence to guidelines as structural issues affecting the quality of HIV

testing and counselling. Women made the decision about HIV testing at home prior to visiting the antenatal clinic and were well aware of HIV and its related issues. Women were primarily motivated to get tested in order to know their status so they could protect their baby and get access to treatment and care. The findings also revealed that the right to opt out of the test was not mentioned by the providers before administering the test and there were some women who were not aware of that possibility. In addition the findings revealed some gaps in the counselling process, more especially during the pre test counselling. However the data revealed that the participants were satisfied with the care and the services provided, and emotional needs and well being of participants was well taken care of by the counselors. As a result, a majority of the participants had disclosed their status to someone especially the partner even though some of the partners had not yet gone for testing.

The results of this study indicate that there are still some gaps during HIV testing and counselling especially on the structure and process attributes. Therefore there is a need to ensure quality in HIV testing and counselling services if clients are to benefit from HIV services available. Supportive supervision is necessary to ensure adherence to the guidelines by the service providers so that women receive appropriate and adequate information before and after the test to make informed decisions. In addition there is need for continued community awareness campaigns to ensure that the women have the right information on HIV and PMTCT.

Availability of resources is necessary more especially test kits to ensure timely diagnosis of HIV. This is a critical issue considering the damage that the virus causes to

the immunity of the person who is infected who does not begin treatment, so that the woman can benefit from timely interventions. Finally there is a need to encourage couple counselling as this will ensure that more men are tested together with their partners and provide support in preventing mother to child transmission to their partners. This will in turn contribute towards the achievement of the goals of the prevention of mother to child transmission programs and hence assist in the reduction of the maternal and neonatal mortality rates.

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## **ABBREVIATIONS AND ACRONYMS**

AIDS	: Acquired Immune Deficiency Syndrome
ANC	: Antenatal Care
ART	: Antiretroviral Therapy
CD4	: Cluster of Differentiation 4
CDC	: Centre for Disease Control
CI	: Confidence Interval
COMREC	: College of Medicine research and Ethics Committee
CPT	: Cotrimoxazole Preventive Therapy/ Cotrimoxazole Prophylactic Therapy
DHO	: District Health Officer
GAIA	: Global AIDS Interfaith Alliance
HAART	: Highly Active Antiretroviral Therapy
HIV	: Human Immunodeficiency Virus
HSA	: Health Surveillance Assistant
HTC	: HIV Testing and counselling
KCN	: Kamuzu College Of Nursing
MDGs	: Millennium Development Goals

MDGs : Millennium Development Goals

MDHS : Malawi Demographic Health Survey

MTCT : Mother to Child Transmission

NAC : National Aids Commission

PMTCT : Prevention of Mother to Child Transmission

SDA : Seventh Day Adventist.

TCA : Thematic Content Analysis.

UN : United Nations

UNAIDS: United Nations Programme on HIV/AIDs

UNESCO: United Nations Educational Scientific and Cultural Organization

VCT : Voluntary Counselling and Testing

WCBA : Women of Child Bearing Age.

WHO : World Health Organization

## **DEFINITION OF TERMS**

### **Opt out testing**

This refers to HIV testing and counselling to persons attending healthcare facilities as a standard component of medical care.

### **Opt in testing**

It involves individuals actively seeking HIV testing and counselling to determine their HIV status.

### **Routine HIV testing**

HIV testing is offered routinely to all patients attending a particular healthcare service even though they are asymptomatic for HIV disease.

### **Pre-test counselling**

Counselling provided prior to taking an HIV test to ensure that clients are fully informed and emotionally prepared to deal with the testing procedures and the implications of either a positive or negative test result.

### **Post-test counselling**

Counselling that is done following the administration of a test, and involves providing the results. .

**Quality care**

Care provided to women guided by guidelines, in the presence of adequate resources, provided by well trained services providers within adequate infrastructure to ensure satisfaction with care and wellbeing.

**Antenatal care**

The care that is provided to women during pregnancy and it includes health education, counselling, screening and treatment to monitor and to promote the well being of the mother and the unborn child.

**Newly HIV Positive**

Those people who have been tested and are receiving the HIV positive test result for the first time.

**Informed consent**

A voluntary authorization by an individual regarding medical treatment, an intervention, or participation in a study when one is competent to act, receives thorough information, has an understanding of the risks and costs involved and has an unimpaired judgement.

**CD4 cell**

These are specialized cells that are part of the immune system and are measured to determine the strength of the patient's immune system.

## **CD4 Count**

Measure that is used to determine the strength of the immune system more especially in people infected with HIV usually reported as the number of cells in a Cubic millimeter of blood (Normal being between 500-1600).

## **CHAPTER 1**

### **Introduction and Background**

#### **Introduction**

In 2008 it was estimated that 33.4 million people were living with HIV and AIDs globally. Out of these about 15.7 million (approximately 50%) were women and 1.4 million of them became pregnant (UNAIDS, 2009). The greatest burden of the HIV and AIDS pandemic is in Sub-Saharan Africa .Sixty-seven percent of the people living with HIV are in Sub- Saharan Africa (UNAIDS, 2009) and the majority (61%) are women (Eyakudze, Jones, Starrs & Sorkin, 2008). Malawi is one of the ten countries with the highest HIV prevalence in the world estimated at 10.6 % among the adults aged 15-49 years (National Statistical Office, 2011). About 10 % of all new infections are via mother to child transmission (National AIDS Commission, 2009).

The joint United Nations Programme on HIV and AIDS (UNAIDS) in its global report stated that there were 920, 000 adults and children living with HIV in Malawi in 2009 (UNAIDS, 2010). Included in the 920, 000 are HIV-positive children under the age 15. Mother-to-child transmission (MTCT) accounts for approximately 25 percent of all new HIV infections (NSO, 2004). HIV prevalence in urban areas is twice that of rural areas. 17 percent of women and men aged 15-49 in urban areas are infected with HIV compared with 9 percent in rural areas (National Statistics Office, 2010).

Among the women who received ANC services, HIV prevalence is 10 percent for those using the public sector and 9 percent for those using services outside of the public sector (National Statistics Office, 2010). HIV testing and counselling is important in the prevention and treatment of HIV. It provides benefits through encouraging behavioral change and the provision of access to HIV services including prevention of mother to child transmission (PMTCT) (Collin, 2006). HIV testing and counselling also provides an entry point for provision of HIV services to pregnant women.

In Malawi, most facilities offering PMTCT services conduct routine HIV testing consistent with the recommendation of NAC and Malawi Government in the National HIV and AIDs policy of 2003. Subsequently, the WHO and UNAIDS issued a joint policy statement in 2004 which introduced routine opt out testing. This study describes the quality of care offered to the HIV positive pregnant women during routine HIV testing and counselling at Dedza District in Malawi. The study was guided by the quality of care framework by Donabedian. The study focused on the structure for the provision of HIV testing and counselling, their decision to get tested, education/information given, process of informed consent, counselling provided, referral and continuity of care, client satisfaction, and psychological well being.

### **Background Information**

Globally, without any intervention, between 15 and 45 percent of infants born to HIV infected mothers will acquire the virus. For Malawi in particular, according to the PMTCT Scale up Plan (2008-2013) with no PMTCT interventions, an estimated 30-45% (197, 815 to 296,722) of infants will be maternally exposed to HIV (Ministry of Health, 2008).

Global HIV transmission without any intervention during pregnancy is estimated at 5-10%. During labour and delivery, the transmission rate is 10-20% while during breastfeeding the rate is at 5-20% (UNAIDS, 2009). Interventions to reduce HIV transmission are considered a priority for Malawi to decrease mother to child transmission (MTCT). The transmission of HIV infection from mother to child can be reduced if antiretroviral drugs are administered to women perinatally. However, first it must be determined whether the pregnant woman is infected with HIV (CDC, 2008) and this is achieved through HIV testing.

As access to ART and PMTCT programmes become a reality in most of the African countries, where the HIV infection in women is disappointingly high, pregnant women need improved access to HIV testing and counselling if they are to benefit from these initiatives (Matovu & Makumbi, 2007). In addition, the early identification of HIV infection, through testing and counselling on a large scale, is increasingly understood as the critical gateway to providing individuals living with HIV with antiretroviral treatment (ART) and care (Matovu & Makumbi, 2007).

Efforts to expand HIV testing led to the introduction of the routine offering of HIV testing in antenatal clinics. This is called opt out approach or provider initiated approach to HIV testing (Salari & Azizi, 2009). Before 2003, antenatal HIV testing was on a voluntary basis called opt in testing. However coverage was very low, with the number of pregnant women tested remaining low and hence a small percentage of people were benefiting from the Highly Active Antiretroviral Therapy (HAART) (Collin, 2006) and prevention of mother to child transmission services. Hence the introduction of opt out testing. In opt out approach, testing is offered routinely to all patients attending an antenatal clinic. However, the clients have the right to refuse the

test (opt out) (Salari & Azizi, 2009). Emphasis therefore changed from client initiated to provider initiated testing (Collin, 2006). The direct aim of the policy of routine opt out testing was to promote wide spread coverage of testing and ideally to integrate HIV testing into routine antenatal care (Sherr et al., 2006). In Malawi all pregnant women on their first visit to the antenatal clinic are first provided with information about HIV and testing in group health education sessions before HIV testing is done. After the results are provided, individual post-test counselling is done. Those pregnant women who turn out to be positive for HIV are managed accordingly including the administration of drugs like Bactrim and ARVs. Clients are also referred for CD4 cell count or staging to determine their level of immunity.

The WHO/UNAIDS 2004 guidelines clearly state that opt out testing can only take place in a setting where mechanisms exist for adequate pre test counselling, counselling after testing, and referral for medical and psychosocial support (Collin, 2006). In addition, the guidelines recommend that with opt out testing the basic components of an informed consent namely confidentiality, consent, and counselling should be observed. However, a key component of the HIV testing, pretest counselling is now minimized in that the Provider Initiated Testing and Counselling (PITC) guidance pretest counselling has been replaced with simplified pre test information in a group (Grushkin, Ahmed & Ferguson, 2008).

It is believed that opt out approach in the antenatal clinic decreases the stigma associated with choosing to have a test as everyone is having it done (Collin, 2006). Other benefits include the identification of previously undiagnosed HIV infection (Homsy et al, 2006), provision of an opportunity for women to be tested without seeking permission from their male partners (Weiser et al. 2006), ensurance for early

referral to the HIV prevention, treatment and care services (Creek et al. 2007) and an increase in the HIV testing uptake among women since many pregnant women already attend antenatal care (Homsy et al. 2006; Weiser et al. 2006) ( as cited in Matovu & Makumbi, 2007).

A study done in Zimbabwe to assess the impact of routine HIV testing for the PMTCT of HIV discovered that out of the 4,551 women presenting for routine antenatal care, 4,547 (99.9%) were tested for HIV (Chandisarewa et al., 2007). Similarly, in Thyolo District of Malawi, in a prevention of mother-to-child HIV transmission (PMTCT) programme, a study was conducted to determine the acceptability/utilization rate of offering the opt out counselling and HIV-testing. Out of the 3,136 new antenatal mothers, 2,996 (96%), (95% confidence interval (CI): [95–97] were pre-test counselled. 2,965 (95%) CI: (94–96) underwent HIV-testing, all of whom were post-test counselled. Only thirty-one (1%) of the mothers refused HIV-testing (Manzi et al., 2005).

Malawi as a country has made tremendous progress over the last few years in scaling up HIV Testing and Counselling (HTC) and the Prevention of Mother to Child Transmission (PMTCT). By the end of 2008 a total of 88% of 544 health facilities were providing PMTCT services in Malawi. This led to an increase in the number of pregnant women accessing the HIV testing and counselling from only 320 in 2002 to 405, 694 mothers by December 2008 representing 87.8% of all first time prenatal visits (National AIDS Commission, 2009). However, it should be noted that the main aim of conducting an HIV test during pregnancy is to prevent HIV transmission from mother to child. This is achieved by providing the prevention of mother to child transmission services.

The Prevention of Mother to Child Transmission (PMTCT) programme in Malawi was initiated in 2001, and was piloted in Embangweni Mission Hospital, Chiradzulu and Thyolo district hospitals. Currently, PMTCT is provided routinely through the antenatal clinics (ANC), maternity and labour wards, as well as outreach programmes that incorporate antenatal care services (Ministry of Health, 2008). As new opportunities emerge to increase access to HIV treatment in the world, there is a renewed effort to prevent MTCT of the virus (Durojaye, 2008). It has been found that the maternal HIV transmission directly increases child morbidity and mortality (Durojaye, 2008). Increasing HIV testing rates allows more women to know their HIV status to prevent MTCT and also to focus on their health appropriately.

Usually, women's health care needs are ignored by privileging, the health and rights of the infant over the mother (HIV Law project, 2009). As approaches evolve, concerns about the possible adverse consequences of testing and counselling will continue to require careful balancing of the infant's rights against the woman's individual rights to benefit from knowing their HIV status (Nieburg, Cannell & Morrison, 2005).

The belief exists that autonomy in decision making should be considered when pregnant women are offered HIV testing. Specifically, all pregnant women should be offered HIV testing services with pre-test counselling information that enables truly informed consent (Canadian HIV/AIDs Legal network, 2007). Obtaining informed consent involves educating, disclosing advantages and disadvantages of testing for HIV, listening, answering questions, and seeking permission to proceed through each step of counselling and testing (Canadian HIV/AIDs Legal network, 2007).

It is well known that HIV testing is associated with serious psychological risks such as rejection, stigma, and discrimination if the result is positive. Hence, a need for

more time, and information for one to make a decision. As the United Nations Educational Scientific, and Cultural Organization (UNESCO) Chair in Bioethics (2003) states the purpose of an informed consent is to enable the patient to consider, weigh, and balance the benefits and disadvantages of the proposed medical treatment in order to undergo or refuse it. However, according to Collin (2006), a sense of needing to comply with the perceived authority of health staff in favour of testing, a lack of time to consider fully the information pertaining to this decision, and the strong normative message to “get tested” that universal routine testing implies may all contribute to undermining patient autonomy.

Currently, in spite of the global agreement on the necessity of increasing HIV testing, the quality of the service provided before and after testing is being debated (Salari & Azizi, 2009). Therefore, the provision of quality care to pregnant women tested through routine opt out testing in Malawi is crucial. This can be achieved in Malawi if the health care providers offer the test to the women as is stipulated in the guidelines, obtain their consent before testing, and respond to their fears and concerns. This will ensure patient trust which is a crucial element to the continuity of care and treatment of the woman and her baby and finally to the successful prevention of mother to child transmission (Nieburg et al., 2005).

Additionally, mechanisms should be put in place to provide an environment protective of the rights of those who are tested (Terantola, 2005). This will in turn lead to increased adherence to advice and improved PMTCT services in Malawi. Furthermore, this will improve maternal, newborn and child health and survival in the context of HIV to reach millennium development goal targets (WHO, 2009). Despite the need for the issues mentioned above, focus has been on increasing uptake of HIV testing and counselling to improve access to ART and PMTCT services while little

has been done on ensuring quality in HIV testing and counselling. In addition more studies have been done to assess the uptake of HIV testing and counselling since the introduction of routine HIV testing and counselling and not on quality of HIV testing and counselling. Not much is known regarding the quality of HIV testing and counselling of pregnant women in Malawi. However, ensuring quality HIV testing is a key issue to ensure that the pregnant women really benefit from knowing their status and the PMTCT services. It was therefore necessary to conduct this study as it generated new knowledge in as far as this phenomenon is concerned.

### **Problem Statement**

According to UNAIDS (2009), nearly 90 percent of the HIV positive pregnant mothers live in 22 countries of Sub-Saharan Africa and India. HIV epidemic has contributed to the high maternal and neonatal mortality rates. In 2009, 370,000 children became infected with HIV globally and an estimated 42 000-60 000 pregnant women died because of HIV (UNAIDS, 2009). Approximately 529, 000 maternal deaths occur each year in developing countries (Eyakudze et al., 2008). Malawi is one of the developing countries in sub-Saharan Africa with a high maternal mortality ratio (MMR) which is currently at 675 per 100 000 live births (NSO, 2011). Non pregnancy related infections such as HIV and pneumonia account for 23 % of the deaths (Kinney et al., 2010). In addition HIV-infected mothers' risk of dying is ten times higher than that of HIV negative mothers (Bradshaw et al., 2008). To ensure that more women are benefitting from HIV management and services available, routine HIV testing and counselling was introduced as stipulated in the Malawi National HIV and AIDs policy of 2003 and later in the joint policy statement by WHO and UNAIDS. Studies around the globe have demonstrated a high uptake following its

introduction. Despite the high uptake of HIV testing and counselling, PMTCT, ART and other related services, HIV still remains one of the major contributing factor to maternal deaths in Malawi. Consequently, the government of Malawi adopted the option B+ of PMTCT in which a pregnant woman is tested during antenatal care and HIV positive women are initiated on lifelong ART regardless of CD4 count. Though HIV testing and counselling is routine during ANC, women have the option to opt out.

During ANC, women may not plan to be tested on the day, they are starting ANC. As a result, they may need adequate information and time in order for them to make informed decisions, which would ensure the voluntary nature of taking the test rather than being coerced into accepting the test. According to Becker et al. (2009), given the substantial social status that health providers hold in many societies, there is a concern that patients are either intentionally or unintentionally coerced at the point of testing and cannot really opt out of Provider Initiated Testing and Counselling (PITC) as the guidelines stipulate. Furthermore, the hospitals may be overwhelmed with the increased uptake in terms of infrastructure and resources, leading to gaps in the provision of quality HIV testing and counselling services. HIV diagnosis is a traumatic event that can have a significant emotional impact on the affected people and their family as a result it raises many difficult ethical, legal and human rights questions (Eyakudze et al., 2008). Focus should not only be on increasing number of people being tested but also ensuring that they really benefit from the services available if they tested positive. This can be achieved if the care that is provided during HIV testing and counselling is of good quality as this is the entry point to HIV management and services. The quality of care offered to pregnant women during PITC at Dedza District hospital was not documented. Therefore there was a need to

describe the quality of care that was offered during routine HIV testing and counselling.

### **Significance of the Study**

Describing the quality of care offered to the antenatal women during the routine HIV testing and counselling can inform the practice, management and policy makers on the measures that can be undertaken to ensure that the care that is provided during the HIV testing and counselling is of good quality. Specifically, describing the quality of care can assist in identifying the gaps during testing and counselling in the opt out testing and assist the policy makers as they review the counselling guidelines and procedures to better meet the needs of the HIV positive women and their families. In addition, the findings of the study can inform the midwifery practice as it provides a foundation for designing effective midwifery interventions for informing and educating women on HIV testing and counselling.

