TO EXPLORE FACTORS INFLUENCING WOMEN ON ADHERENCE TO PMTCT REGIMENS IN TANZANIA

Monica J. Dedu Mollel

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A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health.

by Monica Dedu Mollel Tanzania

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List of abbreviations

Abbraviations		
Abbreviations	Meaning	
3TC	Lamivudine	
ANDS	Acquired immune Deficiency Syndromes	
ANC	Antenatal clinic	
ART	Antiretroviral therapy	
ARV	Antiretroviral	
AZT	Zidovudine	
СВО	Community based organization	
CD4	Cluster of Differentiation 4	
CTC	Care and treatment clinics	
DRC	Democratic Republic of the Congo	
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation	
GDP	Growth domestic product	
HAART	Highly active antiretroviral therapy	
HBM	Health belief model	
HDT	Human Development trust	
HIV	Human Immune Virus	
HIV ⁺	Human Immune Virus positive	
IGA	Income generating activities	
MCH	Maternal and child health	
MDG	Millennium development goals	
MoH	Ministry of health	
MTCT	Mother to child transmission	
NACP	National AIDS control program	
NBS	National bureau of statistics	
NGO	Non-governmental organizations	
OOP	Out of pocket	
PCR	Polymerase chain reaction	
PICT	Provider initiated counselling and testing	
PIH	Partners In Health	
PLWHA	People living with HIV and AIDS	
PMTCT	Prevention of mother to child transmission	
PPP	Public private partnership	
RCH	Reproductive and child health	
SEM	Social ecological model	
TACAIDS	Tanzania Commission for AIDS	
TB	Tuberculosis	
TBA	Traditional birth attendant	
THE	Total health expenditure	
T-MARC	Tanzania Marketing Research Communication	
UNAIDS	United Nations Programme on HIV/AIDS	
UNGASS	United Nations General Assembly special session	
VCT	Voluntary Counselling and testing	
WHO	World Health Organization	
ZAC	Zanzibar AIDS Commission	
	Zamni Lasante	
ZL	Lannin Lasante	

Definition of terms

- 1. Adherence Is an art of adopting and taking active changes of behaviours corresponding to agreed recommendations from a health care provider to maintain or reach optimal health outcome (WHO, 2003), (Osterberg, 2005), (Vrijens, 2012). In this study the term "adherence" meant being consistence and stick to the agreeable recommendations pertaining to PMTCT regimens.
- 2. Children Are human being below 18 years of age unless, under the law applicable to the child, majority is attained earlier (UN General Assembly, 1989). In this study, the term "children" was used to describe human being under the age of 14 years. Depending on the context in this study; the term "children" describe both individuals below 14 years of age who are HIV⁺ or not.
- 3. Loss to follow up (LTFU) Is the term used to describe patients who do not turn up for a medical intervention after the 90th of the last scheduled appointment. The period of 90 days can vary according to the condition of the patient and therefore need to be adjusted reasonably according to the relevance and urgency of monitoring of the patient within the care continuum. Therefore loss to follow-up could be defined more precisely as referring to patients who are lost from the continuum of care with unknown outcomes (WHO, 2012b). In this study, the term "loss to follow up" was used to describe HIV⁺ women who failed to return for their medical appointment visits at any point of time.
- 4. Regimen Is a planned standard course of a program which regulates aspects of one's lifestyle such as a diet, exercise or medical treatment, designed to give a positive result (http://medical-dictionary.thefreedictionary.com/regimen). In this study the term regimen was used to describe all intervention recommended for PMTCT
- **5. Women -** Are adult human beings who are biologically female and who are capable of bearing children (http://www.thefreedictionary.com/women). In this study the term was used to represent women who are HIV+ during pregnancy labour or after delivery who were enrolled in PMTCT program. Depends on the use, the term women also was used to represent children especially when describing issues of adherence because they are the key actors for their children.

Abstract:

Background: About 80,000 children are estimated to be infected with HIV through mother to child transmission (MTCT) annually in Tanzania. MTCT can be reduced to <1% if women adhere to prevention of mother to child transmission (PMTCT) of HIV regimens. Adherence to PMTCT regimens is influenced by individual factors, social network factors, community context factors and social cultural environment factors. Therefore lead to loss to follow up of HIV⁺ women during PMTCT process to as higher as 15%-30%.

Objective: To explore factors influencing HIV⁺ women on adherence to PMTCT regimens in Tanzania in order to make recommendations to MoH and its partners on development or improving existing interventions that will facilitate HIV⁺ women to adhere to PMTCT regimens.

Study design: The study was a literature review; Social Ecological Model and Health Belief Model were used as guides for literature review.

Findings and discussion: The main factors that hinder HIV⁺ women from adhering to PMTCT regimens are stigma, discrimination and violence; poor economic status and poor referral, follow up and monitoring. Male involvement in PMTCT program was found to be the main factor to enable women to adhere to PMTCT regimens.

Conclusion: Adherence to PMTCT regimens is still a challenge. Male involvement in PMTCT program and improving referral, follow-up and monitoring system are key factors to improve adherence to PMTCT regimens.

Recommendations: Improve male involvement into PMTCT program, improve referral, monitoring and follow-up systems for HIV⁺ women and children in PMTCT program and empower women on economic capacities

Key words: Women, PMTCT, adherence, barriers, Tanzania

Word count: 13,194

Introduction:

HIV and AIDS continued being the leading causes of morbidities and mortalities among children in Tanzania for years. Since HIV was declared in the country in 1983, by 2011 about 230,000 children were reported to be infected with HIV mainly from their HIV⁺ mothers. This mode of HIV transmission is known as mother to child transmission (MTCT) or vertical transmission. It is a dominant mode of HIV transmission among children 14 years and below that accounts for more than 91% of all HIV infection (TACAIDS, 2010), (WHO, 2011), (UNAIDS, 2012).

The risk of MTCT ranges from 15%-45%; of which 5%-10% of the infections occurs during pregnancy, 10%-15% occurs during labour and delivery and 15-20% occurs during breastfeeding. In Tanzania, these figures represent an estimate of 70,000-80,000 children who get infected with HIV annually as estimated by the Tanzania Commission for AIDS (TACAIDS) (TACAIDS, 2010). However; in 2009 alone, UNAIDS (2009) reported about 33,000 children who contracted HIV from their mothers. The two data from TACAIDS and UNAIDS show a big difference of HIV infection among children per year. It might be is due to poor quality of data, or they are true figures. But even if the figure 33,000 is taken into account, still the infection is high.

Prevention of MTCT is defined as prevention of mother to child transmission (PMTCT) of HIV (WHO, 2010a). PMTCT is one of the most powerful and cost-effective healthcare program to prevent HIV among children. With effective PMTCT interventions, the risk of MTCT can be lowered to <5% in breastfeeding children or <1% in non-breastfeeding children (WHO, 2010a). It was initiated by WHO in 2000 aiming to prevent new HIV infection among children by 50% or to less than 5% by 2015 through four main components as follows (UNICEF, 2009), (WHO 2010a), (WHO, 2012):

- 1. Primary prevention of HIV among women of child bearing age
- 2. Prevention of unintended pregnancy among HIV⁺ women
- 3. Prevention of transmission from HIV⁺ women to their infants
- 4. Provision of appropriate treatment, care, and support to HIV⁺ parents and their children

According to WHO (2012) new PMTCT guidelines; PMTCT program starts as soon as the woman encounters antenatal clinic (ANC) services and be diagnosed HIV+ and ends one week after cessation of breastfeeding for Option A while for Option B and Option B+, PMTCT ends after the cessation of breastfeeding (annex 3). It is mainly focusing on HIV treatment for HIV⁺ women and infants and implementation of infant feeding options. The aim is to prevent HIV infections from HIV⁺ women to their unborn babies during pregnancy, labour and delivery and for newborn babies during breastfeeding while leaving their mothers alive and healthy (MoH, 2007), (WHO, 2012).