Without this information, women will continue being affected by the HIV pandemic. Consequently the current prevention of mother to child transmission strategies for prevention may not be as effective as desired (Eyakudze et al., 2008). Reducing new infections through PMTCT and reducing the AIDS related deaths will have a direct impact across all the MDGs (Millennium Development Goals Summit, 2010). Specifically millennium development goals 4 and 5 on reducing child mortality and improving maternal health respectively.

### **Purpose of the Study**

Using a descriptive exploratory design, the study aimed at describing the quality of care provided to the HIV positive pregnant women during the routine opt

out HIV testing and counselling through the pregnant women's experiences and perspectives. Observation was also utilized to address the descriptive part of the study

### **Theoretical Framework**

This study was guided by the theoretical framework developed by Donabedian (1966). The conceptual framework outlines three elements of quality and these include structure, process, and outcome. Quality is defined as the degree to which health services for individuals and populations increase the likelihood of the desired health outcomes and are consistent with the current professional knowledge and can be developed into different dimensions according to the aspects of the care being assessed (Mainz, 2003). It is an optimal balance between possibilities realized and a framework of norms and values (Mitchell & Soule, 2008). That is it reflects the fact that quality is an abstraction and does not exist as a discrete entity. Rather it is constructed based on an interaction among relevant actors which agree about standards (the norms and values) and components (the possibilities) (Mitchell & Soule, 2008).

Donabedian postulated that the structural input and the process influence the outcome. That is, an appropriate structure and process will lead to favorable outcomes. The structures are thought to affect processes, which in turn lead to desirable or undesirable outcomes. A good structure promotes a good process and a good process in turn promotes a good outcome (Donabedian 1988a).

According to Donabedian, structure refers to the context or conditions under which care is provided, such as institution resources, organizational culture, provider credentials, and patient characteristics. On the other hand process refers to activities done for the patient, including both the technical and interpersonal aspects of care

(Donabedian 1980). This includes the interventions and activities done for the clients.

Finally outcomes refer to the consequences of the health care process including clinical parameters and patient perceptions of the experience, such as patient satisfaction. The model was adapted to guide the study.

### **Structure.**

In this study structure refers to resources (human and material) for example service providers/counsellors and their qualifications, supplies such as gloves, HIV test kits, cotton, drugs (ARVs, Bactrim) and condoms. It also includes characteristics of the unit that is the physical infrastructure and the guidelines/policy to guide care delivery.

### **Process.**

Process includes the decision to get tested, health education/information given, process of informed consent, post-test counselling. Process quality also examined diagnosis and the provision of health promotion information and referral system (for CD4 count and ART).

### **Outcome.**

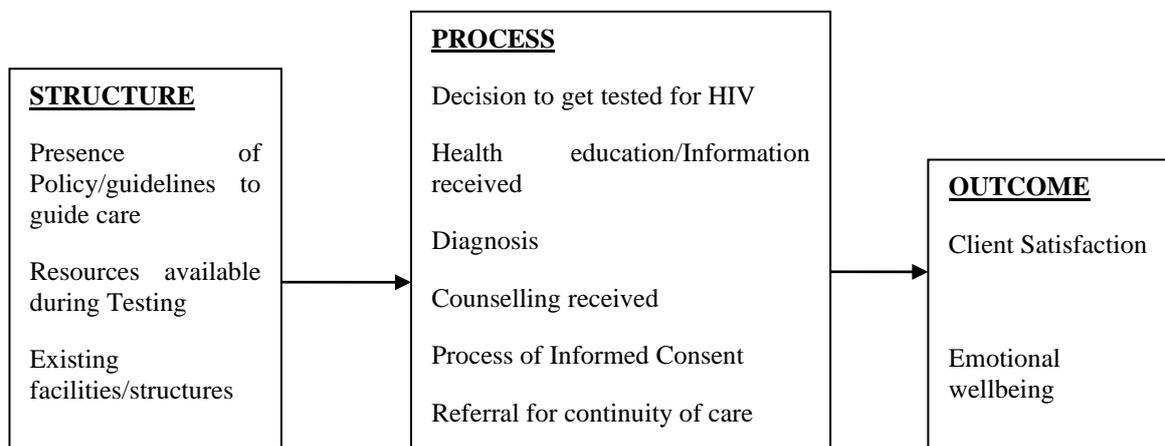
Outcome in this study was defined as women's perception of the process of HIV testing through opt out strategy. It included their emotional and psychological wellbeing after being diagnosed HIV positive.

In this study structural issues such as the presence of guidelines and adherence to them, presence or lack of necessary resources and the nature of the setting or building within which care is being provided are thought of having an impact on the

process of HIV testing and counselling leading to a good or bad outcome. Therefore the client's expression of satisfaction or dissatisfaction would reflect the goodness or the badness of the process (the care that has been provided) which is influenced by the structures. Any disparity in the structure such as availability of resources, presence and use of guidelines, the infrastructure for the provision of care, will have an impact on the quality of care that the women will have during HIV testing and counselling. This will then have a significant impact on their perception of the services in general. Consequently the women's expectation of care may not be what they experience practically due to inadequate resources, lack of adherence to guidelines or inadequate infrastructure. As a result the clients may be dissatisfied with the care and may not benefit more from the services provided.

For instance, lack of adherence to ART or Bactrim, failure to return for treatment or resupply of drugs when they finish may be due to the negative experiences encountered during care provision. For example, this may include a lack of or inadequate information or counselling, poor relationship with the service provider which may be influenced by a lack of adherence to guidelines, pressure of work, and consequently the client may be lost to follow up. As a result more children will acquire the virus from their mothers and the woman's health will be affected as well leading to more maternal and neonatal deaths. The UNAIDS (2009) states that the programmes to eliminate new HIV infections among children and keep them and their mothers healthy and alive are heavily dependent on the availability of key commodities such as antiretroviral drugs, rapid HIV test kits, CD4 counts, and viral load tests.

Therefore to ensure good quality HIV testing and counselling services for pregnant women, the service providers need to be well trained or qualified, have the necessary and adequate resources, adequate infrastructure, and the care should be guided by policy/guidelines. These have significant impact on how the care is provided, how clients are handled and the information that is provided. In turn this will in the long term contribute to the clients well being and continuity to care. As the women are passing through the process of HIV testing and counselling, they also experience the impact that structural issues have on the process leading to negative or positive experiences with care. Negative or positive experiences in turn will affect the way the clients respond to advice and treatment provided hence contributing to the overall goal of prevention of mother to child transmission programme. According to Ministry of Health (2006), the administration of antiretroviral prophylaxis, therapy, and quality care during the antenatal and intrapartum periods including counselling and support can significantly reduce the rates of MTCT of HIV.



*Figure 1:* A summary of the elements of Donabedian Framework as adapted by The Author.

## **Main Objective of the Study**

- To describe the quality of care offered to HIV positive pregnant women during routine HIV testing and counseling.

## **Specific Objectives:**

- To determine the availability of adequate infrastructure, resources (human and material) and, guidelines for the provision of HIV testing and counselling services in routine opt out testing and counselling.
- To explore the HIV testing and counselling process
- To determine women's perception of the testing and counselling process and their satisfaction of the care provided.
- To explore psychological response to positive HIV diagnosis and its possible impact to continuity of care.

## **Conclusion**

HIV/AIDs remain a significant health concern in the world even after more than 20 years since its discovery. HIV testing and counselling is an important service in the management of HIV/AIDs as it is the entry point for services to HIV positive individuals. Specifically opt out testing and counselling has increased the number of women benefiting from access to these services. It is therefore important to ensure that quality care is provided during counselling and testing if women are to benefit. This study described the quality of care offered to antenatal women counselled and tested through opt out HIV testing as guided by the Donabedian quality of care frame work.

## **CHAPTER 2**

### **Literature Review**

#### **Introduction**

This chapter provides a review of literature focusing on studies that investigated routine opt out HIV testing and counselling and related activities that are involved during the process. The literature review will be guided by the components of quality care conceptual framework by Donabedian which include structure, process, and outcome in as far as HIV testing and counselling is concerned.

#### **HIV and AIDS**

The HIV and AIDS pandemic has continued to devastate humanity worldwide (Durojaye, 2008). In recent years, global efforts to combat the HIV pandemic have increased dramatically. In the United Nations Millennium Declaration the world made an unprecedented commitment to halting and reversing the epidemic by 2015 (Jurgens, 2007). However, while some countries have made great strides, others are falling short (UN Millennium Development Goals Summit, 2010). In addition, HIV infection still carries the stigma and potential for discrimination such that people living with or affected by HIV and AIDs continue to require special protection when undergoing HIV testing (Canadian HIV/AIDS Legal Network, 2007).

It is estimated that approximately 33.0 million (30.3-36.1 million) people live with HIV worldwide (UNAIDS, 2009). Nearly 3 million people were newly infected with HIV in 2008, which represents a 17% decline in new cases over the past 8 years since 2001 when the United Declaration of Commitment on HIV and AIDS was signed. During this time period new HIV infections in East Asia declined by nearly 25% and in South and South East Asia by 10%. In Sub-Saharan Africa the number of new infections declined by 15 % during this time period, a decrease of nearly 400,000 infections by 2008 (USAID, 2009). According to the WHO (2010), an estimated 370,000 children (less than 15 years) worldwide were newly infected with HIV in 2009, the vast majority of them through MTCT. About 90% of these MTCT infections occurred in Africa.

In Malawi, though the prevalence rate has reduced, it is still high at 10.6 % of the population (National Statistics Office, 2011). According to National AIDS Commission Sentinel Surveillance (2005), the HIV prevalence rate among 15-24 year old pregnant women was 14.3% in 2004 versus 14 % in the general population (Cited in the Status of Reproductive Health within the Sector Wide Approach Context Malawi, 2008).

An overwhelming majority of more than 90 percent of HIV infections in infants and children are acquired directly from their mothers (UNAIDS, 2009) and this accounts for 10 % of all new HIV infections. Hence there is a need to reduce this transmission to assist in the reduction of the overall prevalence rate. This can only be achieved if more women are aware of their status through HIV testing and counselling.

According to Obermeyer and Osborn (2007), the provision of testing has been changing. Rapid test techniques have eliminated some of the obstacles such as the

need to return for results. Home testing is making it easier for individuals to accept testing. The routine offer of testing in prenatal care settings appears to elicit positive responses. Also the routine offering of testing in medical settings, through provider-initiated testing and counselling, has led to positive outcomes in terms of acceptance of testing and linkage to services.

### **Prevention of Mother to Child Transmission**

PMTCT is one way of preventing new HIV infections. The entry point to PMTCT services is HIV testing and counselling. Therefore, access to quality HIV testing is essential for an effective global response to HIV and AIDS ((Jurgens, 2007). Rapid expansion of effective HIV testing and counselling capacity is a pressing operational and policy priority in many programs and countries (Nieburg et al., 2005). Malawi has introduced routine HIV testing in antenatal clinics. Previously there had been a concern about the slow up take of voluntary counselling and testing, hence the introduction of routine HIV testing ( opt out strategy) to increase the uptake. Clients are informed that they will be tested as part of routine procedures unless they refuse (opt-out testing) (Obermeyer & Osborn, 2007). This varies from opt in testing whereby clients have to make the decision to go for testing themselves and they are merely informed that the services are available. This policy is necessary because the traditional model of voluntary client counselling and testing (VCT) did not result in adequate numbers of people tested to meet prevention goals. (De Cock, 2005).

It is encouraging to note that Routine HIV counselling and Testing seems to be acceptable to pregnant women. A cross sectional Survey of 388 women, who were attending the antenatal clinic for the first time with their current pregnancy at Mbale Regional referral hospital in Uganda from August to October 2009, was conducted.

The objective was to assess attitudes of antenatal attendees towards routine HIV counselling and testing. In addition they assessed their knowledge about mother to child transmission of HIV and infant feeding options for HIV-infected mothers.

Results showed that a majority of antenatal attendees (98.5%, 382/388) had positive attitudes towards routine HIV counselling and testing. More than 60% had correct information of how mother to child transmission of HIV could occur during pregnancy, labour and through breastfeeding and ways of preventing it (Byamugisha, Tumwine, Ndeezi, Karamagi & Tylleskar, 2010). Similarly, another study involving 484 pregnant mothers attending the antenatal care in Arba Minch Hospital and Arba Minch health centre, that was conducted from June 15-August 30, 2003. Four hundred and eighty four mothers were interviewed at the antenatal clinics. Results revealed that the risk of transmission of HIV, prenatally and through breastfeeding, is well known to most mothers. However, the use of ARV prophylaxis was not known to 386 (80%) of the mothers.

Studies have also shown increased utilization and coverage of the PMTCT services since the introduction of routine HIV testing and counselling. To assess the utilization of prevention of mother to child transmission (PMTCT) services, a study was conducted in five reproductive and child health clinics in Moshi, northern Tanzania after implementation of the routine counselling and testing.

The study was conducted in 2007 and 2008 in rural and urban areas of Moshi in Kilimanjaro region of Tanzania. Mixed methods were used and 446 mothers were interviewed when they brought their four week old infants to reproductive and child health clinics for immunization. In addition, 13 in depth interviews with mothers and nurses, four focus group discussions with mothers, and four observations of mothers receiving counselling were conducted. On average the urban clinics included in the

study had implemented the programme two years earlier than the rural clinics. Results showed that nearly all mothers (98%) were offered HIV testing, and accepted the testing (Falnes, Tylleskar, Depaoli, Manongi & Engebretsen, 2010).

Another study where one of the objectives was to report coverage of the PMTCT services was conducted in Kwa Zulu-Natal, South Africa. Interviews were conducted with mothers in postnatal wards and immunization clinics. Antenatal and child health records were reviewed. In addition, interviews were conducted with nurses and lay counselors in primary health care clinics. Results showed that 882 interviews were conducted with mothers of which 397 were in Post Natal Wards (PNWs) and 484 in immunization clinics. 97.3 % were tested for HIV. Out of 312 mothers reporting themselves HIV positive during ANC, 91.3% received Niverapine, 78.2% had a CD4 count carried out and 33.1% had a CD4 result recorded. In the immunization clinic, 47.6% HIV exposed babies had a PCR test and 47 % received Cotrimoxazole. Of the HIV positive mothers, 42.1% received follow-up care. However, despite a high coverage of the PMTCT interventions during pregnancy and delivery, follow up of mothers and infants was poor (Horwood, et al., 2010).

Generally the perception of the PMTCT services is good and women show satisfaction with the services offered. For example more women were satisfied with PMTCT services in a study which aimed at determining the perception, acceptance, and satisfaction with the HIV counselling and testing services offered in the PMTCT centres in Rivers State, Nigeria. The acceptance rate of HIV testing was high (89%), and the degree of satisfaction with the services provided was also high (98.6%). However three major barriers to accessing the services were identified including distance from home (31.7%), cost of transportation to clinics (20.1%), and long waiting time to receive results (16.5%). Overall 98.1% would recommend the services

to other pregnant women. Women were mostly satisfied with the pretest counselling for HIV and there was high acceptance of HIV testing among the pregnant women attending antenatal clinics in Rivers State (Mezie-Okoye & Tobin-West, 2010).

### **Uptake of HIV Testing and Counselling**

Recent studies have shown a relatively high uptake, in the range of 70-97%, of HIV testing when offered as part of the antenatal care services (Grushkin et al., 2008). A study examining how routine offering of HIV testing to all pregnant women affected the utilization revealed that HIV uptake with routine offering was high. There was a significant increase in HIV testing over time from 85% to 91% (Sherr et al., 2006). Similarly, a study that assessed the uptake of the HIV counselling and testing services before and after the introduction of Routine Counselling and Testing in Botswana revealed that the percentage of all HIV-infected women, delivering at Francistown regional hospital who knew their HIV sero-status, increased from 47% to 78%. Furthermore, the percentage of HIV-infected women participating in the prevention of mother-to-child transmission (PMTCT) of HIV interventions increased from 29% to 56% (Creek et al. 2007).

Other studies conducted in resource rich settings like USA, Canada, Singapore, the Netherlands, and UK (Collin, 2006), have also reported an increased uptake of HIV testing after the introduction of an opt out policy (Collin, 2006). An audit was conducted in an antenatal clinic in Melbourne, Australia with the objective to examine the uptake of HIV screening in pregnant women attending a tertiary hospital antenatal clinic. Results indicate that after the recommendation that all pregnant women be given the opportunity for HIV screening, a significant increase in the participation rate was noted. Over 80% of pregnant women agreed to have HIV testing

(Grover & Petterson, 2005). Similarly in Asia, studies have shown an increased uptake of HIV testing if it is provided through routine HIV testing. In India, a study examined acceptability among pregnant women and their husbands to HIV testing. Acceptance was high at 83% of eligible women attending the antenatal clinic (851 of 1,025) (Shankar et al., 2003).

Several factors have been identified as contributing to the high uptake of routine HIV testing. In Zimbabwe, the significantly high uptake of HIV screening (99.9%) was partially attributed to women being less fearful of participating in routine HIV testing. They reported that routine testing was perceived by their partners and families as the standard of care offered to all ANC clients. This reduced the risk of stigma and other adverse social consequences as compared to the opt-in VCT policy (Chandisarewa et al., 2007). Other factors identified to contribute to an increased uptake of routine testing include low health literacy, younger age, being single, and care provided by a female, a midwife, or a non-obstetric specialist in the antenatal setting (Collin, 2006). In Malawi, increased uptake has been attributed to three factors which include reduction of stigma of HIV testing when the test is offered routinely, well trained and sufficient staff for counselling, and adequate availability of services (Cotrimoxazole prophylaxis, Niverapine, and counselling) (Manzi, Zachariah & Teck, 2005).

Despite the improved uptake of testing worldwide approximately 3-30% of women still decline to be tested for HIV (Creek et al., 2007). According to studies, reasons given for refusal include fear of the test itself, fear of the consequences of a positive test result, knowledge that antiretroviral therapy (i.e. longer term treatment for the woman herself) is often not available, and the woman's need to consult their partner before testing (Grushkin et al., 2008). Also women who decline testing are

reported to have a perception of the test being low risk (Independent Online, 2006 cited by Mugore, Engelsmann, Ndoro, Dabis & Perez, 2008).

### **Stigma and Discrimination Related To Testing and Counselling**

Stigma and discrimination is still an issue even though HIV has been there for more than 20 years. The effect of stigma and discrimination on the people living with HIV (PLHIV) or those perceived to be positive has posed a challenge in HIV prevention efforts (National AIDS Commission, 2009) including use and acceptability of the HIV testing services and prevention of mother to child transmission services. In a cross sectional study of antenatal women attending antenatal clinics in Kenya (N=1525) associations of stigma measured with HIV testing refusal were examined using multivariate logistic regression. In the study, rates of anticipated HIV/AIDS stigma were high as 32 % anticipated a breakup of their relationship and 45 % anticipated losing their friends. Women who anticipated male partner stigma were more than twice as likely to refuse HIV testing (Turan et al., 2011). Similarly, in a study in Nigeria which was assessing pregnant women's knowledge of HIV and AIDS, awareness and attitudes towards voluntary counselling and testing. 13.0% disapproved of VCT. The main reasons for disapproval were fear of stigmatization, isolation and effect on marriage security (Iliyasu, Kabir, Galadana, Abubakar & Aliyu, 2005).

However, a study of the attitudes to people living with HIV and AIDS, which was carried out among antenatal clinic attendees at the University of Uyo Teaching Hospital was conducted. The aim was to develop site-specific information and counselling interventions to reduce stigmatization and discrimination of people living with HIV and AIDS in Nigeria. Awareness and knowledge of HIV and AIDS was

high, (95.8%) and (86.7%) respectively. Majority of the respondents (55.6%) were also assessed as having a positive attitude to people living with HIV and AIDS (PLWHA). There was a statistically significant association between good knowledge of HIV and AIDS and a positive attitude to PLWHA ( $P=0.000$ ) and a high educational status with a positive attitude to PLWHA ( $P=0.009$ ). (Bassey, Abasiubong, Ekanem, & Abasiatai, 2007).

### Quality of Care Framework

Donabedian developed the quality of care assessment framework based on the systems theory. The model has three elements which include structure, process, and outcome. Donabedian (1966) asserted that these three components of quality measures are not independent but are linked in an underlying framework. Good structure promotes good process and good process in turn promotes good outcome (Donabedian 1988a). He continued to refine these three concepts in subsequent writings of 1976, 1986b, 1987a, 1987b, 1988, 1989a, 1990b, 1992 and 1997 (cited in Berg-Corpas, 2009). For three decades, Donabedian (1966) theory has guided work used to evaluate health care quality (cited in Mitchel, Ferketch, Jennings & Bonnie, 1998).

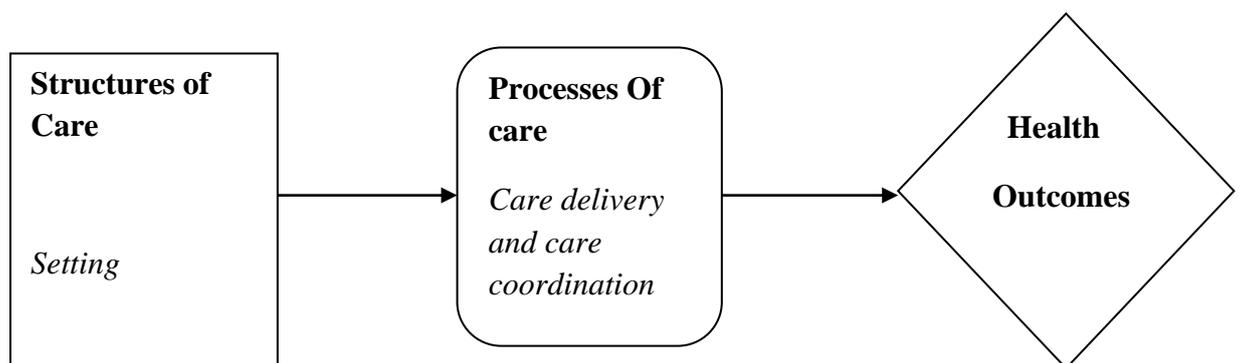


Figure 2: Donabedian quality framework adapted from McDonald et al. (2007)

### **Structure.**

According to Donabedian, Structure represents the organizational factors that define the health system under which care is provided. Structure is defined as the conditions or settings in which care is given (Donabedian, 1987, P.7). This includes amenities such as food, cleanliness, and privacy (1986a). Donabedian acknowledged that this may represent a weak relationship between the goodness of care and goodness of conditions. Therefore, according to Donabedian, the structure components also include the quality of care with respect to the professional and organizational resources associated with the provision of care. Additionally it includes a review of staff credentials, staff coordination, the organizational system and the facility's operating capacities and resources.

### **Process.**

Process as defined by Donabedian refers to what is done for the patient (1992, p357) or how the care itself is conducted (1989, p407). He divides the care process into two elements which include the technical and interpersonal components (1986a, 1987a, 1988, 1989, and 1997). Technical skill includes the practitioner's knowledge and the judgement he/she uses in arriving at strategies of care. Additionally the skill to implement the strategies is examined. Donabedian postulated that caring is an important component of quality (1989). Clinical interventions are also regarded as part of the process. However the interpersonal relationship is the main vehicle whereby success is achieved (Donabedian, 1966, 1988).

### **Outcome.**

Outcome is defined as the effect of care provided on the health status of patients. Donabedian (1980) referred to health outcome as change and as a result of antecedent health care. Patient characteristics are sometimes considered as mediating

outcomes. Donabedian defined outcome as the impact on health, wellbeing of the patient, and their overall satisfaction with the care (1989 p407). Outcome also includes the improvement in the patient's knowledge and changes in their behavior. Clinical outcome is incorporated into the health status (Donabedian, 1966, 1988). Outcome quality according to Donabedian refers to changes (desirable or undesirable) in individuals and populations that can be attributed to the health care provided.

### **Structure in Respect to HIV Testing and Counselling**

Presence and adherence to policies and guidelines by the service providers, availability of resources and infrastructure are key issues if good quality is to be achieved in the provision of HIV testing and counselling services. Related studies are reviewed under the subheadings policies, resources, and infrastructure.

#### **Policies.**

Guidelines and policies provide concise instructions on which diagnostic or screening tests to order, how to provide medical or surgical services, how long patients should stay in hospital, or other details of clinical practice (Woolf, Hutchison, Eccles, Grol & Grimshaw, 1999). In addition, their successful implementation improves the quality of care by decreasing inappropriate variation in delivery of the service, and by expediting the application of effective advances to everyday practice (Cabana et al., 1999). However, insufficient staffing also compromises the successful implementation of policies. This may have an adverse effect on successful service delivery (Brynard, 2005).

The expansion of Provider Initiated Testing and Counselling has a potential for massive impact on nursing roles and workloads. In Sub Saharan Africa, nurses are in the fore-front of HIV care and diagnosis. However, sadly, there has been little nursing

involvement in HIV policy development and surprisingly little research on nurse's experiences of conducting HIV testing (Evans & Ndiragu, 2008). However studies show adherence problems to the guidelines and policies. A study conducted in the United Kingdom examined adherence of obstetric units to implementation of antenatal HIV testing policies. A postal questionnaire was constructed to monitor policy and practice in all obstetric units in the UK and Eire. Results indicated that adherence to policy was generally a challenge (Sherr, Bergenstrom, Bell, McCann and Hudson, 2001). Only ten per cent of the units operated consistently with the universal screening policies, 37% selectively adhered, and the majority (54%) was adhering on request only. The universal offer of ante-natal testing was concentrated in London Units. Those utilizing selective policies rarely invoked all the CDC risk criteria as a basis for selection. Consent to test was verbal in 53%, written in 20% and unrecorded in the remainder. Auditing/evaluation of adherence to guidelines were infrequent (Sherr et al., 2001).

### **Resources.**

Adequate resources for the provision of health are a prerequisite for health care delivery (Anand & Barnighausen, 2004). Countries with poor economies and weak healthcare infrastructure are the ones that frequently have inadequate resources for health (Bangdiwala, Sharon, Okoye & Tollman, 2011). The lack of resources contributes to poor quality of care. In Botswana, the routine testing program for HIV added to the resource burden on health facilities and to the workload of already burdened nurses and other health workers. This contributed to limiting effective HIV-prevention counselling (Nieburg. 2005). The initial sharp expansion of HIV testing identified laboratory logistics and infrastructure as additional bottlenecks in the HIV/AIDS control program operation. They identified shortages of materials needed

for CD4 testing of the immune systems of the newly identified HIV-infected individuals, and rapid test kits were also reportedly in short supply.

On the contrary, a London based study whose objective was to assess the resource use, feasibility, uptake, and consumers' perspective of introducing routine HIV testing, reported that routine HIV testing was introduced into a hospital antenatal clinic with minimum resource implications (Dennison et al., 1998). In 2006, a survey of HIV/AIDs services in Malawi and the PMTCT Acceleration Action Plan, April – September 2007 identified several challenges related to the delivery of comprehensive services in Malawi. These included shortage of staff at all levels, inadequate monitoring and evaluation system, inadequate procurement and supply chain management system, inadequate resources to scale up the response, inadequate laboratory equipment, supplies and services, as well as inadequate facility and accommodation (Ministry of Health, 2008).

### **Infrastructure.**

Infrastructure is defined as the basic facility, service, and installation (set up) needed for the functioning of a community (Moteff & Parfomak, 2004). According to the Commonwealth of Australia (2009), adequate physical facilities and equipment are important catalysts for quality health care delivery. They conducted a review focusing on the role of housing, health-related essential infrastructure and, its relevance to the health status of Indigenous peoples in Australia. Findings indicate that, improvements made to the physical environment during the first half of the 20th century led to substantial gains in the health status of the general Australian population. That is substandard and badly maintained housing together with the lack of functioning infrastructure created serious health risks (Australian Indigenous

Health / InforNet, 2008). An article describing the first 2 years of the implementation of the national PMTCT programme in Ukraine, showed that interventions for prevention of MTCT have been implemented as a national programme within Ukraine's well developed infrastructure for maternal and child health ( Malyuta, Newell, Thorne, Ostergren & Zhika, 2005). Similarly, in Malawi, quality care may be impacted since the infrastructure has not changed even though new interventions have been added in the existing infrastructure.

### **Process in Respect to HIV Testing and Counselling**

The process of HIV testing and counselling during antenatal care is critical. Specific literature in the areas of education, counselling, informed Consent and referral in respect to HIV testing, and counselling is reviewed in this section.

#### **HIV testing information and education.**

The purpose of health education is to positively influence the health behavior of individuals and communities. Education improves the health status of individuals, families, communities, states, and the nation. It enhances the quality of life for all people (Tolleson, 2000). The goal is to prepare clients to make wise decisions on matters concerning personal, family, and community health (Tolleson, 2000). Education promotes understanding and an appreciation of a healthful lifestyle that promotes lifelong wellness in as far as health is concerned.

Studies conducted throughout Africa demonstrate that the education provided during group health education in routine HIV testing is adequate for one to make a decision. A descriptive cross sectional survey was conducted in Zimbabwe assessing the understanding of routine HIV testing among women using antenatal care (ANC) services in a rural African district. Most respondents reported that the information

provided during the group education was sufficient to make a decision on whether or not they would have an HIV test (Mugore et al., 2008).

Group pretest counselling can contribute in addressing workload as it was found in a study in Malawi. In March 2007, a short study was conducted to measure the impact of group pretest counselling (GPTE) on the time spent in one on one counselling. 112 write out clients (53%) men, 47% HIV positive were counseled at Martin Preuss Centre. 81 write out clients (72%) went through GPTE and 31(28%) went through individual pretest counselling. Average time spent in one on one HTC was 31 minutes for those who had pretest counseling individually, and 26.5 minutes for those passing through GPTE. It was concluded that group pretest education can reduce one on one counselling time and increase the potential number of clients seen by a counselor per day and that group pretest counselling has the potential to increase efficiency of HTC services (Lighthouse Group, 2011).

### **Counselling.**

Studies have shown that the quality of the counselling process affects long term care utilization of services for those found to be HIV positive. The way counselling for HIV testing is organized and conducted may influence its effectiveness. According to Toivo (2005), the acceptance of HIV testing is influenced by the quality of the counselling received. However, evidence from a qualitative study in Northern Tanzania indicates that the main aim of counselling is often seen as persuading women to consent to being tested (De Paoli et al., 2002). The conclusion that counselling is often provided in a coercive manner is also supported by findings of a randomized controlled trial ((Minnie, Van der Walt & Klopper, 2009). Studies in Africa reveal that women attending antenatal care do not receive proper information nor are they adequately informed before they are tested for HIV (Durojaye, 2008).

This study found that routine HIV testing denies women the opportunity of pre test counselling which is a very important aspect of HIV/AIDS prevention programme. For consent to be deemed to have been given for a treatment, it must be provided with adequate and understandable information.

A study analyzing factors affecting uptake of HIV counselling, HIV testing, and returning for test results was conducted in a rural setting in Burkina Faso. Findings indicate that the quality of pre-test counselling was inadequate as 42% did not understand the process (Sarker, Sanu, Snow, Gename & Gondos, 2007). In Canada, women did not recall having been offered an HIV test or thought that it may have been presented as part of a long list of tests (Canadian HIV/AIDS Legal Network, 2007). A study done in Mombasa, Kenya, appraising the quality and quantity of HIV testing in routine testing, 14 group educational sessions, 66 pre-test counselling sessions and 50 post-test counselling sessions were observed and assessed. In general, the frequency and duration of the counselling was low and crucial topics such as window period and partner involvement and follow-up support were covered haphazardly (Delva, Mutunga, Quaghebeur & Temmerman, 2006). Generally speaking, a haphazard method of giving information and obtaining consent in antenatal HIV provision is probably counterproductive in terms of test uptake and the ultimate goal of minimizing maternal foetal HIV transmission (Sherr, Bergenstrom & Hudson, 2001). Therefore the women were not prepared psychologically to undergo HIV testing let alone to receive a positive result since pre test counselling was not properly conducted.

In addition, it should be noted that providing insufficient information minimizes the opportunities for ensuring informed consent and potentially makes receiving a positive test result more difficult to deal with (Grushkin, 2008). Thus in

order to make an informed decision to be tested, literature supports that a pregnant woman needs information and that the information should include why the HIV test is being offered, where and how it will be done, the implications of going through such a test and how one will be managed in case of negative or positive results.

### **Informed consent.**

Fears have been expressed that with the change in emphasis to the provider initiated testing, the autonomy (and the individual human right) of the patient to freely decline or accept testing could be undermined (Collin, 2006). Two recent studies from the United Kingdom found incompatibility between ensuring informed oral consent and routine HIV testing in antenatal care. Although testing uptake appeared to increase when routinely offered gradual erosion in adherence to criteria to ensure informed consent was noted (Grushkin et al, 2008). Similarly, a quantitative cross sectional survey, undertaken in the antenatal booking clinics of a hospital in central London, reported that of the 32 women interviewed, only 10 were prepared for HIV testing at their booking interview. The study suggests that, although routine screening, combined with professional recommendation may be successful in increasing uptake, this may be at the cost of eroding the informed consent process ( De zulueta and Boulton, 2007).

Other studies have shown that women's subordinate status can interfere with their autonomy to refuse testing. A 2004 Center for Strategic and International Studies (CSIS) mission to India found that at one site, virtually all women agreed to be tested, but few stayed to receive their results. A similar pattern of patients not returning for test results has been observed in Botswana (Rennie & Behets, 2006). This illustrates how girls and women may feel intimidated or obliged to comply with the health care

provider's request to be tested, but also perceive too many risks in actually learning their status and in acting upon that knowledge (Rennie & Behets, 2006) .

A prevention of mother-to-child HIV transmission (PMTCT) programme in Thyolo, Malawi, to determine the acceptability of offering 'opt-out' voluntary counselling and HIV-testing (VCT) noted a progressive loss to follow up of HIV-positive mothers during the antenatal period, at delivery, and to the 6-month postnatal visit. The cumulative loss to follow up (n /4 646) was 358 (55%, CI: 51–59) by the 36-week antenatal visit, 440 (68%, CI: 64–71) by delivery, 450 (70%, CI: 66–73) by the first postnatal visit and 524 (81%, CI: 78–84) by the 6-month postnatal visit. This left just 122 (19%, CI: 16–22) of the initial cohort who remained in the programme (Manzi et al., 2005). This attrition significantly affected the quality of the PMTCT programme since continuity of care has been widely viewed as an indicator of the quality of care (Tait & Lester, 2007).

### **Referral.**

A study conducted in Ethiopia examined trends in PMTCT service utilization and assessed the rate of MTCT in relation to policy changes in the PMTCT programme. Results revealed that HIV positive women were 18 times ( $p < 0.0001$ ) more likely to be referred for treatment, care and support in 2009 than in 2004 before the policy changes (Mirkuzie & Hinderaker, 2010). This indicates that after change in policy to routine HIV testing and counselling, people were linked more to care than before. The importance of HIV Testing and counselling is to ensure effective linkages to care and treatment for those who test positive.

## **Outcome in HIV testing and counselling**

This section focuses on client outcomes as a result of undergoing HIV testing and counselling. Perception about the care provided and emotional wellbeing after undergoing HIV testing and counselling will be reviewed.

### **Client satisfaction.**

The primary outcome of screening for and treating HIV in pregnancy is a marked decrease in the rate of vertical transmission of HIV from mother to foetus. Secondary outcomes include confirmation of HIV infection in the woman, which allows optimization of her health and long-term management of the condition (Lindsay & Yudin, 2006). Studies conducted across the globe indicate mixed reactions to routine HIV testing and counselling. While some women revealed satisfaction, others demonstrated dissatisfaction with routine HIV testing.

A study was conducted in Zimbabwe to assess the impact of routine antenatal HIV testing for preventing mother to child transmission of HIV. Findings indicate that women were satisfied with counselling services and most (89%) stated that offering routine testing is helpful (Chandisarewa et al., 2007). Similarly, a study in Toronto found that eighty-six percent were completely satisfied with the testing experience and that informed consent for prenatal HIV testing is generally being obtained in a manner consistent with provincial guidelines (Guenther et al., 2007).

A cross sectional population based study was conducted in Botswana to assess knowledge of and attitudes toward routine HIV testing, months after the introduction of this policy. Most participants (81%) reported being extremely or very much in favour of routine testing. The majority believed that this policy would decrease barriers to testing (89%) and HIV related Stigma (55%), and would increase access to ARV treatment (93%). Only 43% of the participants believed that this policy could

increase gender based violence related to testing (Weiser et al., 2006). Similar results were found in a cross sectional qualitative study in Balaka, Malawi, which identified factors that were related to low PMTCT service uptake. Participants said that community knowledge of the woman's HIV positive status predisposes the woman to stigma and discrimination (Nyasulu, 2007).