The program is composed of a set of interventions (annex 1) that are offered in a systematic flow (annex 2) regardless which stage the woman

encounters the ANC. The interventions include; pregnant women informed and counselled for HIV and PMTCT (emphasis are for couples); be offered and accept HIV testing; receive antiretroviral therapy (ART) for women and ARV prophylaxis for infants after birth (annex 3); be delivered with skilled attendants; follow safe infant feeding recommendations and infant testing for HIV at 18 months of age or by PCR at any time; continue with medical follow up as scheduled (MoH, 2007), (WHO, 2010a), (WHO, 2012).

In Tanzania; PMTCT program was initiated in 2000 aiming to reduce MTCT and increase survival among children born to HIV⁺ mothers by 50%. By 2010; 86% of pregnant women were tested for HIV for PMTCT and 59% of HIV infected pregnant women were enrolled on ART (TACAIDS, 2010). In 2010; Tanzania commission for AIDS (TACAIDS) reported a LTFU of 35% of children who were enrolled in PMTCT program (TACAIDS, 2010). For effective and optimal PMTCT outcomes; HIV⁺ women and children must adhere to all PMTCT interventions and follow the PMTCT recommended regimens. That means; accepting and taking active changes of behaviours equivalent to agreed PMTCT recommendations from a health care practitioner to prevent mother to child transmission of HIV (WHO, 2003), (Osterberg, 2005), (Vrijens, 2012).

In relation to high uptake of PMTCT services at ANC (86%), high number of children infected with HIV annually (80,000) and low level of adherence to PMTCT regimens reported; I was elicited to investigate the reasons for this discrepancy. I'm interested to investigate the reasons for why low adherence to PMTCT regimens among women. These might be important factors that contribute to unacceptably high HIV infection among children.

By tackling factors that influence women on adherence to PMTCT regimens; it will improve the women's behaviours on adherence to PMTCT regimens thus reducing chances of MTCT (UNICEF, 2009), (WHO, 2010a). Factors influencing women on adherence to PMTCT regimens might be reflecting factors that influence people living with HIV and AIDS (PLWHA) in general population on uptake and adherence to HIV regimens as a whole.

Therefore; the study findings will help to improve adherence to PMTCT regimens among HIV⁺ women in PMTCT programs. Also the findings will be replicated to improve adherence to HIV and AIDS regimens among PLWHA in the general population. By improving adherence to PMTCT regimens; it will reduce MTCT therefore reduce child mortalities to meet MDG 4 while simultaneously also it will contribute to combat HIV infection to meet the MDG 6. As part of PMTCT regimen; adherence to ART will contribute to improve maternal health therefore meet MDG 5. Correspondently as the lives of HIV⁺ women (15-49 years) improve, they will participate in production activities thus it will contribute to meet MDG 1 (eradicate extreme poverty and hunger) (UNAIDS, 2011).

CHAPTER 1.0: BACKGROUND INFORMATION

1.1. Geographical, political and administrative structure

Tanzania is a United Republic of Tanganyika and Zanzibar that were united in 1964 (annex 4). It is located in East Africa and it borders with Uganda and Kenya in the north; Rwanda, Burundi and Congo in the west; Mozambique, Malawi and Zambia in the south and Indian Ocean in the east. It has an area of 945,090Km² that is divided into 30 administrative regions and 150 districts. Each district is further subdivided into divisions, wards and villages. The district is the central administrative and implementing unit for public services connecting the local government authorities and the central government authorities while the village is the first level of government administration. Since independency in 1961, Tanzania has been operating under democracy presidential system of mono party followed by multi party in 1995. Socially Tanzania applies patriarchy system (TACAIDS, 2011), (NBS, 2011b).

1.2. Demographic and Socio-economic

Tanzania has an estimated population of 45million whereby 51% (23million) are females and 49% (22million) are males. Children aged 0-14 years are 19 million and population at child bearing aged 15-45 years are 12.2million. The crude birth rate is 42.5births/1000 populations while the death rate is 11.9 deaths/1000 populations. The fertility rate is 5.4children/woman and annual population growth rate is 2.7%. Life expectance at birth is 53.14% (54.7% for women and 51.6% for men) (NBS, 2012a), (NBS, 2012b).

The economy of the country depends on agriculture that accounts for 30% of the growth domestic product (GDP) and employs 80% of the population. In 2010 the nation GDP growth rate was 7% with 36% of the population being living below poverty line of \$ 1.25/day (Bhakta, 2011), (NBS, 2011a).

1.3. Health care system, deliveries and HIV situation in Tanzania

1.3.1. Health care system and deliveries

The Ministry of Health (MoH) and social welfare is responsible for all matters pertaining to health in the country. Health care services are provided through three levels of facilities; the dispensaries being at the lowest level, health centres and the hospital as a highest level. Health services are decentralized at district level in order to improve efficiency and effectiveness of health services. In 2010 the total health facilities were 5,987 and were owned as follows (MoH, 2009).

Table 1. Distribution of health facilities by ownership

FACILITY	PUBLIC	PARASTATAL	FBO	PRIVATE	TOTAL
Hospital	95	6	96	35	232
health centers	398	6	103	56	563
Dispensaries	3526	189	635	842	5192
Total	4019	201	834	933	5987

Source: (MoH, 2009).

Utilization of health care services is as low as 15.6% among people without health insurance and 13.2% among rural residents (Makawia, 2010). However; only 68% of pregnant women attend reproductive and child health (RCH) services and only 46% of pregnant women deliver in health facilities (MoH, 2008). Inaccessibility, un-affordability, inadequate resources (financial, human and non-human resources) and poor health care services are some of the factors among others that affect utilization of health care. To improve the challenges and striving to meet the MDGs; Tanzania has adopted the public private partnership (PPP) system in its health care delivery system (MoH, 2008), (TACAIDS, 2012).

Health care system is financed by various sources including public financing, external donors, out of pocket (OOP) and private insurance schemes. 26% of the total health expenditure (THE) is contributed by public financing, 39.6% by external donors, 32.3% by OPP and 2.1% by private sectors. In 2009/2010 THE was \$1,751millions equal to 8% of the GDP (MoH, 2009).

1.3.2. HIV situation in Tanzania

Human Immuno-deficiency Virus (HIV) that causes Acquired Immune Deficiency Syndrome (AIDS) is one of the major public health problem in Tanzania. HIV is described as stable and unevenly distributed across geographic areas, gender, age groups and social economic classes. Its effects affect all sectors and people of all ages leading to poor social and economic development. The nation prevalence of HIV is 5.7% (6.8% in women and 4.7% in men). The prevalence differs from one region to another ranging from 0.3% to 15% across the country (UNAIDS, 2010).

Population aged 15-49years who are sexually active are mostly infected with HIV. The HIV prevalence among this group is 5.6% (4.6% male and 6.6% female). Heterosexual is the dominant mode of HIV transmission accounts for >80% of the total HIV infections among this group. However Mother to child transmission (MTCT) of HIV accounts for 91% of HIV infection among children aged 0-14 years and 18% of the total HIV infections in general population. In 2009 alone, it was estimated that 33,800 children were newly infected with HIV through MTCT (UNAIDS, 2010). By 2009; a total of 86,000 people had died due to AIDS (TACAIDS, 2011). The following table 2; displays HIV prevalence among different population groups in Tanzania.

Table 2: HIV infection among different population groups in 2009

Population category	%	Estimated number
National HIV prevalence	5.7%	1.6 million
HIV prevalence among adults 15-49 years	5.6%	1.3million (81% of total HIV infections)
HIV prevalence among women 15-49 years	6.6%	760,000 (59% of total HIV infections)
HIV prevalence among pregnant women	5.5%	88,653
HIV prevalence among children 0-14 years	1.3%	230,000 (14% of total HIV infection)
HIV incidence among children	0.2%	33,000

Source: (UNAIDS, 2010).

HIV and AIDS pandemic has substantially changed the nature of health care and delivery system by increasing the demand for health services and at the same time have reduced the ability of the health systems to supply the services. Priorities on resources, budgetary and managerial efforts have moved towards HIV and AIDS prevention, care, treatment and support while other health delivery systems and care are inadequately supplied to meet the demands (Mubyazi, 2012).

The coverage and utilization of HIV services including PMTCT services are still insufficient. These are associated with stigma as the major barrier for accessing and utilizing the services (TACAIDS, 2010), (T-MARC, 2010), (UNAIDS, 2010), (Akarro, 2011), (TACAIDS, 2012a). To overcome stigma and discrimination; in 2008 the Tanzanian parliament passed the HIV and AIDS Act against stigma and discrimination towards people living or affected with HIV and AIDS (National Assembly, 2008).

1.4. Responses to HIV and coordinating structure:

1.4.1. HIV coordination structure

HIV interventions are coordinated by National AIDS Control Program (NACP) which was formed in 1985. To complement to NACP; Tanzania Commission for AIDS (TACAIDS) was established in 2002. Its aims are to coordinate and provide strategic guidance to HIV and AIDS programs, projects and interventions to all stakeholders. All interventions are in line with the national HIV and AIDS policy which was put in use since 2001 (TACAIDS, 2009), (TACAIDS, 2011).

1.4.2. HIV responses:

97% of national HIV expenditure is from external donors (TACAIDS, 2012*b*). This has made available and affordable for HIV and AIDS services to every individual. All HIV services are provided free of charge or in subsidized costs in private facilities. Implementation of HIV activities is done by public, private, NGO and CBO (MoH, 2005), (TACAIDS, 2011). In response to PMTCT; in 2008 PMTCT program was integrated into routine RCH package in order to increase PMTCT uptake. Since then; the total PMTCT uptake improved from 59% in 2008 to 86% in 2011 (TACAIDS, 2012*a*).

CHAPTER 2.0: PROBLEM STATEMENT, JUSTIFICATION, OBJECTIVES AND METHODOLOGY

2.1. Problem statement

Although prevention of HIV infection from HIV⁺ women to their children is quietly possible with effective PMTCT services; still every year about 430,000 children globally and 80,000 children in Tanzania are infected with HIV through MTCT (UNICEF, 2009), (TACAIDS, 2010), (WHO 2010*b*).

Adherence to PMTCT regimens is a major challenge that hinders the effectiveness of PMTCT program in developing countries causing unacceptably high MTCT. Loss to follow up (LTFU) and poor adherence to PMTCT regimens is high at every stage of PMTCT cascade (Theuring, 2011), (Kalembo, 2012a).

In Sub-Saharan Africa it is estimated that, about 15%-30% of women who are enrolled in PMTCT program do LTFU before completing the PMTCT program. 20%–28% of all LTFU occurs during antenatal, up to 70% at four months after delivery and up to 81% at six months after delivery (Busza, 2012), (Kalembo, 2012a).

According to Kirsten (2011); a cohort study that was done at a rural district hospital in Tanzania to study adherence to combination prophylaxis for PMTCT among HIV⁺ women during pregnancy, delivery and after delivery; reported an overall adherence level of 38.4% to ARV prophylaxis among women who were enrolled in the study. Moreover; in 2010, TACAIDS reported an overall LTFU of 35% among children who were enrolled in PMTCT program in Tanzania (TACAIDS, 2010). All these confirm that there is poor adherence to PMTCT regimens.

2.2. Study justification

Adherence to PMTCT regimens and treatment is critically important among HIV⁺ pregnant and lactating women and infants for effective PMTCT. Good adherence suppresses and maintains down the viral load therefore improves maternal health to enable PMTCT. With effective adherence to PMTCT regimens, MTCT can be reduced to less than 1% (WHO, 2010*a*).

The ability for women to optimally adhere to PMTCT regimens is frequently compromised by one or more barriers that could be related to different factors. Addressing factors causing poor adherence is essential in order to enable HIV^+ women to adhere to PMTCT regimens correspondingly reduces the risks for MTCT (WHO, 2012 \emph{b}).

This study therefore, is primarily intended to benefit HIV⁺ women and their newborn infants. It also provides recommendations to Ministry of

health (MoH) in Tanzania and its partners on development of or improving existing interventions that will facilitate HIV⁺ women to adhere to PMTCT regimens. Also will assist on developing interventions that will address barriers that hinder HIV⁺ women from adherence to PMTCT regimens.

2.3. Study objectives

2.3.1. General objective is to:

Explore factors that influence HIV⁺ women on adherence to PMTCT regimens in Tanzania in order to make recommendations to MoH in Tanzania and its partners on development of or improving existing interventions that will facilitate HIV⁺ women to adhere to PMTCT regimens. Also develop interventions that will address barriers that hinder HIV⁺ women from adherence to PMTCT regimens.

2.3.2. Specific objectives are to:

- 1. Analyse an overview of PMTCT adherence among children and HIV⁺ women in Tanzania
- 2. Explore factors that hinder HIV⁺ women from adherence to PMTCT regimens
- 3. Explore factors that enable HIV⁺ women to adhere to PMTCT regimens
- 4. Explore interventions that have been used in Tanzania and in other countries in Africa to improve adherence to PMTCT regimens among HIV⁺ women.
- 5. Make recommendations to the MoH in Tanzania and its partners about the interventions that can improve adherence to PMTCT regimens among HIV⁺ women and how to address factors that hinder HIV⁺ women from adherence to PMTCT regimens.

2.4. Methodology

2.4.1. Study type and design

The study was a literature review; to explore factors that influence HIV⁺ women on adherence to PMTCT regimens in Tanzania.

2.4.2. Data collection technique

Data collection was done through literature review of published peer-reviewed journals, scientific reports, national and international policy documents and guidelines, and chapters in books. The literature review was focused on studies that were done on MTCT especially on factors influencing adherence to PMTCT in Tanzania and from other countries in Africa. Both qualitative and quantitative studies were studied.