A qualitative study conducted by Thomas M. Painter et al in Abidjan, Ivory Coast, involved interviewing 27 HIV positive pregnant women over a period of 8 months. Findings revealed negative experiences the pregnant women had while interacting with the programme staff. The negative interactions with staff affected their view about the programme and it was noted to be a significant barrier to returning to the clinic (Worku, 2007). This indicates that women may be dissatisfied with how HIV testing and counselling is conducted.

#### **Emotional well being.**

As already stated one important benefit of scaled-up testing is the opportunity to identify people with HIV at an early stage (Jurgens, 2007) so patients can benefit from HIV services. This can only be possible if emotional needs of the women are dealt with accordingly during pre and post test counselling. Pregnant women are often the first member in a family to be tested for HIV. Additionally, the women may not have time to psychologically prepare themselves for HIV testing and may not have a chance to talk to their partner before deciding to test for HIV (Reference Group, 2007). As a result, women who test positive may be exposed to consequences which may include the burden of disclosing to partner, being forced to leave home, and/or physical or emotional abuse, stigma and discrimination.

Fearing violence can prevent women from disclosing their status to their husbands and thereby limiting their access to HIV management services, treatment and care. However, in a study which was done in Lilongwe, Malawi, informants explained that the information they were given following their HIV positive result did not address the mental and emotional challenges related to living with HIV during pregnancy and after. The post test counselling information was largely limited to detailed explanations about condom use and about the importance of an adequate nutritious diet. The need for consolation, and discussion of the more intricate emotional challenges of being HIV positive and pregnant were missed in the counselling (Gombachika, 2004).

## **Conclusion**

HIV testing and counselling is the entry point for treatment and care for antenatal women. Without effective approaches to HIV testing and counselling women cannot benefit from the treatment and services. The literature review presented studies on routine HIV testing and counselling and it has been guided by Donabedian's quality framework. The literature review demonstrates that many studies have been conducted to assess uptake of HIV testing after the introduction of routine HIV testing and counselling. However there is limited data regarding patient perceptions of care offered during routine HIV testing and counselling. Generally speaking, studies show both satisfaction and dissatisfaction with routine HIV counselling and testing and identify factors which contribute to the dissatisfaction and satisfaction. Some studies have been conducted on pre-test counselling and the quality of informed consent. However, few studies have been conducted to assess the quality

of care offered to the pregnant women passing through routine HIV testing and counselling and the quality of the process of HIV testing and counselling in antenatal.

## **CHAPTER 3**

### **Methodology**

#### **Research Design**

The research design was descriptive exploratory using a qualitative phenomenological method. Qualitative descriptive study is the method of choice when straight descriptions of phenomena are desired (Sandelowski, 2000). The phenomenological method allow the participants to speak freely about their experiences and care hence ensuring that the information that is collected is practical and real and that it gives a clear understanding of the quality of care provided during routine HIV testing. For this study, descriptive phenomenology was used. One assumption of descriptive phenomenology is that for any human experience, there are distinct essential structures of a phenomenon regardless of the person who experiences it (Polit & Beck, 2006). Sample size in a phenomenological study may vary from 2 to 25, although there is no generally agreed upon consensus on the number of informants required (Klenke, 2008) as this is determined by data saturation.

#### **Study Setting**

The study was conducted in the antenatal clinic at Dedza District hospital in the Central Region of Malawi. The District has a population of approximately 671,137 of which 154,362 are women of child bearing age (NSO, 2011). The District shares boundaries with Lilongwe, Ntcheu, Salima, Mangochi and Mozambique.

The site was chosen because of its high prevalence rate of HIV which is currently at 11.3% (Dedza HMIS Data, 2009). The health facility offers antenatal services, prevention of mother to Child transmission services, and provides counselling and testing services through routine HIV testing and counselling as recommended by the National HIV/AIDs policy (2003). From January to December 2008 of the 5, 629 new antenatal clients, 6,342 (112%) antenatal women were pre-counseled and tested for HIV. This number reflects the inclusion of clients at subsequent visits that were not tested at their initial visit. All 6,342 (100%) women were tested. Out of the 6,342 women who were counseled and tested 6,339 (99%) women received post test counselling and 348 (5%) women were found to be HIV positive and 245 of these women were provided with Niverapine for prevention of mother to Child transmission (Dedza District HMIS, 2009).

### **Target Population and Sample**

The target population was married antenatal women between the ages of 15 to 49 who tested HIV positive during opt out testing and were attending antenatal care at Dedza District. Health workers taking care of clients at the time were also interviewed to verify findings since the descriptive part of the study was done through observations. The researcher targeted women between the age group of 15 to 49 because it captures the women of child bearing age in Malawi. These women, when pregnant, attend antenatal care. According to the Malawi demographic Health Survey (2010), 95 % of women age 15-49 received antenatal care (ANC) from a skilled attendant (NSO, 2011). Despite the decline in HIV prevalence, the National HIV Prevention Strategy (2009-2013) indicates that, there are nearly 90,000 new HIV infections each year with over 50 % occurring among young people aged 15-24

(NAC, 2009), who are within the age group of the women of child bearing age. In addition, married women were targeted because they are likely to have greater impact from a positive result versus women who are not married. According to the National HIV Prevention Strategy (2009-2013), young women aged 15-24 who are married or in stable sexual relationships have a much higher prevalence of HIV than those not involved in a stable union ( NAC, 2009). It further suggests that many new infections in Malawi are occurring in groups of people which previously were considered to be at low risk, i.e. those in stable sexual relationships.

### **Inclusion Criteria and Exclusion Criteria**

To be eligible, the women had to be pregnant, married, newly diagnosed HIV positive between 15 to 49, able to communicate in English or Chichewa and attending a subsequent antenatal visit after diagnosis. Women were excluded from the study if they passed through routine offer of HIV testing but tested HIV negative, were not newly HIV positive, were not able to communicate in Chichewa and English, were unmarried, and were below 15 years or above 49 years.

### **Sample Size**

Data saturation was attained after interviewing 12 participants. There was repetition of responses indicating that data collection was complete. According to Speziale and Carpenter (2007), saturation refers to the repetition of discovered information and confirmation of previously collected data. Therefore rather than sampling a specific number of individuals to gain significance based on statistical analysis, the qualitative study looks for repetition and confirmation of previously collected data. The decision to stop seeking new subjects is made when the researcher ceases learning new information (informal redundancy) (Burns & Grove, 2007).

## **Sampling Method**

Purposive sampling was utilized to identify participants meeting the criteria of study sampling among HIV positive antenatal women at the antenatal clinic. Once identified, it was determined if they met the inclusion criteria, and they were requested to participate in the study. According to Polit and Hunglar (1999), purposive sampling is a form of non probability sampling. The researcher has prior knowledge about possible participants and deliberately selects them because the subjects are seen as likely to produce the most valuable data. That is respondents are chosen because they have particular features or characteristics which will enable detailed exploration of the phenomenon under study (Office for National statistics, 2008). Purposive sampling groups participants according to preselected criteria relevant to a particular research question (Mack, Woodson, Macqueen, Greg & Nancy, 2005).

## **Data Collection**

### **Instrument.**

This study used a checklist to conduct observations on the structure attribute and a semi structured interview guide to conduct in depth interviews (Appendix E). According to Boyce and Neale (2006), in depth interviews provide much more detailed information than what is available through other data collection methods such as surveys. In addition they provide a more relaxed atmosphere in which to collect information. The interview guide provided a frame work for the interview and it allowed an open forum which allowed for focused conversational, and a two way communications.

The interview guide contained open ended questions which promoted discussion to expand from the interview guide. Semi structured interviews allow

informants the freedom to express their views in their own terms. The instrument composed of three parts namely Part A, Part B and Part C. Part A addressed demographic data, part B was more of a check list for observation to collect data consistent with the first objective which was assessing the structure attribute, while part C was the interview guide and data collected under part C was done through interviews and collected data on the process and outcome attributes.

Pretesting of the interview guide was performed and this was conducted at Bwaila and Dedza antenatal clinics. Three pilot interviews were conducted. This assisted the researcher to become familiar with and refine the questions and obtain feedback on two way communication skills. The interview guide was amended following the pretesting. The pretesting assisted the researcher to come up with more appropriate follow up questions and probes. In addition, those questions which were not clear were refined to ensure appropriate data was collected. Pilot studies are a crucial element of a good study and give advance warning about whether proposed methods or instruments are inappropriate or too complicated (Van Teijlingen & Huddley, 2001). The interview guide was also reviewed by experts in the field and their comments were incorporated.

#### **Data collection process.**

- Data collection was conducted during the months of August and September of 2011(Appendix D).
- The researcher arrived daily at the study setting at 8 a.m. during data collection.
- To gain more understanding of the process and the environment within which the women were being tested, the author took part in the provision of care

during data collection and made observations on health worker's activities during provision of care. Notes were taken accordingly. This allowed observation without affecting the normal behaviour of the health workers who might change behaviour if they knew they were being observed. However, the health workers providing care were sometimes interviewed to verify findings. As Sandelowski (2000) states, data collection techniques in a qualitative descriptive may also include observations of targeted events and also examination of documents.

- Potential Participants were identified by the clinic midwives or by the researcher herself.
- All potential participants were interviewed and those that met the inclusion criteria were identified.
- Interviews were done privately and participants were informed of the purpose of the study and asked to participate in the study. Study details were reviewed and consent obtained from women agreeing to participate in the study (Appendix B).
- The interviews were conducted in Chichewa and a digital recorder was used to ensure all data were captured. Consent was obtained to audiotape the interview before the initiation of the interview. All interviews were conducted by the researcher to ensure consistency of the data collection process.
- Data transcription and analysis was completed on the same day as data collection.
- Constant review of data was done to modify and expand the interview guide to discover in depth information.

- Field notes were recorded to gain an impression of the informant's surroundings, non verbal cues (emotions, facial expression) and other contextual factors. Field notes included an assessment of the structure for the provision of HIV testing and counselling services to meet objective number one and this included resources, infrastructure and policies. It also included information on observational data for the purpose of description of the settings, activities, people, and meanings of what was observed from the perspective of the participants.
- A check list was used to obtain data to meet objective number one (Appendix E, part B). This was confirmed by interviewing health workers and clients. The checklist included taking note of the availability of the guidelines, resources and availability of adequate infrastructure.
- Specifically, examination of the walls and tables was done to check for the presence of policies. To assess infrastructure, the number of rooms was counted and their use established. Additionally, a lack of or availability of resources was noted. All these were verified by asking the nurse midwife available or the nurse midwife in charge.
- From the interviews with clients, data related to structure was also noted.
- Objective number two which was looking at the process of HIV testing and counselling was determined through interviews. This collected data about the care that was received during HIV testing and counselling. The women were asked to explain how they got tested for HIV that is how they made the decision to get tested, the education given, the process of informed consent, the diagnosis, post test counselling and referral for continuity of care

- In addition, the author observed and compared care and information provided with the PMTCT guidelines from the National Prevention of Mother to Child Transmission of HIV (PMTCT) Training Package (2006).
- Finally, objectives number three and four which focussed on the outcome after passing through the process were obtained through interviews and these included client perception about the whole process and their emotional response. Interviews were combined with observations since observation can lead to deeper understanding than interviews alone, because it provides knowledge of the context in which events occur and may enable the researcher to see things that participants themselves are not aware of or that they are unwilling to discuss (Patton, 1990).

### **Trustworthiness**

Together, credibility, transferability, and confirmability comprise the concept of trustworthiness or authenticity of research which Guba (1981) explicitly linked to quantitative reliability and validity (Klenke, 2008). Therefore, trustworthiness of the results was assured through credibility, confirmability, dependability, and transferability.

#### **Credibility.**

Credibility includes activities that increase the probability that credible findings will be produced. (Speziale & Carpenter, 2007). This was established through prolonged engagement with the subject matter and the participants during data collection. This was also ensured through building of a good rapport to make them feel comfortable. At the end of the interview, the researcher provided a summary of the responses for the participants to confirm if they were true.

### **Dependability/Confirmability.**

Dependability is a criterion met once researchers have demonstrated the credibility of findings (Speziale & carpenter, 2007). This was done by leaving an audit trail with specific details of the research process and, a recording of activities over the length of the research period. This recording provided an audit trail consisting of raw data, analysis notes, reconstruction and synthesis products, process notes, personal notes and preliminary developmental information. The objective was to illustrate as clearly as possible the evidence and thought processes that led to the conclusions (Speziale & Carpenter, 2007).

### **Transferability.**

This refers to the probability that the study findings have meaning to others in similar situations (Speziale & Carpenter, 2007). Sufficient data has been provided in the report to ensure applicability of the study findings to other contexts. Furthermore, a detailed description of the participants has been provided to ensure transferability to a population of similar characteristics.

### **Data Management and Analysis**

Data analysis was done simultaneously with data collection. This allowed the refinement of the interview guide content as new information emerged. Data was analyzed manually through thematic content analysis (TCA). This is a descriptive presentation of qualitative data (Anderson, 2007). In other words, it is analysis based on the identification of themes, identified by means of a coding scheme.

### **Steps.**

- According to Colaizzi's method (Polit & Beck, 2010), data in audio tape was listened to and arranged according to the interviews
- Data was transcribed verbatim and translated from Chichewa to English.
- Data was then filled in notes and summarized according to the theme and the themes and subthemes have been presented as results.
- Specifically data was read several times and coded manually line by line and identified distinct units, grouping and regrouping similar and dissimilar units was done, and relabeling of categories. To ensure validation of the analysis this was done with the assistance of experts.
- Finally similar responses were grouped together into themes.

### **Ethical Consideration**

Approval was obtained from College of Medicine Research Ethics Committee (COMREC) (Appendix G). Consent was obtained from the District Health officer for Dedza to conduct a study at the district hospital (Appendix H). Participants were informed about the details of the study in order to obtain their consent. This included the purpose of the study, procedures involved, the risks or discomforts, and benefits of the study and, how data will be used. They were informed that their participation was voluntary and that they could withdraw consent anytime and that their refusal would not affect care. They were also informed that they would not be paid for participating in the study. Participants were allowed to ask questions. They signed a consent form to indicate their willingness to participate in the study (Appendix B). This ensured respect of the participant's autonomy regarding participation in the study.

Anonymity and confidentiality of participant's responses were maintained throughout the study through the use of identification numbers in place of names. The responses were stored in a lockable cabinet which was accessible to the researcher only. Data analysis expresses group information and there is no identification of individual responses. There were no known risks associated with the study. Clients may have been uncomfortable with some of the questions and topics about their personal situation. Participants were also at risk for stigma and discrimination once other women knew that they were participating in a study about HIV. To make participants feel comfortable the researcher ensured a good rapport with the participants. In addition interviews were conducted in a private room, with closed windows to ensure privacy and confidentiality. Additionally to avoid stigma and discrimination, participants were identified by midwives working with them or the researcher and the midwives were advised on privacy and confidentiality measures.

## **CHAPTER 4**

### **Presentation of Results**

#### **Introduction**

This chapter consists of a presentation of the findings of the study. The aim of the study was to explore the quality of care offered to HIV positive women during routine HIV testing and counselling in the antenatal clinic. The study was guided by the quality of care framework by Avedis Donabedian. The results are presented under several subheadings namely demographic data, structure for provision of HIV testing and counselling services, process of HIV testing and counselling and outcome after HIV testing and counselling. Quotes have been used to demonstrate emergent themes and subthemes.

#### **Demographic Data**

The study sample was comprised of married HIV positive antenatal mothers who tested positive through routine HIV testing and counselling at the antenatal clinic. Twelve antenatal mothers were interviewed. All the participants were coming for their subsequent antenatal visit after the visit where they were informed of their positive HIV status. The ages of the women ranged from 25 to 37, with the majority being those 35 years of age (33.3%) followed by the 29 year olds and 25 year olds both (16.3% each).

The majority of the women had reached primary and secondary education both at (41.6 % each) with a few having no education at all (16.7%) and none had reached above secondary education (Table 1).

Table 1-*Summary of the Demographic Data.*

DEMOGRAPHIC DATA (n=12).			
Characteristics	Category	Percentage (%) (n).	Total (%)
Respondents Age.	25	16.7 (2)	
	26	8.3 (1)	
	28	8.3 (1)	
	29	16.7 (2)	
	31	8.3 (1)	
	35	33.3 (4)	
	37	8.3 (1)	100
Level of Education	No Education	16.7 (2)	
	Primary 1-4	8.3 (1)	
	Primary 5-8	33.3 (4)	
	Secondary 1-2	33.3 (4)	
	Secondary 3-4	8.3 (1)	100.

### **Structure for Provision of HIV Testing and Counselling services**

Structural issues are presented under the following subheadings:

Policy/guidelines, infrastructure and resources.

#### **Policy.**

There were no policy/ guidelines pasted on the walls to guide health workers in delivering care during HIV testing and counselling. However midwives reported that they follow the guidelines in the PMTCT manual as a guide even though the

guidelines and the manual were not available in the clinic. It was discovered that there are new guidelines for managing HIV services in Malawi which have been developed and the providers were being trained. This was noted during data collection since midwives were being sent for training while the researcher was there. Among the new guidelines is a policy that all HIV positive women should be put on ARV therapy as soon as diagnosis is made regardless of CD4 count. However a copy of the new guidelines was not available in the clinic. Findings also revealed a lack of adherence to guidelines. For example on information provided before the test, some women explained that they were not given any information about HIV testing and counselling. They were tested without any education contrary to what the guidelines stipulate. The following is an example of what one participant said: “What happened was that when I reached here I was weighed. Then I was told to go inside to get tested.”(Participant 1). Another participant explained the following: “But we were not taught we just went into the testing room to be tested.....”(Participant 5). Another one had this to say: “Because at first .....after we had just been weighed we went for HIV testing.”(Participant 8).

### **Infrastructure.**

According to one of the midwives one room was specifically allocated for HIV testing and counselling. However, it was observed that this room was also used for dispensing drugs including ARVs and Bactrim and taking blood samples. The building had four rooms and a waiting area. Services that were offered within the building apart from HIV testing and counselling included antenatal care, family planning, cancer screening and postnatal checkups in addition to the PMTCT services. Other screening tests are performed with the HIV test. These include Hb and

syphilis testing. However findings revealed that privacy and confidentiality was followed during counselling and clients had no problems with the building and the environment where the testing and counselling was conducted. One participant stated the following: "...Ah I didn't find any problem with that place.....because I saw that during the time that I entered into the room when they found that I had that problem, where they were explaining nobody entered the room." (Participant 5). Another one said: "The place where you are testing blood. That place is alright, because even though the testing is done in a group but when they want to reveal the results everyone enters into a room alone with the counselor."(Participant 4). However the findings revealed that occasionally counselling was being conducted outside the buildings. Midwives and clients would sit somewhere where they thought people could not overhear what they were discussing. For example, one participant said "Because during the group counselling I learnt. They also took me behind this building where we had a chat. So they were explaining clearly to me" (Participant 1).