Social ecological model (SEM) and Health Believe Model (HBM) were used as frameworks to guide searching and analysis of factors that hinder and

that enable HIV⁺ women on adherence to PMTCT regimens (the models are described in details in section 2.4).

2.4.3. Literature Search strategy

Review of hardcopies from different sources including libraries; and use of electronic sources like PubMed, Scopus and Google scholar search engines were used to obtain published peer reviewed journals, scientific reports, national and international documents and guidelines and books of related research objectives.

2.4.4. Selection criteria

After screening all titles and abstracts from different sources; eligible studies were selected based on the following criteria:

- 1. Full articles that answered the research objectives.
- 2. Articles of studies that were done between 2005-2013
- 3. Purposively; national and international guidelines, policies, document, reports and publications published or unpublished before or after 2005 were used basing on their significance importance for this study.
- 4. Published and unpublished studies that were conducted before 2005 and that were in languages other than English were excluded.
- 5. Gray literatures were only used to expand knowledge on background information but were not included on analysis of the results.

2.4.5. Study limitation

- 1. Literature review methodology was not suitable to studying current actual behaviours of HIV⁺ women on adherence to PMTCT regimens in Tanzania.
- 2. The study was limited to unpublished data especially on trend of PMTCT program and interventions that are done in Tanzania to improve adherence to PMTCT

2.5. Conceptual frameworks

In order to systematically explore and describe factors that hinder and that enable HIV⁺ women to adhere on PMTCT regimens; the SEM and HBM were adopted and used as guides.

The SEM was mainly used in this study to explore both internal/individual and external factors influencing women on adherence to PMTCT regimens. The model is strong on external factors that contribute to one's behaviour of doing/not doing an action; in this case adherence to PMTCT regimens. The individual factors in SEM do overlap with the modifying factors and individual beliefs in HBM. Therefore both models were used

complimenting to each other to explore these factors. HBM was used to explore internal factors. It is strong on internal factors that affect one's behaviour on doing an action; in this case adherence to PMTCT regimens. The "likelihood to take action" of the HBM was used to analyze the reasons why HIV⁺ women take such actions and behaviours for adhering to PMTCT regimens or not. The SEM and HBM are described as follows below.

2.5.1. Social Ecological Model

SEM is a theoretical framework that analyses social communications and behaviour changes. The model provides a systematic approach to understand why people do the things they do and how their environment context contribute for their behaviours. The model is divided into four main levels; individual level (internal factor), social networks, community context and social cultural environments (external factors). The levels are linked but not necessarily dependant to one another to cause an effect. Although; it is acknowledged that change in one level may influence other levels (Busza, 2012).

This model was adapted from Busza (2012). The model was used in this study as a guide in literature review for factors that influences HIV⁺ women on adherence to PMTCT regimens. It helped to make linkages between one factor to the other and how the factors affect HIV⁺ women's adherence to PMTCT regimen basing on the main four levels of the model. The following is a figure of the SEM showing the four levels and factors influencing adherence as used in this study.

HEALTH SYSTEMS COMMODITIES SOCIAL CULTURAL ENVIRONMENT FACTORS Religion Health beliefs **Delivery practices Breastfeeding practices** Gender norms COMMUNITY CONTEXT FACTORS Perceived quality of care Distance to health services Cohesion and empowerment Social network Stigma SOCIAL NETWORK FACTORS Access to resources Partner involvement Communication and disclosure Social support INDIVIDUAL FACTORS Risk perception Self efficacy Mental health Physical health **LEGAL AND POLICIES STRUCTURES INFRASTRUCTURES**

Figure 1: Social Ecological Model.

Factors influencing adherence to PMTCT regimens

Adopted and modified from (Busza, 2012).

Levels of social ecological model in linkage to PMTCT program

1. Individual factors

Identifies women's personal factors that influence their abilities on adherence to PMTCT regimens.

2. Social networks

Examines women's close relationship with closest friends, peers, relatives or spouses that may influence women's ability on adhering to PMTCT regimens.

3. Community context

Explores social structures or institutions such as health facilities, religious institutions and social network where social relationships occur. It seeks to identify characteristics of these structures and how they influence HIV⁺ women on adherence to PMTCT regimens.

4. Social cultural environment

Explores broad societal factors such as social and gender norms and believes; legal and policies structures and religious beliefs that create a climate that either promote or hinder HIV⁺ women from adhering to PMTCT regimens.

2.5.2. Health Belief Model

HBM is a psychological model that describes individual behaviours on adherence to medical/health regimens. It is usually used in studies of preventable diseases and diseases of lifestyle behaviours to explore attitudes and beliefs of individuals about health and its outcomes. The HBM was first developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels in response to the failure of a free tuberculosis health screening program. Afterward, the HBM has been modified to study different health conditions related to individuals' health-related behaviours and ways to stimulate positive behaviour changes. The HBM contains several primary concepts that forecast why people will take action to prevent, to screen for, or to control illness conditions including HIV and AIDS. These include susceptibility, seriousness, benefits and barriers to behaviour, cues to action and self-efficacy (Glanz, 2008).

Evidences for the model's performance

Glanz (2008) reported that; a critical review of HBM studies were conducted between 1974 and 1984 and the findings were compared with other earlier findings to certify the effectiveness and performance of the model. Until these years HBM is still used in many health behaviour researches.

Limitations of the model

In both descriptive and intervention researches where HBM is to be used, measures of specific behaviour of study must be specific and relevant to the population to be studied. This is because for example; barriers to a certain disease may be quite different from barriers to the other disease (Glanz, 2008). The following table 3 shows concepts of HBM and their linkages as used in this study. Table 4 defines the concepts to give their meanings and how they are applied in studies.

Table 3: Health Belief Model

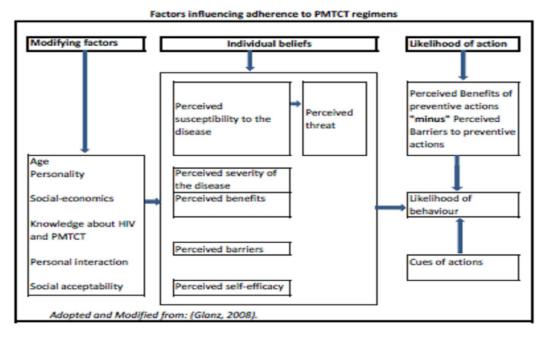


Table 4. Explanation of concepts in health belief model

Concept	Definition	Application
Perceived Susceptibility	These are one's belief about the chances of experiencing a risk or getting a condition or disease	Define population(s) at risk and risk levels. Personalize risk based on a person's characteristics or behaviours. Make perceived susceptibility more consistent with individual's actual risk
Perceived Severity	These are one's belief about how serious a condition and its consequences are	Specify consequences of risks and conditions
Perceived Benefits	These are one's belief in the efficacy of the advised action to reduce risk or seriousness of impact	Define action to take: how, where, when; clarify the positive effects to be expected
Perceived Barriers	These are one's belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, and assistance
Cues to Action	These are strategies to activate readiness to perform an action eg. preventive interventions	Provide 'how' to information, promote awareness, use appropriate reminder and follow up systems
Self-Efficacy	Is a confidence in one's ability to take action	Provide training and guidance in performing recommended action Use progressive goal setting Give verbal reinforcement Demonstrate desired behaviors Reduce anxiety

Source: (Glanz, 2008).

CHAPTER 3.0: OVERVIEW OF ADHERENCE TO PMTCT REGIMENS AMONG HIV* WOMEN AND CHILDREN IN TANZANIA

This chapter answers the first objective that is to analyse an overview of adherence to PMTCT regimens among children and HIV⁺ women in Tanzania. Data from different sources about adherence to PMTCT regimens among HIV⁺ women and children were presented followed by short analysis of the results.

3.1. Status of adherence to PMTCT regimens among HIV⁺ women

Between 2000 and 2010, about 86% of pregnant women who attended RCH had HIV tests for PMTCT. But only 55% of those who were eligible for ART received ART for PMTCT (TACAIDS, 2010), (MoH, no year). However; there were no data that showered the percent of women who adhered to treatment during this period. But studies suggests that in developing countries; about 15%-30% of women who are enrolled in PMTCT program (including ART) do LTFU before completing the PMTCT program (Busza, 2012), (Kalembo, 2012a).

These data by TACAIDS (2010) and MoH (no year) show a country broader overview of enrolment of women into PMTCT program in 10 years period collectively. The data might not be generalized to represent the real picture of adherence at different times, settings e.g. rural/urban areas, or at different levels of health care system e.g. primary, secondary or tertially levels. This is to say; when these data are segregated probably the status might be worse.

In order to explore more about adherence status among women in segregated aspects, the following study was explored.

A cohort study was conducted at a rural district hospital in Tanzania to study adherence to ARV prophylaxis among HIV⁺ women during pregnancy, delivery and after delivery. The hospital has been providing PMTCT services since 2001; and PMTCT program is supported by the German Agency for Technical Co-operation. The adherence results are presented on figure 2 below (Kirsten, 2011).

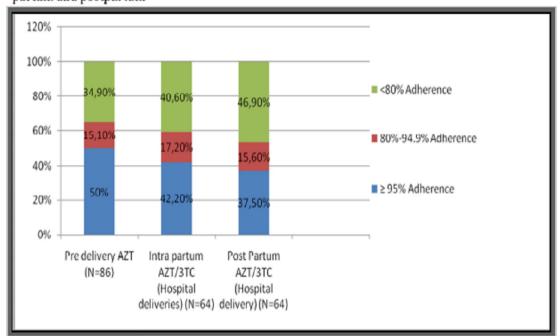


Figure 2. ART adherence levels among HIV* women during pre-delivery, intrapartum and postpartum

Source: (Kirsten, 2011)

The data above show that; among 86 HIV⁺ women who were tested for AZT adherence level before delivery, 34.9% had adherence level below 80%, 15% had adherence level between 80%-94.9% and 50% had adherence level ≥95%. However; among 64 HIV⁺ women who tested for AZT/3TC adherence level during delivery, 40.6% had adherence level below 80%, 17.2% had adherence level between 80%-94.9% and 42.2% had adherence level ≥95%. Moreover; adherence level after delivery among 64 HIV⁺ women who tested for AZT/3TC adherence level shows that, 46.9% had adherence level below 80%, 15.6% had adherence level between 80%-94.9% and 37.5% had adherence level ≥95%.

The overall adherence level during the study was reported as only 38.4% despite the hospital being providing PMTCT services for 10 years with additional external support apart from government incentives. This implies that, still there is a challenge of adherence to PMTCT regimen among HIV⁺ women but the results can't be generalized to reflect the situation in urban or remote rural areas or in lower level health facilities.

3.1.2. Status of adherence to PMTCT and ART among children

As reported by TACAIDS (2010) and MoH (no year); 57% of infants born to HIV^+ women were initiated on ARV prophylaxis between 2000 and 2010 while 35% of them LTFU before completing the PMTCT program. Moreover; among infants who contracted HIV; only 18% of those who

were eligible for ART were enrolled in treatment; 35% of them LTFU by 12 months and 46% LTFU by 24 months.

These data show a country overview of enrolment and LTFU of children from PMTCT and ART programs. In general, there is inadequate enrolment of children into PMTCT and ART program and a big problem of retaining children into the programs. Because the data give a general country overview of ten years; the situation of enrolment and retention might be different to worse if data are segregated in different periods or as per settings (rural and urban) or as per levels of health facilities (primary, secondary or tertially). LTFU among children might also reflect LTFU among HIV⁺ women because they are key prayers for children's adherence to PMTCT regimens.

In summary; this chapter showed an overview of adherence to PMTCT regimens among HIV⁺ women and children on ART. Overall, the results revealed that there is poor adherence to PMTCT regimens among HIV⁺ women and children. The following chapter will explore factors that might cause this situation and furthermore it will also explore and discuss factors that enable HIV⁺ women to adhere to PMTCT regimens.

CHAPTER 4.0: FACTORS THAT HINDER AND THAT ENABLE HIV+WOMEN TO ADHERE ON PMTCT REGIMENS

This chapter answers the second and the third objectives of this thesis about exploring factors that hinder HIV⁺ women from adherence to PMTCT regimens and that enable HIV⁺ women to adhere on PMTCT regimens. To answer these objectives, factors influencing adherence to PMTCT regimens were explored from Tanzania and from other African countries. These factors might have contributed to poor adherence to PMTCT regimens as analysed in chapter 3. Both barriers and enablers factors were explored and analysed by using the SEM and HBM conceptual frameworks as described in chapter 2.

4.1. Factors that hinder HIV⁺ women from adherence to TMTCT regimens

4.1.1. Individual factors:

Perceived susceptibility to the disease

According to Busza (2012); majority of women who perceived themselves to be at low or no risk to HIV infection (e.g those in monogamy marriage) were more likely to refuse taking HIV tests. For those who happened to test for HIV and tested HIV⁺; they refused to enrol into PMTCT program because of denials. Likewise; HIV⁺ mothers whose children were born with good body weight were found to resist starting and adhering to PMTCT regimens because they perceived their children would have not being infected with HIV.

Perceived severity of the disease

Apart from perceiving to be at low risk to HIV infection; beliefs about seriousness of HIV and AIDS and the related consequences has been a challenge to most of women to decide taking HIV test. This is driven by fear of being tested HIV⁺; the fear that is built on the fact that HIV has no cure. Therefore, women often fear knowing their HIV⁺ status because they feel it could lead them into deep emotional sufferings and deteriorate their health conditions as quoted below (Moth, 2005), (Muchedzi, 2010), (Akarro, 2011), (Sprague, 2011), (Kalembo, 2012a).

"I would like to know my status if this will prevent my baby from getting infected, but on the other hand I fear knowing that I am among the dead and I am to experience much suffering of AIDS, so I would not want to know my HIV status for fear of those deep thoughts" (Akarro, 2011).

Knowledge about HIV and PMTCT

Knowledge about HIV and PMTCT has a great role on influencing HIV⁺ women on adherence to PMTCT regimens. As described above, poor perception about susceptibility to HIV infection and severity of HIV and AIDS can be associated with inadequate knowledge about HIV and MTCT. According to T-MARC (2010); women who have inadequate knowledge about HIV and PMTCT were more unlikely to take HIV tests and ARV prophylaxis. In T-MARC's study; only 18% of women knew MTCT was a mode of HIV transmission among children.