### **Resources.**

#### ***Material resources.***

Findings revealed that there was adequate availability of most of the necessary resources like drugs (Bactrim and ARVs). All the clients reported having been started on Bactrim immediately they were diagnosed HIV positive. They also reported having been taking either ARVs or short course combination therapy depending on their level of immunity. One participant stated this: "In her saying after she had told me how my blood was she gave me medications. She gave me Bactrim and she also gave me two other drugs that I should keep and should take them when labour starts."(Participant 4). Other supplies such as condoms were also available as most clients reported

having been provided with some. In this regard, one participant said: “She also told me that I should tell my husband so that he should also get tested. I was also given some condoms” (Participant 12).

However, findings revealed that during some days there were no test kits at the clinic: “I made the decision myself. Because that day there was no test kits and we were sent to VCT. So I could have chosen not to go or run away on the way.”(Participant 12). In addition, on the days of data collection, it was observed that there were few or no HIV test kits during most of the clinic days. Test kits were only available sporadically and as a result many women coming to start antenatal were returning home without being tested.

#### ***Human resources.***

The nurse midwife in charge explained that there were four nurses/midwives and one health surveillance assistant who had been trained in HIV testing and counselling mainly allocated to the clinic. The nurses/midwives were also providing other client services which included family planning, cancer screening, post natal check up and antenatal care in addition to HIV testing and counselling. On a daily basis, one midwife and one HSA was allocated to conduct the HIV and other screening tests as well as providing counselling. Those who were HIV positive were counseled by a midwife while those who are negative were counseled by the HSA.

#### **Process of HIV testing and counselling**

Results on the process of HIV testing and counselling are presented under a number of themes including decision to get tested, pretest information and education, consent to HIV testing, post test counselling and treatment and referral for care.

### **Decision to get tested for HIV.**

Subthemes under the theme of decision to get tested include prior decision before testing and motivating factors to accepting HIV testing.

#### ***Prior Decision before Testing.***

The researcher explored if participants had previously decided to get tested for HIV before they came for their antenatal visit or were surprised to have to make that decision when they arrived at the antenatal clinic. Findings revealed that the participants had decided prior to the visit to be tested when they started antenatal care. However, some did not plan on being tested. The participants revealed several reasons for planning to participate in the testing. They explained that they had been informed at home and in the community that everyone is tested for HIV when starting ANC. It emerged that they felt one cannot receive antenatal care without testing. Reasons that emerged for being tested included that they felt it was important to know their status and also because they were feeling sick. To this effect one participant said:

I was already aware that these days when you are starting antenatal care you are also tested for what. Ya you are also tested for HIV. So I was going there already aware that whether I want or not I will be what? I will be tested.

(Participant 7).

Another participant said: "I should say that I was ready because of how I was. I was often sick. So because of how I was feeling that there were a lot of things, I wanted to know my HIV status." (Participant 12). Those who did not plan on being tested at the clinic explained that they had to be tested because they were told to be tested. They stated that, they had to accept the test because of how things are these days. One

participant said: “Even at that time I myself forced myself to go there. Not that I wanted and believed in myself that I can go for testing but because it was a requirement to do so that is why I had to do it.” (Participant 7).

### ***Motivating factors to accepting HIV testing.***

Many explanations emerged from the participants as to the reasons they chose to be tested. The majority of the participants explained that they wanted to know their status and to protect the baby. Other reasons included sickness and wanting to know status, to get advice from the providers, to know how to protect self, having been told that they should be tested first before being examined, encouragement they received regarding if they will be found with HIV then that will not be the end of life. One participant stated: “Only that I wanted to know more about my life and how it is. Also because of what am expecting what its life will be like.”(Participant 1). Another participant explained: “It was because of the way I was feeling in my body and how sick I used to feel that time. So I told myself that I should go for the test.”(Participant 2). Another participant stated: “Because if you get tested then you know your status and how you are and you learn how you can protect yourself. (Participant 3).

### **Pre test information given.**

Subthemes under pretest information given include type of counselling provided and preferred counselling approach.

### ***Type of counselling provided.***

The women stated that they were educated about the test and given some information before the test and after the test. Most of them stated that they were taught in a group before the test and that counselling was done individually after the

test. One participant stated that she was counselled both in a group as well as individually together with her husband. This woman states about the education and information that she received before the test as follows:

The nurse said that it is good for one to be tested because when one is expectant, she is able to protect the unborn baby before it is born. Yes that even you, you can be given some advice on what to do at home, what to eat. (Participant 9).

Some participants explained that they were not told anything about HIV testing but were just told to enter into the room to get tested. On this one, one woman said: “Aah but we were just told that today everyone should be tested. Before they touch our abdomens (fundus) we should make sure that we are tested.”(Participant 5). In addition it was observed that group HIV counselling was not being done as is stipulated in the guidelines. The group health information was provided in the group health education talk where they talk about general information on antenatal care and other related issues and a lot of information as the guideline stipulates was not covered.

It emerged that some participants could not recall any specific information that they received before the test. However on further exploration, what they remembered was the post test counselling information. They could only recall information provided during the post test counselling after they had received their result. That is they could not clearly differentiate information provided during post test counselling from pre test counselling. Some women were able to remember some information given during post test counselling and very little from the pre test session.

Despite the differences mentioned above, the women felt that the information that was given to them before the test was sufficient for them to make a decision to get tested. To this effect, one participant said: “It was adequate. Even inside I also received some counselling. It was enough because I felt it was to benefit my life what was being said. So that if I follow that at home it will benefit me.”(Participant 9)

***Preferred counselling approach.***

The researcher explored with the participant’s preferences for group or individual teaching. Findings revealed that the participants did not mind being taught in a group during the pre test counselling. They explained that the information was clear in a group, people were contributing different ideas about what they learnt and they were given encouragement. Most participants explained that at least post test counselling was done individually. However, some participants noted that what the provider was saying during group education was clear but would prefer to be taught individually:

Yah only that the way the nurse explained the information to us was clear. However after delivering and I have this gift in my hands, I would prefer to have individual counselling on how to take care of this friend. Because during the group counselling I learnt. (Participant 1).

Some felt that both options are okay explaining that they learned during both options:

It was like after she had explained in a group, then when I went for the test after hearing about the benefits of testing that is when the provider also explained to me what to do at home while alone. For me both options were

okay because in the group I learnt a lot. Also when the provider was teaching me while alone it was okay. (Participant 9).

However some felt it wasn't right to be taught in a group citing reasons like lack of depth of understanding: "I would have preferred to be taught alone so that I understand in details in order to follow instructions properly."(Participant 4). In addition, some wanted to avoid others taking advantage of the situation to bewitch them:

Some might just take that as an opportunity maybe things were not like that. May be you will not get sick that time. May be you still had time to live so some might just take that as an opportunity because they have heard that.  
(Participant10)

### **Consent to testing.**

Two sub-themes emerged under the theme of consent to testing and these included: getting tested and knowledge on possibility to opt out of test.

#### ***Getting tested.***

Findings revealed that the participants felt they made the decision to get tested for HIV voluntarily and that nobody forced them to. A participant said: "Nobody forced me but I made a decision voluntarily that I should get tested to see how my body was."P2. However, participants despite having explained that they made the decision to get tested voluntarily explained that they felt they did not have a choice because they had come for antenatal care. Otherwise they would not have elected to be tested. This is what one participant said:

I would say I consented to the test but also that I was forced because all this time we were there at home not coming but because of the pregnancy then I got tested. But I wasn't forced I made that decision voluntarily. (Participant 3).

The participants explained several reasons as to why they felt they made the decision voluntarily and that nobody had forced them to get tested. The reasons included to know the status, having had no worries and not thinking of running away, having prepared for the HIV test at home. In this connection one woman said:

No but I made that decision myself. Because when I was coming from home I came with the aim that am going to start antenatal care at Dedza so there I will also go for the HIV test because when you are doing antenatal at Maganga health centre we wait for people from Dedza district to come and test us. So I decided to just come and do antenatal here at Dedza. (Participant 8).

***Knowledge on possibility to opt out.***

Findings revealed that the participants were aware of the possibility to opt out of the HIV test. One participant had this to say:

I already knew that there is that possibility because if I were to choose not to get tested that was going to be my right and choosing to be tested also my right. So the doctor did not force me to get tested.(Participant 9).

It emerged that some of the participants were not aware of the possibility to opt out of the test. It was also observed that the opportunity to opt out of the test was not mentioned by the providers during health talks. However the participants said that they would still have chosen to get tested for a variety of reasons. Different reasons for testing were: to know one's status, being sick often and hence the need to know

status, to know how to protect the baby, and that some had already prepared from home to be tested that day.

They cited knowing their status as the main reason for choosing to get tested despite the option of opting out. One participant said: “I was going to be tested still to know how to protect my unborn baby.”(Participant 3).

### **Receiving the news.**

The participants explained different ways of how the provider explained the results and these included clearly explaining that the client had been found with HIV, results were just written in the health passport, called privately to be told the results, saw results herself. Some participants stated they were asked if they were ready for the results. It emerged that the participants were informed privately. In this regard, one participant said: “The one who was testing me, after she had tested me, she called me in a room where we were only the two of us and told me the results.”(Participant 4). It emerged that all the participants did not feel offended with the way the provider disclosed the results as one participant explained: “The counselor clearly explained to me that they had found me with HIV. She explained it well.” (Participant 1). Another one stated: “She took me aside and told me the results. She told me in a good manner and not in a disappointing manner.”(Participant 11).

### **Post test counselling given..**

The women retained some information provided during the post test counselling. It emerged that most commonly retained information related to PMTCT was nutrition, safe sex, disclosure, CD4 count, medications, importance of reporting to

the hospital early when sick, infant feeding, care of the baby, encouragement, spiritual support, importance of continuing with ANC, and how to take care of herself.

The most commonly mentioned topics were safe sex, disclosure, medications and CD4 count. One participant said:

She counselled me on how I was going to live, on the types of food that I should be eating. She also told me that I should tell my husband so that he should also get tested. I was also given some condoms. Then I was told to come back for CD4 count, which was very low. So I was told to come again for lessons so I can start ARVs. I didn't get tired I came for the lessons and now I take ARVs. (Participant 12).

Another participant explained:

In her saying after she had told me how my blood was, she gave me medications, she gave me Bactrim. She also gave me two other drugs that I should keep and should take them when labour starts. Then she asked me whether I was planning to breastfeed the baby when it is born or not. So I told her that I should breastfeed. So she told me to breastfeed for six months. And also that during the six months the child should not take any other foods apart from breast milk. (Participant 4).

### **Treatment and care provided.**

Findings revealed that the participants had been referred for CD4 count and ARV treatment. A few had not begun taking ARVs because their CD4 count was still high. Hence one participant said: "After they had tested me for HIV I was told to go to the lab where I was done the CD4 count. So I was told that my immunity was

adequate but I should be taking a balanced diet.”(Participant 4). Some participants had not undergone CD4 count and this was due to a lack of reagents. They were informed that it will be done after delivery. However almost all the women were aware and had been told on the availability of the service even though some failed to benefit from it. All the participants had started taking Cotrimoxazole for prophylaxis against opportunistic infections. For those who had not yet started taking ARVs they were also provided with the Prophylactic ARVs (short course combined regime) to protect the baby from contracting virus. In this regard, one participant said: “Yes I was given two different types of drugs. I should say three because there was Bactrim. There was another bunch to take when labour starts. Then there were some to start taking at seven months like last month.”(Participant 9). However some participants explained that they were not told the type of drugs that they were given and their use. What was mainly explained was how to take the drug and what to do if the drug finishes.

### **Outcome of HIV Testing and Counselling**

Outcome of HIV testing and counselling has been presented under two main themes and these include perception of care and emotional well being and support.

#### **Perception of Care.**

Four subthemes emerged under the theme of perception of care and these include satisfaction with the time provided, satisfaction with the counselling provided, satisfaction with the care provided and, satisfaction with the HIV testing and counselling services available.

### ***Satisfaction with the time provided.***

The participants explained that the time provided for one to make a decision about the test was adequate. However some explained that though the time is adequate one may want to go back and bring her husband so they can be tested together. In this regard, a participant said: “Aah, the time available is adequate. But maybe you may decide to come again so you can bring your husband. But for someone who wants to be assisted the time is enough.”(Participant 3). However it emerged that a few participants felt that the time provided was not adequate for one to make a decision and that there was a need for more time for one to decide. Hence one participant said: “No it is not enough. Because they just talk about it and immediately things happen. Had it been that the people were given time after the information so that they can decide.”(Participant 4). The participants explained that they felt the time provided was adequate because they were already aware that they do test when starting antenatal and so had already positioned themselves that they will be tested. One participant said:

Yes it was adequate. Ah it’s because when you are starting antenatal care you knew in advance. So to me there was nothing strange about that. When I was being told to do this and that I didn’t see anything strange. (Participant 7).

### ***Satisfaction with the counselling provided.***

It emerged that the participants were satisfied with the post test counselling that was provided. They revealed that the provider told them all the important information. Hence a participant said: “But no she told me almost anything. If there is something then I don’t know that there is something like that.”(Participant 5). However, despite being satisfied with the counselling, it emerged that some clients

wished the provider had emphasized more on other issues related to being HIV positive. Specifically they desired more information on how the baby can grow healthy, feeding the baby, how to live longer, if the virus had already started working, and infant diagnosis. One participant had this to say:

I wanted to ask her at that time when I had just been found with the virus. I wanted to know whether the virus had already started working in me or not. Yah in my body for me to know how my body is or that maybe that it had just entered. Yah that's what I wanted to know. (Participant 5).

Another one stated: "But I hear from people that when the baby is born he /she is tested. So I would like to know about that." (Participant 12).

#### ***Satisfaction with the care provided.***

All the participants were satisfied with the care and treatment that was provided. They reported that they were assisted adequately and accordingly. They explained that they felt the care was adequate because the providers were talking lovingly, asked clear questions, provided them with encouragement, and provided them with drugs. In addition they passed through all the stages, were not experiencing any problems after receiving the care, CD4 count was done, they started taking ARVs, and that they did not receive any harsh treatment. It emerged that the commonly mentioned reasons were going for CD4 count and starting ARVs, being provided with encouragement and being provided with drugs.

Aah the care that was given was really adequate. Because whatever they were saying I was able to understand. They were not shouting at me. But they were

telling me lovingly. They were asking me questions to which I was able to respond. In addition they encouraged me. (Participant 1).

Another participant explained:

Yes I was assisted because I was told to go for CD4 count in good time to see how things were. Because had it been that I was not told to go for CD4 count I could have been taking Bactrim up to now without starting taking ARVs. (Participant 8).

***Satisfaction with HIV testing and counselling services available.***

The researcher explored if the clients felt there was a need for change in the services of HIV testing and counselling. It emerged that participants were satisfied in general with the services that are offered, as one participant explained:

Ah as for me am just thankful that you are doing fine because on the problem that I was found with, the assistance that you gave me when you found that I had the problem that maybe there is a need for me to be taking such medications, and that there is a need for you to do this I feel it is working in my body. Yes there is no problem that I am experiencing now, but I don't know on the day of delivery. (Participant 5).

Despite the overall satisfaction with the services in general some participants felt that there was need for providers to be empathetic and caring when handling those who turn out to be HIV positive stating that this is a difficult time for the women who learn that they are HIV positive. In this connection, one participant said:

Only those during this time many who are coming do not imagine that they will be found HIV positive. So what is needed is encouragement. Also the providers should be caring because there are some nurses who may shout at patients. What you are asking and explaining or requesting from them they don't understand. (Participant 1).

Another one stated: "Because we don't know but with the way someone is when you are like this there is worry and concern so what is important is encouragement."(Participant 12). Despite having stated that they were satisfied with the care that was provided, some participants had specific wishes for care. This is mainly true for those who had not yet started taking ARVs as they specifically wanted to have access to CD4 counts and ARVs. One participant said: "I wish CD4 count was done so I can know how the immunity of my body is."(Participant 11). Another participant stated: "..... I wish I had started taking the real ARVs not only Bactrim."(Participant 4)

### **Emotional wellbeing and support.**

Subthemes which emerged under the theme of emotional well being and support included emotional reaction and support system.

#### ***Emotional Reaction.***

The participants stated that they were emotionally stable and had accepted their status. However the some of the participants reported that they were affected and worried when they first learned that they were HIV positive. They explained different reactions to positive results, from surprise, pain, worry, and anger/being mad at husband. Below are examples as to how the women responded to the positive result:

Ah as for me I think now the worries and concerns that I had are subsiding. But at that time I really was very worried because when I was found with that problem, I have my first born, I was very worried that my child has just written standard eight examinations. So I was worried that maybe my child will pass the exam so with this problem I don't know how things will be am I not going to die. So I was encouraged by the counselor that I will not die today. So from there I have seen that the worries are subsiding. Accepting that what will happen let it happen. She even said that you can educate your child and even continue to work normally. So that is when I decided that I should just accept and not worry anymore. I was really worried. I remember that day I had money but I didn't buy any food at the market thinking that really so this is how things have turned out to be. I didn't know because if I Knew I could have said my husband lets go for testing. When he came I just said my husband has come that's how we live. So I have removed all the worries and concerns because I was encouraged that as long as you are protecting yourself, and as long as you listen to advice from hospital people you can live longer.

(Participant 5)

Another one explained:

The concerns that I had at first when, after they had just told me that I was positive, I felt pain but then I was thinking that I was just sitting at home and now I am like this. So I went home before I explained anything to my husband I told him that your ways are bad. With the way things are you should continue doing that am going first. So he asked me you are going where. I just said am going you will find me. So he asked me what the problem was. Then I

explained to him. So I said that I will just take drugs to kill myself. So he said don't do that. So I said am lying but that you should change that type of behavior because you will be adding the virus. I just told him like that.”(Participant 8)

Another participant stated:

Yes at first I was really worried. The concern that I had was that this is my first marriage but am also a faithful woman. So I was worried as to how I got the virus. So I didn't find any answer. Yes now I have accepted and am okay.  
(Participant 10)

However it emerged from the data that some participants didn't have any problems when they first learnt that they were HIV positive. One participant said: “After I had received my results I didn't experience any problems because I came to know my status. And I am still alive up to now.” P2. The participants explained that they did not have any concerns and worries due to the encouragement that they got from the provider. One of them said:

There were no concerns because I was encouraged by the provider that it happens and you are not the first person. Being found like this is not the end of life. You will still be living your normal life as long as you take care of yourself. So I had no concerns. (Participant 3).

It emerged that all participants were now coping well with the HIV status. They reported doing income generating activities, being prayerful, and meeting other women in support groups. All of these emerged as evidence that they have now accepted the situation. Other worries and concerns did emerge from the data however they were not related to HIV specifically.

*Support system.*

The women had disclosed their status to at least one person specifically their husband. Other people apart from their husbands were predominantly their guardians. Others included their sister, aunt, mother, and sister in law, and other relatives. Commonly mentioned reasons as to why they chose to disclose to those people included being the ones who will take care of them during delivery, to be assisted accordingly when sick and for the husband to get tested as well. In this regard one participant said:

In case things get worse. Also that they should know in case you become sick. They may start thinking that I have been bewitched. People these days are not looking at each other well. They think ill of each other. So they should know so that when you are sick they should assist you accordingly. (Participant 3).

Another one explained:

I told my aunt because she is the one who is like a parent to me because both my mother and father passed away. So when I say I have parents now it is her. So I wanted her to know how I am. (Participant 4).

Some participants had their own reasons as to why they did not disclose to certain people mostly fearing stigma and discrimination. In this connection, one participant

said: “Eee mother is a difficult person. It would mean that whenever you disagree on something then she will use that to insult you as a result you might end up being disappointed and worried most of the times. (Participant 1). Some had not yet disclosed their status to anyone as one explained: “I didn’t tell anyone. Because you can’t know what the other person is thinking.”(Participant 11). One participant had not yet disclosed to her husband but had disclosed to a sister in law and this woman explained that she really wanted to let her husband know but was experiencing problems. This is what she said:

As for my husband I would like to let him know. So when I try to call his number I am not getting through to his number. He also gave me his phone number; he also sent money, after I had already been found with this problem. So for me to call to let him know about the problem that I have I can’t get through.”(Participant 5).

The participants who disclosed their status did not experience any problems with the people they chose to disclose their status to, as one participant revealed:

No there was no problem. The only problem that was there was that we were just wondering how this has happened because when we were getting married we went for HIV testing. So we were just living together. So it was a surprise. Any way it happen, let it be the way it has turned out to be. But we did not talk bad of each other. (Participant 3).

Another one stated: My husband after I had explained to him he didn’t complain he just came for testing. He was also found like that.” Another one explained:

My husband after I had told him he said alright. So I told him that you should also go for testing. He also said okay to this. So when I explained to him on the part of how we will be living he also understood”. As for my mother I told her in an encouraging manner because she was very worried. So I told her that since I have been found like this and so every time you hear that am sick, because we stay at different places, you shouldn’t be thinking that my daughter is dying. If someone has HIV it doesn’t mean that they don’t get sick. They can also suffer from other diseases that those people who do not have HIV suffer from. I told her like that so she was able to understand. (Participant 8).

Some husbands had not yet been tested after hearing their wives results. The data revealed that some of the reasons as to why the husband refused testing are that they assumed this meant they were also positive and that some were just being lazy. In this regard, one participant said: “But he accepted that he was going to come for testing. But because these young men he thinks he is okay he has not come up to now.”(Participant 12). However for those husbands who went for testing after hearing their wives results, some were HIV negative as one participant disclosed: “He came to know about it as well. He even came for testing. But he is okay he doesn’t have HIV but me.”(Participant 2). Some participants experienced a broken marriage because their husbands were HIV negative.

### **Conclusion.**

This chapter has reviewed the findings of the study from the women who passed through the process of routine HIV testing and counselling. The findings have been guided by the quality care framework by Donabedian. The results have been presented under several main sub headings including demographic data, the structure

for provision of HIV services, process of HIV testing and counseling, as well as outcome after HIV testing and counselling. The next chapter will discuss the implications of these results for future research and practice.

## **CHAPTER 5**

### **Discussion**

#### **Introduction**

This chapter provides a discussion of the findings of the study which described the quality of care offered to HIV positive antenatal mothers during routine HIV testing and counselling in the antenatal clinic at Dedza District hospital. The discussion is guided by the conceptual framework by Avedis Donabedian. The discussion focuses on the demographic data, structure for provision of HIV testing and counselling services, the process of HIV testing and counselling and the outcome after HIV testing and counselling. The strengths, limitations and recommendations will also be provided under this chapter.

#### **Demographic Data**

##### **Age of participants..**

The study sample consisted of 12 married HIV positive antenatal mothers. Their ages ranged from 25 to 37. The majority were 35 years of age followed by the 29 year olds. This information shows that HIV Prevalence was high among the older age group. The finding is consistent with the recent findings of the Malawi Demographic health Survey which found that HIV prevalence increases with age for both men and women and that for women the HIV prevalence is highest among the ages 35-39 (24 percent) which is six times the rate among the women aged 15-19 (4 percent) (National Statistical Office, 2010).

The majority of the clients were also within the high risk group of child bearing age as they were above 35 years old. However it should be noted that complications can develop in any woman but these women are particularly at risk unlike those below 35 years of age and having HIV puts them at an even much higher risk of pregnancy related complications. It is estimated that HIV positive pregnant women are at 1.5 to 2 times greater risk for maternal mortality (Eyakudze et al., 2008). Hence providing them with quality HIV testing and counselling services that ensures continuity of care would contribute to the reduction of the maternal mortality rate.

### **Education level.**

The majority of the participants had reached primary and secondary education, but a few had no education and none had reached tertiary education. It is encouraging to note that very few women had no education since knowledge of HIV prevention increases with the level of education and that education makes people more receptive to health care messages (NSO, 2011). It further states that studies have consistently shown that educational attainment is strongly associated with health related behaviors and attitudes (NSO, 2011). However, contrary to the findings of the study, NSO (2011), found that by education, HIV prevalence in Malawi is highest among respondents with more than a secondary education and those with no education (14 and 13 percent respectively) (NSO, 2011).

### **Structure for Provision of HIV Testing and Counselling Services**

Findings of the study revealed some gaps in the structure for provision of HIV testing and counselling. Generally, there was lack of policies to guide care, inadequate infrastructure, lack of HIV test kits, and shortage of human resources (counselors).

An appropriate structure is one of the determining factors for the quality of care. Lack of appropriate structure affects implementation of care and hence affecting quality. Consistent with the findings of this study, is a study that was done in Uganda whose aim was to understand specific challenges Ugandan providers face in implementing antenatal Provider Initiated Testing and Counselling (PITC) programmes. In this study, health system challenges included lack of adequate space for counselling, frequent stock outs of supplies, and shortages of counselors (Medley & Kennedy, 2010). Other challenges however included shortages of laboratory personnel and inadequate referral services.

Similarly in a qualitative study in the same country which explored the lessons learnt by health workers involved in the provision of PMTCT services in eastern Uganda at Mbale Regional Referral Hospital to better understand what more needs to be done to strengthen the PMTCT programme, these challenges were confirmed. The key lessons for programme improvement were: ensuring constant availability of critical PMTCT supplies, such as HIV testing kits, antiretroviral drugs (ARVs) for mothers and their babies, regular in-service training of health workers to keep them abreast with the rapidly changing knowledge and guidelines for PMTCT, ensuring that lower level health centres provide maternity services and ARVs for women in the PMTCT programme and provision of adequate facilities for effective follow-up and support for mothers.(Rujumba, Tumwine, Neema, Heggenhougen, 2012).

#### **Policy/Guidelines.**

The results of this study indicate that the facility lacked guidelines. It should be noted that guidelines and policies are important for improving the quality of care since they help in standardizing care, and assist in clinical decision making.

It is not surprising to find that the participants differed in their explanations about the process that they had passed through since there was no uniformity in the provision of care among the service providers. This clearly shows lack of consistency and adherence to the guidelines. In a study whose objective was to review barriers to physician adherence to clinical practice guidelines, the findings revealed a lack of awareness, a lack of familiarity and a lack of agreement with the policy as reasons for lack of adherence among other reasons (Cabana et al., 1999).

It is important to ensure that policies and guidelines are followed as this guarantees quality care to clients. As Woolf, Grol, Hutchison, Eccles, and Grimshaw (1999) state that clinicians and policy makers view guidelines as a tool for making care more consistent and efficient and for closing the gap between what clinicians do and what scientific evidence supports. In addition, guidelines offer a remedy, making it more likely that patients will be cared for in the same manner regardless of where or by whom they are treated (Woolf et al., 1999). The most important thing however is to ensure that the guidelines are evidence based if quality is to be achieved.

### **Infrastructure.**

Inadequate infrastructure affected the process of HIV testing and counselling in the delivery of quality counselling since the counselling was sometimes conducted outside in an open area. This compromised on privacy and confidentiality. Nieburg et al. (2005) states a need to bolster the capacities of already beleaguered health care infrastructures in the most acutely affected countries in a way that will make the routine offer of testing and counselling a realistic option as this is usually a challenge to achieve expanded HIV testing and counselling. It is therefore important to improve or modify the existing infrastructure if quality care is to be delivered.

## **Resources.**

The study findings indicate that the clinic had adequate availability of resources like gloves, cotton, and drugs (Bactrim and ARVs). However during most of the days there was a lack of test kits for conducting HIV testing as a result women were returning home without an HIV test on their first visit. This reduced the number of women who could benefit from the services. According to the NAC (2012), there was a decrease of 4% and 27 percent respectively of people being tested for the 2008/09 and 2009/2010 fiscal years. It further explained that evidently, testing was hampered by intermittency in the supply of test kits resulting into unmet need at most service delivery points (NAC, 2012).

This had an implication on the quality in that women were denied the opportunity of timely identification and hence receiving benefits from the HIV interventions available. For those who are HIV positive it meant the virus was continuing destroying their immune system and there is evidence that mother to child transmission increases with an increase in viral load and also with a low CD4 count. For example in a cohort study evaluating mother to child transmission (MTCT) rates and related factors in HIV infected women from a tertiary hospital in Brazil between 2000 and 2009, the factors identified as associated to MTCT were: low CD4 counts, elevated viral loads, maternal AIDS among other factors ( Delicio et al., 2011). In order to ensure good quality of PMTCT services, it is important to diagnose HIV as early as possible so that the woman can receive the necessary care and support to prevent mother to child transmission and to ensure that she remains healthy. In addition, uninterrupted supply of test kits is important to achieve the goal of the PMTCT programme of reducing pediatric HIV infection.

On the issue of human resources, the hospital had an inadequate number of counselors since the available counselors were the midwives who were also involved in other activities at the clinic. The number was inadequate considering the number of activities that took place at the clinic and also considering the number of clients that are tested for HIV in a day. One midwife was allocated to do the HIV testing and counselling together with one HSA and this meant a lot of work for the two since the hospital sees about 5500 new antenatal clients per year which is approximately 65 new clients per day. With the erratic supply of test kits this also implied that some subsequent clients who were not tested on their first visit were also being tested. This therefore can affect the quality of counselling provided to the clients due to pressure of work and so they may miss out important information and activities which could be of benefit to the women. This has an implication on the quality of the services provided to the women during the process of HIV testing and counselling as Ndiragu and Evans (2009) found in their study that Provider Initiated Testing and Counselling (PITC) greatly increases nurses work load and work related stress. However it was good to note that they were all trained counselors and this meant that they were providing quality care depending on what they were trained on.

The issue of shortage can be solved by using lay people as counselors. A study done in Zambia which assessed effectiveness of lay counsellors in addressing staff shortages and the provision of HIV counselling and testing services. Findings revealed that lay counsellors provide counselling and testing services of good quality. Furthermore, it was concluded that they relieve the burden on already overstretched health care workers. In addition facility managers recognized and appreciated the services provided by lay counsellors. So it was concluded that community volunteers,

with approved training and ongoing supervision, can play a major role in providing counselling and testing services of quality, and relieve the burden on already overstretched health care workers (Sanjana et al., 2009).

## **Process of HIV Testing and Counselling**

### **Decision to get tested for HIV.**

Findings from the study revealed that the majority of the participants had already made the decision from home to get tested on the day that they were tested. This can be attributed to increased awareness about HIV/AIDS and the PMTCT hence the majority of the women prepared well in advance to get tested. Many people these days are aware about the availability of the HIV care services like PMTCT, ART and CD4 count. At least there is hope in knowing one's HIV Status more than previously due to the availability of treatment and other support services. Moreover, the women are assured by the fact that medications are available to protect their babies from contracting the virus. For example in a study focusing on a cohort of pregnant women attending public and private antenatal care facilities, this study applied an extended version of the Theory of Planned Behaviour (TPB) to explain intended and actual HIV testing. The TPB explained 9.2% and 16.4% of the variance in intention among public- and private health facility attendees. Intention and perceived barriers explained 2.4% and external variables explained 7% of the total variance in HIV testing. Positive and negative predictive values of intention were 96% and 6% respectively. Across both groups, subjective norm explained a substantial amount of variance in intention, followed by attitudes. Women intended to test for HIV if they perceived social support and anticipated positive consequences following test performance. Type

of counselling did not modify the link between the intended and actual HIV testing (Mirkuzie, Sisay, Moland, & Astrom, 2011).

The increased awareness about HIV and the PMTCT services is also supported by the findings of the Malawi Demographic Health Survey (2010). The percentage of those who know that HIV can be transmitted through breastfeeding and that the MTCT can be reduced by taking special drugs has increased from 37 to 83 percent among women and that from 29 to 71 percent among men (National Statistics Office, 2011). It further states that 99 % of men in Malawi have heard of AIDS.

It is therefore not surprising that the women had already made the decision at home that they will get tested so that they can know their HIV status in order to protect the baby. Even those who did not plan on being tested, they still chose to get tested after being informed about the test, knowing the importance of that decision.

The media has helped in increasing awareness about HIV and PMTCT as there are a lot of programmes talking about it. A study was done in Nigeria assessing acceptability and suitability of offering HIV testing and counselling to women of unknown status presenting in labour. The findings revealed that most women had satisfactory knowledge of HIV testing (Bello et al., 2011).

Similar results in another study in Nigeria which was assessing pregnant women's knowledge of HIV/AIDS, awareness and attitudes towards voluntary counselling and testing were found, all respondents were aware of HIV/AIDS. Fifty seven percent had good knowledge, 32 percent had fair knowledge and the remaining 11 percent had poor knowledge. Most respondents were aware of VCT through health workers, mass media and friends (Iliyasu, et al, 2005).

However, in South Africa, a descriptive survey study determining the women's knowledge about mother to child transmission (MTCT) of HIV infection through breastfeeding despite the findings revealing a high level of awareness of HIV/AIDS, participants had low level of knowledge about the PMTCT of HIV infection through breastfeeding (Mapute & Jali, 2008).

It is discouraging to note that the women had incorrect information from the community that one cannot undergo antenatal care without being tested for HIV. This perception may deter other women from attending antenatal care if they are not prepared to get tested for HIV. Additionally in most cases women are not empowered to make decisions regarding their own health without consulting their husbands. The NAC (2009) states that, because of male dominance in certain situations, women are unable to access HIV and AIDS services such as HTC and the PMTCT without the approval of their partners (NAC, 2009).

Chandisarewa et al. (2007) reported that routine HIV testing and counselling allows women to be tested without consent from husbands. The husbands and other family members cannot disagree with this policy as it is regarded as part of care. Contrary to the findings of this study, a study conducted in Burkina Faso that analyzed factors associated with the uptake of HIV counselling, HIV testing participation was related to discussing HIV screening with their partner ((Sarker et al., 2007).

### **Motivating factors to HIV testing decision.**

The findings of the study reveal that the majority of the participants were motivated to get tested to know their status, so that they can protect the baby. Few

participants mentioned information given by the provider as having motivated them to get tested. This indicates that the participants did not receive much information from the provider to motivate them before the test but that it was their own previous knowledge that helped them to make a decision to have the HIV test.

Sickness was also a motivating factor in that one would want to know what is causing that sickness. It is therefore not surprising that participants who were frequently sick felt they needed to know their status to rule out HIV as the cause of their illness. It is common knowledge that HIV affects one's immunity and hence one suffers from frequent opportunistic infections due to reduced immunity.

Consistent with the findings of this study, were the results of a study conducted in Tanzania which examined the circumstances and social contexts in which individuals were tested. The majority of persons interviewed had been chronically ill when they were tested for HIV. The symptoms of illness mentioned most often were fever, chest pain, coughing, and abdominal pain. Hence more than 90 % were tested because they or their partner were ill with symptoms that suggested a possible HIV infection (Lugalla, Madichi, Sigalla & Mrutu, 2008).

### **Education/Information received.**

The purpose of pre-test counselling in all the PMTCT settings is to provide clients or couples with adequate information to make an informed decision on HIV testing. The pre test counselling session is designed to take approximately 10–20 minutes for the group or individual sessions in the ANC setting (Ismael & Ali, 2009). Findings of the study revealed that the majority of the participants were taught and that it was done in a group. This is consistent with the guidelines for opt out testing

which states that pre test information can be provided in a group or individually. According to Ministry of Health (2006), if demand for testing is high, pre test education can be provided in groups. Group pre test sessions are efficient because they optimize human resources, while allowing for interaction among participants. Group education is to be conducted in small manageable groups contrary to what was being done where the group health education was being done during the general health education talk outside. This confirms lack of adherence to the guidelines.

It also emerged that the majority of those who had the counselling could not recall the pre test information which was provided. Often they confused it with post test information. This therefore provides some questions related to the amount and quality of pre test information provided. In addition, even though the women stated that the information provided before the test was adequate, they had large gaps in their information. The counselling may be inadequate considering that they were not able to remember the information and on probing further they were recalling only post test information. This can also be attributed to a lack of adherence to the guidelines and also pressure of work. Consistent with the findings of the study in Burkina Faso in a study that analyzed factors associated with the uptake and the quality of pre test counselling, findings revealed that pre test counselling was very poor as 42% did not understand the process of HIV testing and counselling (Sarker et al., 2007).

As it was observed, the group counselling was not being done consistent with the national guidelines and a lot of information was missed out. This has an important implication in that the women did not receive all the necessary information which could also be beneficial in preparing them for the HIV test. Some participants indicated that they received no education and that they just went for the

HIV test. This indicated that they did not have any preparation for the test and that even though they stated that they made the decision to get tested voluntarily the decision was not an informed one. However, the National Prevention of Mother To Child Transmission of HIV (PMTCT) Training Package (2006), recommends that the pre test information should include basics of HIV and AIDS, how HIV is and is not transmitted, prevention of HIV, including safe sex, instruction and demonstration on condom use, the interaction between STIs and HIV transmission, and prevention and treatment of sexually transmitted infections (STIs). It also recommends information on HIV testing procedures at site (when and how blood sample will be taken, when to expect the results), post-test counselling, and follow-up services, advantages and disadvantages of HIV testing and knowing one's sero-status in the context of the PMTCT.