T-MARC (2010) continues; in correlation to participants who refused to take HIV tests and ARV prophylaxis; majority of participants who had inadequate knowledge about MTCT being a mode of MTCT, refused to take HIV tests while others refused to take ARV prophylaxis. Additionally, Nassali (2009) reported that; HIV⁺ women who have no previous knowledge or experience about PMTCT are four times more unlikely to adhere to PMTCT regimens than those who have knowledge/experience about PMTCT program.

Poor adherence to PMTCT regimens due to inadequate knowledge about HIV and PMTCT was also supported by Boateng (2013) in a cross sectional study that was done in Ghana on knowledge and perception about ART, PMTCT and adherence to ART among HIV⁺ women. The study revealed that HIV⁺ women who had inadequate knowledge about HIV, PMTCT and ART were more likely to miss their ART appointments. Moreover; LTFU was 29% among HIV⁺ women with inadequate knowledge about HIV, PMTCT and ART compared to 0% among HIV⁺ women with adequate knowledge.

Perceived barriers

Akarro (2011) conducted a study in Tanzania to evaluate male involvement in PMTCT program. The study found that; male partners were among the big barriers that hindered HIV⁺ women from adherence to PMTCT regimens. Women who perceived to be hindered by their spouses from adherence to PMTCT regimens were unlikely to enrol or adhere to PMTCT regimens. Moreover; women's willingness to disclose their HIV⁺ status which is an important aspect on adherence to PMTCT regimens are hindered by perceived barriers e.g. blame, stigma, discriminations and violence from their spouses. To avoid such embarrassments; HIV⁺ women tend to withhold their HIV⁺ status that consequently lead to poor adherence to PMTCT regimens (Sprague, 2011), (Dillabaugh, 2012).

In the following quotes, Duff (2010) highlights different opinions from HIV⁺ women on how perceived barriers to PMTCT program leads to poor adherence to PMTCT regimens:

"I did not tell my husband because he refused to go for a check up with me, so I decided to wait to start these drugs because when I tell him he will say I am the one who brought the disease." (Never enrolled in HAART) (Duff, 2010).

"The reason why I did not tell my husband is that I thought that when he sees me taking the drugs he will say that I am the one who has brought the disease and he will beat me. I was taking the drugs secretly and thereafter said to myself, how long will I keep hiding the drugs, and I decided to leave the drugs." (Defaulted HAART) (Duff, 2010).

"He might find out about my HIV status if I want to use a condom. I haven't decided yet since I haven't yet started on treatment. I still fear him." (Enrolled but never began HAART) (Duff, 2010).

"I realized that I was wasting my time because I was taking HAART and having unprotected sex. It was a waste of time because I am not supposed to be having unprotected sex while on HAART." (Defaulted HAART) (Duff, 2010).

Although Akarro (2011) did not exactly mention the kinds of violations HIV⁺ women get from their spouses following disclosure of their HIV⁺ status; different studies from Africa had the same outcome and described the types of violence as being physical violence such as assaults and battering; sexual violence such as restriction to sexual acts, abandonments and divorces; psychological violence that included blames, judgments, rejections, denials, stigma and discriminations; and financial violence that includes restriction of financial assistance to meet basic needs (HDT, 2009), (Nassali, 2009), (Duff, 2010), (Njunga, 2010), (Sasaki, 2012) and (Madiba, 2013). In relation to the PMTCT related consequences among HIV⁺ women; some people in Malawi term PMTCT program as "the divorce Program" (Nassali, 2009).

The following quotations state women's expressions about fear of adherence to PMTCT regimens when anticipating barriers from their spouses:

"My child was very young and I knew that if I told [my husband] he would run away from me and leave me suffering with the child. So that is why I fear to tell him." (never enrolled in HAART) (Duff, 2010).

"I cannot disclose my HIV status to my spouse because I fear for my life, physical beating and discrimination. He can even chase me from his home and if this happens where do I go at my age?" (Month, 2005).

"My husband might see me with the medicines, and he will want to know what they are for. That way he will find out about my [HIV positive test] status" (Akarro, 2011).

Age

According to the study that was done by Kirsten (2011), about adherence to combination prophylaxis for PMTCT in Tanzania; young HIV⁺ pregnant women are more unlikely to adhere to PMTCT regimens. This was

revealed among study participants who were aged 23 years or below, were unlikely to adhere to PMTCT regimens. It is because; they are still immature for self-efficacy on decision making and psychological stability. Moreover; lack of money due to unemployment causes them to become economically dependents to their spouses who might be unable to fully support their PMTCT financial needs. Therefore affects adherence consistencies (Nassali, 2009).

Perceived self-efficacy

Regardless the age; women who lack self-efficacy to make decisions on adherence to PMTCT regimens are always found themselves doing whatever the family decides because they fear of being socially discriminated and isolated (Roura, 2009). The following quotation reveals:

I was told at home that I should not go to hospital but I should go to church",.....".... this disease has no cure so you are just wasting your time going to hospital....","once you are segregated by your parents, where will you go?" (Roura, 2009).

"They tell him/her, aha, this disease has no cure so you are just wasting your time going to hospital. She comes to tell you again that "I was told at home ... that I should not go to hospital but I should go to church and I have answered them that I want to go to hospital." That's a problem too ... sometimes he/she wants to go and check CD4 but you find that the family takes him/her to traditional healers ... They say "these people just deceive you, you must be bewitched." So when you return tothat family you find that she is not there ... Most of such people we get them from a family that has got so many doubts so they have decided to take him/her totraditional healers." (Roura, 2009).

Social economic

Despite the fact that self-efficacy plays an important role on women's ability to adhere on PMTCT regimens; but lack of money for transport and for paying medical costs are contributing factors that hinder women from accessing PMTCT services also fail to adhere to infant feeding options. Non-breastfeeding women fail to afford formula milk for their infants while those breastfeeding fail to exclusively breast feed for six months if they experience food inadequacy. These lead to mixed infant feedings thus increases the risks of MTCT. Moreover; food shortage increases the severity of ART side effects and upsets that cause majority of HIV+women to discontinue from ART (Moth, 2005), (Hardon, 2006), (Nassali, 2009), (Roura, 2009), (Duff, 2010), (T-MARC, 2010), (Sprague, 2011), (Ekama, 2012), (Sasaki 2012), (Kalembo, 2012a), (Boateng 2013), (McNairy, No year).

In an exploratory study to explore barriers to access highly active antiretroviral therapy (HAART) among HIV⁺ women in Uganda; Duff (2010) reported that; 93% of respondents reported lack of transport fares

as a major barrier for accessing and adhering to ART. The citation below reveals:

"[The reason I defaulted was] the transport issue. Sometimes the transport money would not be enough and I would miss coming so I would feel like if I miss one month, then I should completely give up on HAART." (Defaulted HAART) (Duff, 2010).

Physical health

Health status of HIV⁺ women and children influences adherence to PMTCT regimens. Poor health affects women's ability to maintain appointments and taking drugs (Duff, 2010), (Muchedzi, 2010), (Boateng, 2013), (McNairy, No year). A follow-up study which was conducted in Tanzania to explore attrition from ART program found that; HIV⁺ women whose health status were deteriorating had higher rate of dropping out from PMTCT program than those who were improving (Roura, 2009). The following quotation proves:

"....He is ignoring these drugs. Maybe he has used them without any good results, and hence he decided to quit using them completely. Our friend wanted to get better immediately..." (Non-adherent due to poor health gain) (Roura, 2009).