Additionally, meaning of the test, including the "window period," mother-to-child transmission of HIV (MTCT) in utero, intrapartum and postnatally through breastfeeding, delivery by skilled attendant, birth preparedness (which includes male involvement), use of antiretroviral drugs for PMTCT, modification of obstetric care, modification of infant feeding, couple counselling and shared confidentiality, consulting with partner before and/or after testing, including disclosure should be included. However the participants recalled only receiving a small portion of this information. But Bennet (2006) states that some conditions, such as HIV, have serious social and financial, as well as medical implications and that in such cases it is important to make sure that the patient is given appropriate information about the implications of the test, and appropriate time to consider and discuss the testing. However, consistent with findings of this study, she further states that given the

time constraints, it is usually impossible for health professionals providing antenatal care to give full and detailed information to all pregnant women (Bennet, 2006).

### **Informed consent.**

Participants felt that they voluntarily made a decision to get tested for HIV and that they were not forced by anyone to do so. Consistent with the findings of this study, a study assessing acceptability and suitability of offering HIV counselling and testing to women of unknown HIV status presenting in labour and was done in Nigeria revealed that, no one admitted to feeling coerced to test in fear of being denied care (Bello et al., 2011). Contrary to the findings of that study, in a study conducted in Malawi exploring the perceptions of HIV testing, the majority of the interview respondents who had been tested during an antenatal visit explained that they were not given the option to refuse the HIV test (Angotti, Dionne & Gaydosh, 2010).

The findings of this study revealed that half of the participants were aware of the possibility to opt out while the other half was not aware. This was confirmed during observations since the author observed that opt out is not mentioned at all during the health education session. Consistent with the findings of this study in a study in which factors associated with consent to HIV testing under the 'opt-out' approach were investigated through a large cross-sectional study in Kenya.

Despite the fact that 96% had more than four earlier pregnancies and 37% had been tested for HIV at ANC previously, only 17% of the women surveyed knew that testing was optional. Only 20% of those surveyed felt that they could make an informed decision to decline HIV testing. Making an informed decision to decline HIV testing was associated with knowing that testing was optional (OR = 5.44, 95% CI 3.44-8.59), not having a stable relationship with the child's father (OR = 1.76,

95%CI 1.02-3.03), and not having discussed HIV testing with a partner before the ANC visit (OR = 2.64 95%CI 1.79-3.86). (Ujiji et al., 2011). This indicates that the women do not receive all the required information to make an informed decision. Perhaps with clearer explanations more women would choose to opt out of the test and the celebrated increased uptake since the introduction of routine HIV testing might not be the case.

It is encouraging to note that those who were not aware about the possibility of opting out felt they would still choose to be tested if they knew about opting out. This is consistent with the findings of the study done in Botswana designed to ascertain if women felt coerced within the context of routine provider initiated HIV testing. The women were interviewed in the postnatal ward and were asked if they wanted to take an HIV test when they were pregnant. Ninety-four percent of the postnatal women stated that they wanted to take an HIV test when they were pregnant (Baek et al., 2009). Similarly, in a cross-sectional study assessing the acceptability of the routine offer of HIV testing antenatal clinic (ANC) clients in the WA municipality, Ghana. Out of the 112 clients who had not had HIV test in the current pregnancy, 61.8% claimed the test had not been offered to them while 82.4% expressed willingness to have the test done if offered (Nyuzaghl, Ohene, & Odoi-Agyarko, 2011). This indicates that the women were prepared to undergo the testing despite the fact that they had little information about HIV testing and counselling before the test was performed.

However some felt that they were only tested because they came for antenatal care and they were not thinking of being tested. Similar results were found in a study which was conducted in Malawi assessing the perceptions of HIV testing at antenatal clinics in rural Malawi. The findings of the study revealed that rural Malawians do not

perceive HIV testing as a choice, but rather as compulsory in order to receive antenatal care (Angotti et al., 2010). Similar findings were found in Uganda in a study exploring pregnant experiences of, and views on the policies for opt out, and couple HIV testing, and to understand how the policy implementation could be improved in order to increase access to prevention of mother to child transmission (PMTCT) services.

Findings revealed that pregnant women who received ANC from facilities that provided HIV testing perceived HIV testing as compulsory without actually fully realizing the benefits of HIV testing and the PMTCT (Larsson et al., 2012). This can be looked at in a positive way as it has been stated in most of the studies that routine HIV testing and counselling indeed increases uptake of HIV testing and that many women who do not think they are at risk are discovered HIV positive and hence assisted accordingly.

However, according to Durojaye (2006) some of the women who participate in this programme, especially the illiterate and poor, may be coerced into testing for HIV simply because others are doing it. But the Malawi integrated guidelines for providing HIV services stresses that patients should be reminded during pre test education (group or individual) that they can decline HIV testing without any consequences (Ministry of Health of Malawi, 2011).

#### **Post test HIV counselling.**

The purpose of post-test session is to provide women or couples with the HIV test result, to help them understand the meaning of the result, to encourage disclosure and partner testing, to offer counselling and prevention education including risk-reduction messages as well as support and referrals to services. The post-test session

for the women or couples whose result is HIV-negative typically lasts about 5–10 minutes. The HIV positive counselling generally takes 15–30 minutes or longer, depending on the need for support (Ismael & Ali, 2009).

Findings of the study revealed that most of the participants were able to recall some of the information that was provided to them after they received their results. This is a welcome development as it gives an assurance that the women understood the advice provided to them and that the quality of the counselling was good. However, when asked if there were other issues they wanted to learn more from the provider, the participants brought up some issues which could have been covered during the counselling sessions.

Topics which they identified include how the baby can grow healthy, how to feed the baby, how to live longer, to know if the virus had already started working, and infant diagnosis. This shows that there were some information gaps. These findings are consistent with the findings of a study conducted in Botswana where most women recalled that key topics had been discussed during post test counselling sessions, but gaps remained. In addition consistent with the findings of this study most participants remembered issues of the PMTCT such as condom use, infant formula feeding, and how to be evaluated for ARV therapy (Baek et al., 2009). Furthermore, in the same study it was observed that counselling sessions provided incomplete delivery of important information.

Generally speaking, the findings of this study showed that the basic principles of post test counselling, as stipulated in the guidelines were followed, even though there were some gaps. Most of the important information like the meaning of a positive result, dealing with immediate emotional reactions, discussing personal risk reduction plan to prevent re-infection e.g. abstinence and safer sex practices including

condom use, disclosure of results to ease decision-making for uptake of the PMTCT services, bringing partner for HIV testing and counselling, ARV prophylaxis (or, if eligible, ARV therapy) for PMTCT, infant feeding options and, nutrition were mentioned and participants were able recall some of this information

#### **HIV diagnosis information.**

Participants did not experience any specific problems during the time they were informed of their HIV diagnosis. Participants did not feel offended with the way the results were revealed and that privacy and confidentiality was provided to all the participants. Privacy and confidentiality are very important issues with HIV to prevent stigma and discrimination. Ensuring this promotes the trust of health workers by the patients, and they are likely to come back for other services.

However an overview of the Provider Initiated Testing and Counselling (PITC) policy guidance, to critically consider its implications for the nursing profession in sub-Saharan Africa findings revealed that nurses are particularly stressed by breaking bad news and handling ethical dilemmas (Ndiragu & Evans, 2009). Therefore, nurses also need support from the supervisors if good quality care is to be assured. As it has been stated in the National Prevention of Mother To Child Transmission Of HIV (PMTCT) Training Package (2006), that counselors, like all caring professionals can leave the counselling session stressed and overwhelmed, and unable to effectively perform their roles. Regular supervision and peer support meetings reduce the chances of burnout in the counselor (Ministry of health, 2006).

## **Treatment and referral for continuity of care**

HIV testing and counselling is the entry point to HIV management and services and it allows the woman to protect her baby from getting the virus. It also allows her to receive appropriate care so that she can remain healthy. The majority of the participants had been referred for a CD4 count and ARV treatment in timely manner. In South Africa, it is recommended that all pregnant women who are HIV positive should be clinically staged and have a CD4 count taken on the same day as the HIV is done and preferably at the first ANC visit (or at the earliest opportunity) (National Department of health, South Africa, South African National Aids Council, 2010).

However, contrary to this, the findings of the study which indicate that clinical staging was not done on any of the women. Yet the current Malawi Integrated Guidelines for providing HIV Services states that the WHO clinical staging is mandatory for all HIV patients including those who are eligible for ART or those with a CD4 count result. It further states that CD4 count does not replace clinical staging (Ministry of Health Of Malawi, 2011).

Findings revealed that a few participants had not begun taking ARVs because their CD4 count was still high. However, some participants had not undergone CD4 count testing due to a lack of reagents. These clients were told that it would be done after delivery. This indicates a long delay for the women and considering the above recommendations, staging is to be done to determine the level of their immunity. It should always be taken into account that untreated HIV infection leads to a gradual destruction of the immune system and that different HIV related diseases tend to appear at different levels of immune suppression (Ministry Of health Of Malawi,

2011). It is encouraging however that at least an attempt was made to refer the women for the service and that all the participants were aware of the availability of the service. The current Malawi Integrated Guidelines for Providing HIV Services recommends that pregnant women be offered to start ART on the same day they are tested positive. This means that just by being pregnant and HIV positive one is eligible for ART. This is a welcome development as women will be able to access ART once discovered HIV positive. It is therefore necessary for government to ensure an uninterrupted supply of ARVs if quality of care is to be achieved. Another issue to be considered however is the continuity of therapy after delivery. There is need for clear guidelines on how these women will access treatment after delivery since they can no longer access the drug through antenatal clinics and hence a need for strong referral system between the antenatal clinic and the ART clinic.

All the participants had started taking Cotrimoxazole for prophylaxis against opportunistic infections. Cotrimoxazole Preventive Therapy (CPT) prevents PCP pneumonia, diarrhea, malaria, and other HIV related diseases and prolongs survival (Ministry Of health of Malawi, 2011). In addition CPT reduces the frequency of opportunistic illnesses, decreases the frequency of clinic visits and decreases hospitalizations among HIV-infected people. Evidence has shown that CPT is associated with a 25-46% reduction in mortality in sub-Saharan Africa, even in areas with high bacterial resistance to the antibiotic and specifically in pregnant women living with HIV, CPT has direct maternal health benefits and may have indirect benefits for neonatal and infant health (Ministry of Health, 2006). The health of the women is assured through this service as this is taken for the remainder of the woman's life. Even the women who had not yet started taking ARVs were provided

with the Prophylactic ARVs (combined regimen) to prevent mother to child transmission of HIV. However some participants explained that they were not told the type of drugs that they were given and their use. What was mainly explained was how to take the drug and what to do if the drug finishes. This had an implication on the quality in that it can affect adherence to treatment if one does not understand what she is getting.

This is consistent with the findings of an evaluation which was done in Botswana. The study aimed to describe HIV related services provided to women during their pregnancies, document the content of post test counselling sessions for HIV positive pregnant women, whether HIV positive women remembered what had been discussed, the extent of AZT adherence based on self reports, and the operational successes and barriers to adherence to AZT for PMTCT. Findings revealed that providers discussed the importance of taking the correct dose and taking it on schedule but other important topics such as: the purpose of AZT and side effects were omitted (Baek et al., 2009).

From the findings of the study, it can be concluded that there is a good referral system between the antenatal, lab, and ARV clinic. The CD4 count test and ARV treatment were not being provided within the antenatal clinic at the time but a majority of the women were able to benefit from the services through referrals. As Eyakudze et al. (2008) state that while HIV testing during prenatal care is supposed to provide access to HIV treatment beyond the PMTCT, maternal and Child services within which the PMTCT programmes tend to be located are generally not equipped to provide HIV treatment. In turn HIV treatment tends to be provided in standalone clinics that the women would have to be referred to and that without strong referral

links between the antenatal and treatment facilities, the fourth component of the PMTCT strategy remains very weak.

### **Outcome in HIV Testing and Counselling**

#### **Client satisfaction.**

Participants indicated that they were satisfied with the time that was provided for them to make a decision to get tested. However according to UNESCO Chair of Bioethics (2003), a patient should be able to comprehend the meaning of the information, balance pros and cons, draw inferences from the data with reasonable rationality, assess the circumstances, appreciate the aspects of the situation, and reach a deliberate decision on the basis of the available information. For all the above to be achieved there is need for more time and adequate information to deliberate on. One woman, despite being satisfied, felt that one may decide to go home to bring her husband so they can get tested together. But this opportunity is not provided. The common reason mentioned was because they were already aware about HIV testing. It wasn't viewed as necessary to sit down and think about it.

Findings also revealed that the majority of the participants had no problems being taught in a group because they felt that they received adequate information. However a few stated that they would prefer individual counselling to understand the information better. All the participants stated that the information provided to them before the test was adequate for them to make a decision. This shows that providing information in a group does not affect the quality of information delivered and the way the information is delivered and accepted. However if there is a need, providers should be able to provide individual counselling to those who may need it.

It is also not surprising that all the participants were satisfied with the counselling that was provided after getting their results. Being satisfied with the care can be attributed to trained counselors who knew what they were doing since they were all trained. However this can also be attributed to a lack of knowledge on the information that is to be provided. In addition a good interpersonal relationship between the counselor and the client is the most important thing during counselling. Good interpersonal relationship may be the reason why the clients felt satisfied. However it emerged that there were some gaps as the women felt they needed some additional information on certain areas. This possibly resulted from a lack of adherence to guidelines. If counselling guidelines are followed, then service providers should be able to cover most important areas.

Findings of the study also revealed that all participants were satisfied with the care and treatment that was provided. This is encouraging because the client's perception of the care provided is what determines its utilization as well as acceptability of treatment recommendations. If their perception of the care is negative then this can affect the outcome of the programme in the long term since clients will not have trust in the service providers.

It also emerged that the participants were satisfied in general with the services that were offered. However participants stressed the need for providers to be empathetic and caring when handling HIV positive women. It emerged that despite having stated that they were satisfied with the care that was provided, some participants had specific wishes for care. Specifically it emerged that all would like access to CD4 counts and ARVs.

However, despite participants being generally satisfied with the counselling, the information, the care and the services available, bringing in other issues which were not discussed or done only shows that there were still some gaps remaining in as far as HIV testing and counselling process is concerned.

### **Emotional wellbeing.**

All the participants explained that they were emotionally better and had accepted their status. As the women themselves stated, this can be attributed to the encouragement they received from the counselling. However the majority of the participants reported that they were affected and worried when they first learned that they were HIV positive. Different reactions were mentioned as a response to the diagnosis. These reactions are normal considering the issues that are associated with HIV. The majority of the women had disclosed their status to at least one person, typically their husband. Similar findings were also found in Botswana where there were high rates of disclosure among HIV positive women. Of those who received counselling 96/109 (88%) of ANC clinic respondents and 94/116 (81%) of postnatal respondents had disclosed their status to someone. Partner/husband was mentioned most often when asked to whom they had disclosed their status (Baek et al., 2009). By disclosing her HIV status to her partner and family, the client may be in a better position to: encourage her partner(s) to be HIV tested, prevent the transmission of HIV to her partner(s), access PMTCT interventions, receive support from her partner(s) and family when accessing PMTCT and HIV care and support services (Ministry of Health, 2006). Commonly mentioned reasons as to why they chose to disclose to those people included: being the ones who will take care of them during delivery, to be assisted accordingly when sick, and for the husband to get tested as

well. It is important to have a good support system if adherence to interventions is to be assured. Some participants had their own reasons as to why they did not disclose to certain people, mostly fearing stigma and discrimination. This indicates that there is still some stigma and discrimination within the communities. Efforts to deal with stigma should be encouraged so that women are able to receive care and support without fear of anything in order to adhere to treatment regimes and recommendations. Reducing stigma and discrimination is an important factor in prevention, management and control of the HIV epidemic (National Statistics Office, 2010). However those who disclosed their status did not experience any problems with the people they chose to disclose their status to. This could be because the women chose to disclose their status to those they trusted and avoided those that they did not trust. This finding is contrary to findings of other studies which reported that women were experiencing problems after disclosing their results. According to Thorsen, Sunby, & Martinson (2008), as a result of HIV disclosure some women lost everything home, husband, family friends and financial opportunities. In addition the women were blamed for bringing HIV into the household, ridiculed, shunned by community members and chastised or even excommunicated by church leaders.

Currently people are showing accepting attitudes towards people living with HIV/AIDs. As was reported in the Malawi Demographic Health Survey (2010), most women and men reported that they would be willing to take care of a family member with HIV at home (97 and 98 percent respectively) (National Statistical Office, 2010). This is a welcome development as women will be able to follow the PMTCT interventions and advice without fear and with support from family and friends. People have a better understanding of the purpose and benefits of HIV testing due to

increased awareness of HIV and related issues. One woman however experienced a broken marriage with her husband who was HIV negative after the test. This could prevent other women from disclosing status to their husbands fearing that their marriages will end.

A majority of the husbands had not yet gone for testing despite knowing their wives' status. Even though a majority of the women explained that their husbands were very understanding in as far as that issue is concerned. This could have an impact on prevention of mother to child transmission especially on issues of safe sex. This finding is consistent with the findings of an evaluation in Botswana where despite the fact that many women had disclosed their status to their partners, less than half of the women reported that their partners had taken an HIV test (Baek et al., 2009).

In conclusion the discussion has been guided by the quality of care framework focusing on the three main areas of the framework: the structure, process and outcome. Related studies have been utilized to support the discussion.

### **Constraints and Limitations**

The study consisted of a small sample. Therefore the results may not be representative of the larger population of antenatal HIV positive women. The sporadic supply of reagents was a limitation since it was difficult to find participants because most of the women were of unknown status. Finances were also a limitation for the researcher as money was needed to travel to and from Dedza. Finally, time was also a limitation as the researcher had to comply with the school calendar as well.

## **Recommendations**

Taking into account the findings of the study the researcher recommends that:

### **Structure.**

- DHMT/HIV Unit should take the PMTCT as one of the priority areas and should ensure an uninterrupted supply of test kits as lack of them affects the quality of the PMTCT services.
- Hospitals should invest in renovating or building of new infrastructures. It is encouraging to see a lot of hospitals these days building new structures. Buildings should be updated since these are the same buildings used before the PMTCT services. A lot of programmes are coming in but the buildings are the same. This therefore compromises on quality.
- Hospitals can utilize lay people as counsellors in order to improve on the human resources.