Additionally; nausea and vomiting as pregnancy conditions that affects about 70%-85% of pregnant women, are worsened by side effects of ART e.g. Zidovudine. Therefore alters adherence to ART intake during pregnancy (Hardon, 2006).

Contrary to the deteriorated health as being a factor for poor adherence; Roura (2009), Hardon (2006) and Duff (2010) reported that; HIV⁺ women who had improved from poor health conditions are also more likely to drop out from PMTCT program. The following quotations reveal:

"... she was in a bad condition, she has used these drugs and her condition became well ... she felt that she was cured, hence there was no need of going to the clinic. It will make her think that she is well, she is just healthy and sound, she doesn't feel any pain, and from there she will see those things as useless." (Non-adherent due to good health gain) (Roura, 2009).

"And when she goes to the clinic she uses her own ways, she goes to the clinic and she gets those drugs, and when she brings them at home, she has to take them secretly. Now she starts asking herself, "there is a day when I will be discovered here," now when she regains her health somehow, she thinks that she is cured, she decides to quit taking the drugs. She actually quits." (Roura, 2009).

Additionally, in an exploratory descriptive study to explore barriers to access HAART among HIV^+ women in Uganda; Duff (2010) explored that;

60% of women who refused to enrol on ART had good conditions. The quotation below states:

"How can I start on the drugs and yet I am not yet bedridden and I have not felt anything and not seen any symptoms....." (Never enrolled in HAART) (Duff, 2010).

Mental health

Apart from physical health; poor mental health affect PMTCT adherence behaviours. HIV⁺ women who are depressed or have emotional stresses are unable to maintain their medical appointments, taking drugs and adhere to infant feeding choices (Hardon, 2006), (Busza, 2012), (Sasaki, 2012), (Boateng, 2013).

Emotional health

Poor counselling makes majority of women tested HIV⁺ feel deep emotion stressed due to fear of infecting their babies, fear of HIV infection and related consequences. Therefore, majority despair to follow PMTCT regimens (Nachega, 2012).

Stigma

Self-stigma makes HIV⁺ women feel psychological stressed and depressed. This makes them to refuse disclosing their HIV⁺ status and withdraw from social life including accessing PMTCT services (T-MARC, 2010).

4.1.2. Social network factors

Communication and disclosure

Communication, disclosure and discussion of women's HIV $^+$ results with their spouses do increases opportunities for women to obtain permissions from their spouses to continue with PMTCT services. HIV $^+$ women who fail to communicate and disclose their HIV $^+$ results due to fear of stigma, discrimination and violence have low chances of adhering to PMTCT regimens (Sarker, 2007), (Stutterheim, 2011), (Morfaw, 2013).

According to Morfaw (2013), a systematic reviews study about barriers and facilitators for male involvement in PMTCT programs in Tanzania showed that; HIV⁺ women who communicated their HIV⁺ results to their spouses were three-times more likely to use Nevirapine prophylaxis and six-times more likely to adhere to infant-feeding choices than those who didn't disclose and discuss their HIV⁺ status.

Social support

According to Moth (2005), Hardon (2006), Duff (2010), Busza (2012), Sasaki (2012) and Boateng (2013); HIV⁺ women who lack family and social support e.g. psychological support, support for food and finance to meet basic needs are more unlikely to adhere to PMTCT regimens as

described in section 4.1.1 under *social economic* and *emotion health*. The following quotation states:

"....I doesn't earn anything"... "If I told my husband I were HIV positive he would stop buying food and drinks and that is why I decided to keep quiet and I used to take my drugs secretly. If I told him he would have stopped all forms of assistance..." (Defaulted HAART) (Duff, 2010).

Moreover; pressures from family members e.g. mothers in law on adhering to traditional forms of delivery and infant feeding, hinder women from adhering to delivery and infant feeding options (Busza, 2012). Delivery, infant feeding and weaning will be described in details in section 4.1.4.

Access to resources

Due to iniquities in resource distribution within the family; women who have limited access to resources, found themselves relying on their spouses for financial supports. This alters their adherence to PMTCT regimens due to lack of money for transport and medical costs (Busza, 2012).

Family responsibilities and care

In Tanzania, house works and child care are women's responsibilities. HIV⁺ women find it difficulties to leave the family uncared for medical follow up and drug collections. Therefore majority discontinue from PMTCT services in order to take care of the family (Chinkonde, 2009), (Feinstein, 2010), (T-MARC, 2010). The following quotation verifies:

"Who will be looking after my young ones when I go to the clinic? Each time I go there, my first born has to be absent from school." (Woman defaulted PMTCT 3 month after delivery) (Chinkonde, 2009).

4.1.3. Community context factors

i. Health system factors

Distance to health services

Long distance to health facilities that provide PMTCT services is another important factor that hinders HIV⁺ women from adhering to PMTCT regimens. This is due to lack of transport fares, scarcity of transports and long walking distance to the health facilities (Hardon, 2006), (Chinkonde, 2009), (Muchedzi, 2010), (Sasaki, 2012). These factors also contribute to home deliveries especially when labour start in late nights (HDT, 2009), (Roura, 2009), (O'Gorman, 2010), (T-MARC, 2010).

Although long distance to health facilities was found to be a barrier for adherence to PMTCT regimens among majority of HIV⁺ women; T-MARC (2010) had explored different idea that; HIV⁺ women who live nearby the health facilities were unlikely to utilize the PMTCT services from the nearby facilities instead the farthest due to fear of disclosure of their HIV⁺ status especially when confidentiality from health workers is not assured.

Poor quality of PMTCT services

Perceived quality of health services is subjective due to individual perception towards the care one receives. PMTCT services that are perceived by individual women to be poor showed great influences to hinder them from adhering to; while those who perceived good services were motivated to continue with PMTCT services (Hardon, 2006), (Duff, 2010), (O'Gorman, 2010), (T-MARC, 2010). Poor staff-client relationship as part of quality of services is among the factors that hinder HIV⁺ women from adhering to PMTCT regimens. HIV⁺ women who fear for bad attitude (e.g. poor counselling, stigma, neglects etc) from health workers are unlikely to return for follow up visits (Chinkonde, 2009), (T-MARC, 2010), (Sprague, 2011), (Kalembo, 2012a), (Morfaw, 2013). The following quotations reveal:

"They insult these women who go to deliver, one woman totally refused to go to the health facility and she was ready to lose her life with the child because when she is taken to the health facility she is insulted. This contributes To women not wanting to go to health facilities, they are bitter about their experiences, we hear them saying." (T-MARC, 2010).

"I have seen women being neglected. Once I was visiting a health facility for prayer sessions with patients. I reached there and found a pregnant woman in pain; she was in the last stage of delivery. The nurse knew this but she said that those were only shouts with no importance, she just looked at the woman and left. That mother delivered there on the floor" (T-MARC, 2010).

"I was hearing from friends that there is Nurse X who is harsh to patients but never believed it until it happened to me." (8 months gestational, dropped out) (Chinkonde, 2009).