### **Process.**

- Use of guidelines should be encouraged and supported by supervisors and or nurse midwife managers. This will ensure standardized and quality information during HIV testing and counselling.
- There is a need for supportive supervision by nurse/midwife managers to ensure adherence to policies and guidelines and also to assist in interpretation of policies which other health care workers may not be able to understand.

### **Outcome.**

- There is need for continued community sensitization on HIV issues to increase awareness and hence decrease stigma and discrimination and also to ensure that women have the right information on HIV and PMTCT.

- Efforts to deal with stigma should be encouraged so that women are able to receive care and support without fear of anything in order to adhere to treatment regimes and recommendations.
- There is need to encourage couple counselling as this will ensure that more men are tested together with their partners.

### **Areas for Further Study**

Further research is needed to assess the quality of the services among those who are HIV negative or among women who are tested at the antenatal clinic in general. It may be that the midwives try to put all their effort only on those that are HIV positive and less effort on those who are negative in trying to cope with pressure of work. Those who are HIV negative also need information so they can be protected from catching the virus as this will also assist in reducing the number of new infections. A study is needed on service providers as the data of this study relied only on the perspectives of women who may not have adequate knowledge on what is really required.

### **Conclusion**

The findings of the study show increased awareness on HIV issues and that people are very ready to undergo testing, stating the benefits of such a decision. However the findings show that there are still some gaps on the quality of the HIV testing and counselling services that are provided in Dedza. Gaps were identified mainly on the two elements of the quality framework by Donabedian of Structure and process. As Donabedian stated, the gaps in the structure affected the delivery of care that is the process of care which in turn had some effect on the outcome quality.

However, the outcome was generally good as the women were satisfied with the care provided and even of the services that are available. Being satisfied with care and services is the basis of trust on the health system and health workers and adherence to treatment recommendations is assured. Findings also showed that emotional needs of these women were dealt with accordingly.

However, despite showing satisfaction with the care and services the participants identified issues they felt were needed. This provides evidence of gaps in the quality of care that was provided. In addition it is discouraging to note that there are low testing rates among partners of the women. The findings therefore show that there is still a lot to be done if quality in HIV testing and counselling is to be achieved fully so the women can benefit from quality care and services. It is believed that the findings of this study can assist in improving the quality of HIV testing and counselling services in Malawi to ensure that the service providers are providing good quality care and that mothers are adhering to advice and treatment. This will in turn help in the achievement of the goals of prevention of mother to child transmission programs and hence contributing to the reduction of the maternal and neonatal mortality rates.

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## Appendices

### Appendix A-Budget.

Below is a detailed presentation of all activities that will be done and their corresponding costs:

ITEM	COST PER ITEM	TOTAL COST
<b>Stationery</b>		
10 Reams	K1000 each	K 10, 000
10 pens	K20 each	K 200
20 pencils	K10 each	K 100
3 rubbers	K150 each.	K 450
2 flash disk	K4500.00 each.	K 9000
20 large envelopes	K100 each.	K 2000
20 medium envelopes	K50 each	K 1000
1 Tape Recorder	K35,000 each	K 35000
3 Pairs Batteries	K1, 000 each	K 3000
<b>Secretarial services</b>		
Printing and Binding Proposal.		K 10,000.00
Printing and Binding Thesis		K 20, 000.00
Photocopying Research tools		K 14,000.00
<b>Allowances</b>		
1 Researcher	K2500/ day x 15 days	K 37500
Transport.		K 30,000
<b>TOTAL</b>		K 172,000
<b>Contingency</b>		
10 % of the proposed Budget		K17,200
<b>GRAND TOTAL</b>		<b>K 189, 200</b>

### Justification for Budget

#### Stationery

There was need for such an amount of money because adequate stationery supplies were required for note taking, proposal printing, data analysis and the actual dissertation writing.

**Transport**

Also money was required for travelling to and from Dedza for clearance and data collection. In addition there was need for money for allowances for data collection for the researcher and assistants.

**Secretarial**

Money was required to pay for secretarial services such as printing, photocopying and binding.

## **Appendix B- Consent Form**

### **Information Sheet**

#### **Quality of Care Offered to HIV Positive Antenatal Women during Routine Opt out HIV testing and Counselling in Dedza**

Investigator: Ellasy Khonje Mtumbuka, Kamuzu College Of Nursing, P.O Box 415, Blantyre. Tel: 088871497.

This study will be done as a requirement for a masters degree in midwifery. The purpose of the study is to describe the quality of care provided to the HIV positive pregnant women during routine opt out HIV testing and counselling at Dedza District Hospital. Specifically, the study will determine the availability of adequate infrastructure, resources (human and material) and guidelines for the provision of HIV testing and counselling services in routine opt out testing and counselling, will also explore the HIV testing and counselling process, and will determine the outcome after going through the process. Findings from this study will generate new knowledge which will in turn inform practice, management and policy makers on measures that can be done to ensure that the care that is provided during HIV testing and counselling is of good quality.

Be informed that your participation in this study is voluntary and that you have to sign this consent form if you are willing to participate in this study. You can withdraw from this study anytime you feel like doing so without any penalties. You will be interviewed by the researcher using an interview guide and the information collected will be used solely for study purposes. Numbers will be used instead of names. Information collected will not be shared with anyone except the researcher and the questionnaires will be kept under lock and key and destroyed later. Even your

participation in this study will be kept confidential. Opportunity to ask questions about the research or your participation shall be provided

If there are any concerns regarding your participation in this study you can contact:

Kamuzu College of nursing research committee, COMREC and Ellasy Khonje  
Mtumbuka at 0888714987.

### **Consent Form**

I have read the consent form/it has been read to me. I have understood the purpose of the study and the problems involved and I am willing to participate in the study.

I agree to voluntary participate in the study, be questioned and provide answers to the best of my knowledge. I understand that I am free to withdraw anytime without giving reasons and this will not influence the health care given to me

I understand that I will not benefit financially

I know how to contact the researcher if I need to.

Participant Signature..... Researcher

Signature.....

Date.....

Date.....

For more information about the study you can ask the chairperson of COMREC or the researcher at 0888714987

## **Appendix C-Chichewa Consent Form**

### **Chithandizo Chimene Amayi Oyembekezera Amalandira Nthawi Yoyesetsa Magazi Kusikelo Ku Dedza Ku Mmalawi.**

#### **Mfundo Zofunika Kuwerenga**

Kafukufukuyu akupangindwa ngati mbali imodzi ya sukulu ya masters degree ya Uzamba. Cholinga cha Kafukufukuyu ndi Kulongosola chithandizo chimene amayi oyembekezera amalandira nthawi yoyezetsa magazi kusikelo Mmalawi muno. Makamaka kafukufukuyu akufuna kufufuza m'mene zinthu zimakhala koyezetsa magazi, kuyambira nthawi yomwe m'zimayi amapanga chiganizo choyesetsa, amauzidwa zoyezetsa magazi kufika nthawi yokumva zotsatira za magazi. Komanso momwe kulandira kwa zotsatira kumakhudzira moyo wawo wa mtsogolo. Pali chikhulupiriro chakuti zotsatira za kafukufukuyu zidzathandiza kupeza njira zothandizira kuti azimayi azilandira chithandizo choyenera, komanso azisamalidwa moyenera panthawi yomwe akuyezetsa magazi.

Ndikufuna kwanu kusankha kutenga nawo mbali mukafukufukuyu kapena ayi. Mukasankha kutenga nawo mbali mukafukufukuyu mudzafunsidwa kuti mutsindikize chizindikiro choti mwavomera. Komanso mudzafunsidwa kuyankha mafunso okhuzana ndi zomwe mwadutsa ndikukumana nazo pa nthawi yoyezetsa magaziyi. Mayankho anu azasungidwa mwa chinsinsi ndipo sizizadziwika kuti anayankha mafunso awa ndi ndani chifukwa mayina anu sazayikidwa pamapepala a mafunso mmalo mwake tizagwiritsa ntchito manambala. Mapepala amafunso ndimayankho onse zizawonongedwa pomaliza pakafukufukuyu.

Muli ndi ufulu kufuna kusiya nthawi imene mukufuna popanda kupereka zifukwa. Ndipo izi sizisokoneza chithandizo chimene mungalandire. Ngati pangakhale mafunso okhuzana ndikafukufukuyu muli omasuka kufunsa.

Ngati pangakhale nkhawa ina iliyonse yokhuzana ndi kafukufukuyu khalani omasuka ndikudzeretsa madandaulo anu ku sukulu ya za unamwino ndi Uzamba ku Blantyre, college of medicine research committee ku Blantyre ndi Kwa Ellasy Khonje Mtumbuka pa 0888714987.

## **Kalata Ya Chivomerezo**

Ndawerenga (kapena wina wandiwerengera) kalata yolongosola za kafukufuku ali pamwambayu ndipo ndamvetsetsa cholinga cha kafukufukuyu ndi zovuta zake.

Ndikuvomereza kutengapo mbali pakafukufukuyu mosaumirizidwa, kufunsidwa mafunso ndikuyankha mafunso mmene ndingadziwire. Ndamvetsanso kuti ndili ndi ufulu kusiya nthawi ina ili yonse popanda chifukwa ndi kuti izi sizidasokoneza chithandizo ndingalandire.

Ndikumvetsa kuti zones zomwe ndiyankhule kapena kupereka mukafukufukuyu zidasungidwa mwachinsinsi ndikugwiritsidwa ntchito ndi opanga kafukufukuyi

Ndamvetsetsa kuti palibepo phindu la ndalama

Ndikudziwa mmene ndingapezere opanga kafukufukuyu ngati kuli kofunika kutero

Dzina la otenga mbali..... Mwini

Kafukufuku.....

Date.....Date.....

.....

## Appendix D-Time Table

This indicates the process of the project starting from research proposal to the time when the research findings were disseminated. The study approximately took one year. Below is time table indicating study period in months:

*Table 1: showing a time table of activities*

Activity	July-October 2010	October – November 2010	November 2010	January 2011	February 2011	May 2011	April-September 2011	October 2011
Topic search and literature review								
Literature review and proposal development								
Submission of proposal to supervisor								
Submission to RPC								
Submission to COMREC								
Data collection								
Data analysis & Report writing								
Submit Dissertation								

## Appendix E-Instrument

### QUALITY OF CARE OFFERED TO HIV POSITIVE ANTENATAL WOMEN DURING ROUTINE OPT OUT HIV TESTING AND COUNSELLING AT DEDZA IN MALAWI

#### Participant In depth Interview Guide

Date of

Interview.....Number.....

#### A. Demographic Data

Age .....

Level of Education (a) No education

(b) Primary 1 to 4

(c) Primary 5 to 8

(d) Secondary 1 to 2

(e) Secondary 3 to 4

(f) Tertiary

#### B. Observation Guide/checklist

##### *Structure*

- Existing HIV/AIDS policies and guidelines
  - HIV testing and Counselling guidelines
  - PMTCT guidelines
- Availability of necessary resources (both human and material)
  - Counsellors
  - Trained or not.
  - Test kits, Gloves, Cotton/Swabs, Disinfectant, Drugs (Bactrim, ARVS)
- Appropriate structures available
  - Proper counselling rooms
  - Number of rooms available
  - Use

## **C. Interview Guide**

### *Process*

Did you plan on being tested the day you were tested?

How did it happen that you got tested then?

Can you tell me the information that you had before you got tested that motivated you to get tested

Did you prefer being in a group or individual counselling. Explain.

Do you feel like you had enough information about HIV testing and counselling before being tested?

Did you make the decision to get tested voluntarily or you feel you were forced. Why?

Probe: Did you know that there is a possibility to opt out of the test if you do not want to get tested at that time.

Was the time provided enough for you to make a decision to get tested?

How was the process of giving you the results?

Can you tell me the information that you got after the test that assisted you to cope with the results/ that assisted you to make decisions for the future

What other services available were you referred to or advised on ((CPT, ART, PMTCT, CD4 count, Staging).

*Outcome*

Is there any more information that you wanted to know from the care provider

What was your overall experience with the provider?

Did you receive the quality care that you expected?

What could we do different

To whom did you share the results with? Why? Why not?

What problems are you facing now or any concerns that you have

## **Appendix F-Chichewa Instrument.**

### **CHITHANDIZO CHIMENE AMAYI OYEMBEKEZERA AMALANDIRA NTHAWI YOYEZETSA MAGAZI KUSIKELO KU DEDZA.**

#### **Ndondomeko Ya Mafunso**

Tsiku Lofunsa..... Nambala.....

#### **A. Kudziwa za Otenga Mbali pa Kafukufuku.**

Kodi muli ndi zaka zingati.....

Kodi sukulu munalekeza pati (a) Osaphunzira.

(b) Pulaimale 1-4.

(c) Pulaimale 5-8.

(d) Sekondale 1-2.

(e) Sekondale 3-4.

(f) Kuposera Sekondale

#### **B. Ndondomeko Ya Zokaona**

#### **C. Ndondomeko ya mafunso.**

##### ***Zandondomeko Yoyezetsa ndi Uphungu.***

Munakonzeka bwanji kuyezetsa magazi tsiku loyamba sikelo?

Probe: Zinatheka bwanji kuti mupezeke kuti mwayezetsa?

Mungandiuze za zomwe anakulangizani musanayezedwe magazi zomwe zinakupangitsani kuti mupange chiganizo choyezetsa magazi.

Munasangalala ndi maphunziro apagulu kapena mukadakonda adokotala akanakulangizani panokha. Longosolani.

Mukuona ngati munalandira uphungu mokwanira musanayezedwe magazi? Longosolani.

Munadzipeleka nokha kuti muyesedwe magari kapena munachita chokakamizidwa? Longosolani.

Probe: Mumadziwa kuti pali mwayi osankha kusayetsesa magari ngati mwafuna kutero?

Mukuona ngati nthawi yomwe munapatsidwa inali yokwanira kupanga chiganizo choyezetsa

Mungandiuze momwe okuyesani magari anakuuzirani zotsatira?

Munganenepo chani za uphungu omwe munalandira wa chilangizo chomwe anapereka atakuuzani zotsatira za kuyezetsa magari omwe unakuthandizani kukonzekera za kutsogolo komanso kuvomereza zotsatira.

Probe: Zithandizo ziti zowonjezera zomwe munalandira kapena anakutumizani kumalo ena kuti mukalandire (CPT, ART, PMTCT, CD4 count, Staging).

***Za zotsatira za Kudutsa Mundondomeko***

Pali zina zomwe mukadakonda kuti okuyesani magari akuuzeni

Munganenepo chani pa chithandizo chomwe munalandira. Mukuona kuti munathandizidwa mokwanira?

Mungakonde titakonza ziti pa ndondomeko yoyeza magari kwa amayi apakati?

Munauza ndani za zotsatira za magari? Chifukwa chani?

Munakumana ndi mavuto anji/kapena munali ndi nkhwana zANJI?

## Appendix G-Approval Letter 1



UNIVERSITY OF MALAWI

Principal

K.M Maleta, MBBS PhD

Our Ref.:

Your Ref.: P.02/11/1032

College of Medicine

Private Bag 360

Chichiri

Blantyre 3

Malawi

Telephone: 01 877 245

01 877 291

Fax: 01 874 700

Email: [comrec@medcol.mw](mailto:comrec@medcol.mw)

15<sup>th</sup> March 2011

Mrs. E. Khonje Mtumbuka

KCN

P O Box 415

Chichiri

Blantyre 3

Dear Mrs Khonje Mtumbuka

**RE: P.02/11/1032 - Lived Experiences of Married HIV Positive Women Passing through Routine HIV Testing in Dedza: A Qualitative Study**

---

I write to inform you that COMREC reviewed your proposal mentioned above which you resubmitted for expedited review. The following points have been dealt with:

1. You have signed on the cover letter/letter of introduction.
2. The statement has been edited and corrected on page 8.
3. An explanation has been made on what measures will be taken to ensure that participants are made to feel comfortable on page 10.
4. Data collection will be done in two months.
5. On pages 34 and 35, the questionnaire has been edited and punctuation marks have been inserted.
6. The Chichewa translations has been edited.
7. The question asking clients about their feelings has been removed from the questionnaire.
8. The literature review is now included in the body of the proposal (background).
9. COMREC format has been followed.

I am pleased to inform you that your protocol **was approved** after considering that you addressed all the queries raised in the initial review.

As you proceed with the implementation of your study we would like you to adhere the amended protocol ICH GCP requirements and the College of Medicine Research requirements as indicated on the attached page.

Yours Sincerely,



Prof. J.M Mfutso-Bengo  
**CHAIRMAN - COMREC**

JMMB/ck



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**REQUIREMENTS FOR ALL COMREC APPROVED RESEARCH PROTOCOLS**

1. Pay the research fees as required by College of Medicine for all approved studies.
2. You should note that the follow-up committee will monitor the conduct of the approved protocol and any deviation from the approved protocol may result in your study being stopped.
3. You will provide an interim report in the course of the study and an end of study report.
4. You are required to obtain a continuation approval after 12 months.
5. All investigators must be fully registered with the Medical Council of Malawi.

## Appendix H-Approval Letter 2

TELEGRAM:  
TELEPHONE: 01223437/439  
FAX: 01223523



*In reply please quote NO. DZH/MALAWI*  
THE DISTRICT HEALTH OFFICER,  
DEDZA DISTRICT HOSPITAL,  
P.O. BOX 136,  
DEDZA,  
MALAWI.  
28<sup>th</sup> January, 2011

**TO :** The Principal  
Kamuzu College of Nursing (Blantyre Campus),  
Post office Box 415  
**BLANTYRE**

**cc :** Mrs Ellasy Khonje Mtumbuka  
Kamuzu College of Nursing

**RE : APPLICATION FOR A RESEARCH PERMIT**

I acknowledge receipt of your letter dated 28<sup>th</sup> January in which you requested permission to use Dedza District Hospital as study site. I am pleased to inform you that you have been granted permission to conduct a research study titled:

"Lived experiences of married HIV positive women passing through routine HIV Testing and Counselling (HTC) in Malawi."

Please note that the office will require a feedback through a copy of study results for District Health Office's action.

Wish you good luck in your studies

Yours Faithfully

MINISTRY OF HEALTH  
DEDZA DISTRICT HOSPITAL  
2011-01-28  
Dr Zondjwe Mwanza  
(DISTRICT HEALTH OFFICER)