"....it can be when the mother delivered at home, she can have fear to go to the hospital [for nevirapine syrup], because most of us fear to be shouted at by doctors because of delivering at home." (Antenatal woman) (O'Gorman, 2010).

Moreover; poor staff-client relationship also alters communication while providing instructions and information about ART and PMTCT services as a whole. This makes the women frustrated and fails to follow PMTCT recommendation (e.g. missing appointments, mix infant feeding, altered ART intake etc) (Hardon, 2006), (Roura, 2009), (Dillabaugh, 2012), (McNairy, No year).

Lack of confidentiality

Lack of confidentiality for clients' personal health information and lack of privacy for clients' dignity, demotes HIV⁺ women from discontinuing with PMTCT program (T-MARC, 2010).

Lack of privacy and accommodation

Lack of privacy while providing PMTCT services is a factor that hinders HIV⁺ women from adherence to PMTCT regimens. According to EGPAF (2010), the study found that; most of health facilities had scarcity of space for providing PMTCT services. In some facilities; a single room or table is used by more than one service providers. This caused discomfort and embarrassment to HIV⁺ women and men while discussing private or HIV issues. In such a situation majority of HIV⁺ women discontinue from PMTCT program. Similar findings were reported from other countries in Africa. In Kenya; 92% of women participated in the study that was exploring reasons for LTFU reported to experience lack of privacy while accessing PMTCT services where one room was used by more than two counsellors (Kalembo, 2012a).

Moreover; scarcity of space is a problem to accommodate male who attended PMTCT services. Failure to accommodate male into PMTCT program interferes with disclosure of HIV⁺ status among HIV⁺ women, therefore hinders adherence to PMTCT regimens (Hardon, 2006), (EGPAF, 2010), (T-MARC, 2010), (Ekama, 2012).

Staff shortage and inadequate quality of service

Tanzania is among the countries worldwide with few health workers (WHO, 2006). It account to a shortage of 65% (MoH, 2008). Regardless other staff cadres; still 35% of available staff are un-proportional to 86% of pregnant women who receive PMTCT services at RCH. Moreover, number of deliveries assisted by skilled attendants is as low as 46% (MoH, 2008), (EGPAF, 2010). With this staff: client disproportional ratio; the ability of staff to provide the recommended quality of PMTCT services is questionable. Poor PMTCT services influences majority of HIV⁺ women to opt out from PMTCT program including refuse for HIV testing, taking test results, taking ARV prophylaxis and refuse for institutional deliveries (EGPAF, 2010), (T-MARC, 2010), (Kalembo, 2012a).

Apart from Tanzania, other countries in Africa reported shortage of staff and its consequences on quality of PMTCT services that affects PMTCT adherence (Hardon 2006), (Muchedzi, 2010), (Sprague, 2011), (Kalembo, 2012a). For instance; in Uganda, the study by Duff (2010) identified that; shortage of staff caused counsellors to provide group counselling to pregnant women on ART and then provide them with pamphlets containing ART information to read for themselves. Majority didn't read because of illiteracy while others feared being identified by other people

as HIV⁺. That consequently affected uptake and continuation of ART intake as quoted hereunder:

"I didn't go back to enroll so I haven't been counseled about HAART yet. So how can I know about HAART?" (Never enrolled in HAART) (Duff, 2010).

"I won't lie. I haven't kept those books for fear that someone will come and read them. They will find out what I am. The information was there but I didn't read it." (Never enrolled in HAART) (Duff, 2010).

Time

In relation to shortage of health workers; women spend about 4-12 hours in average before being offered with PMTCT services. Long waiting time was associated with high number of patients and unfair treatment of clients. Majority of women fail to wait and continue with PMTCT services because they get exhausted and hungry whist waiting for the services. Additionally the delay affects family care; therefore increases risks of family conflicts (Moth, 2005), (Hardon, 2006), (HDT, 2009), (EGPAF, 2010), (Muchedzi, 2010), (T-MARC, 2010), (Kwesigabo, 2012). The following quotations state:

"We were told priority is given to those who come first. We may arrive at the clinic around 9 am; at 10, 11 and 12 we are still there. They attend us around 1 pm. We get tired, our children become weak. Next time, we just give up." (Respondent with 6 month old child) (Chinkonde, 2009).

"We visited this clinic on two occasions but in both cases, service providers told us to come back next time because they had reached the maximum number they manage daily. On our next visit, we even slept there and got numbers three and four in the queue. Nevertheless, we were sent away so we just gave up...The problem is that people book in advance and some workers beckon their affluent friends to enter the consultation rooms. It is often us, the poor, who get deprived of these services." (Focus group discussion participants 2 and 6) (Chinkonde, 2009).

"When I went for follow-up, the nurse said the clinic was busy, so she gave me another appointment date. When I went again, it was the same, and when this happened for the third time, I just gave up. [They] do not know that I have to walk 5–8kms and often depart from home around 4 am." (Respondent dropped out 2 months post-partum) (Chinkonde, 2009).

"The reason why I stopped taking my drugs is because I would sometimes come and the services at the clinic wouldn't be good. We would spend the whole day at the clinic and you don't even see the nurse and you even end up not getting the drugs and you go back home empty handed. I waited so long and no one was giving me the drugs. I decided to go home." (Defaulted HAART) (Duff, 2010).

Disintegration of PMTCT services and poor referral system:

Partial integration of PMTCT services to ANC services hinders HIV⁺ women to maintain maternal and child health (MCH) and PMTCT appointments from different facilities. Of no doubt; >81% of HIV⁺ women do LTFU

within six months after delivery, the critical period for attending ANC for child growth monitoring and immunization (Busza, 2012), (Kalembo, 2012a). In the study to assess referral success among HIV⁺ women and HIV-exposed children referred to CTC in Tanzania; Arreskov (2010) found that; of 91 women who were enrolled in the study at RCH; only 36% (33 women) were referred to CTC, of whom only 15% (5 out of 33) reached the CTC. Among those reached CTC, only 1 person (20%) was still in program by the end of the study while 4 (80%) LTFU. This implies due to poor referral that 64% women were not referred to CTC. Poor follow up lead to high (85%) LTFU. Moreover; disintegration of PMTCT services adds transport and time costs to women while others are unwilling to disclose HIV+ to third part (Arreskov, 2010), (EGPAF, 2010), (Busza, 2012), (Kalembo, 2012a). Poor referral, follow up and high LTFU between RCH and CTC were also found to be major problems in other countries e.g. South Africa, Zimbabwe and Kenya (Muchedzi, 2010), (Sprague, 2011), (Dillabaugh, 2012).

Lack of commodities

According to HDT (2009) it was found that; there is lack of diagnostic machines for basic HIV tests in most of health facilities in Tanzania while polymerase chain reaction (PCR) tests especially for testing HIV among infants is done in only 4 referral hospitals countrywide. PCR tests were also reported to be expensive for majority of clients to fail to afford. Additionally; EGPAF (2010), T-MARC (2010) reported stock out of ARV drugs and reagents for HIV tests for over one month in most of health facilities. In South Africa, Botswana, Zambia, Mozambique, Kenya and Uganda; shortages of PMTCT commodities were also reported. Lack of PMTCT commodities delay care, interrupt continuity of care and discourage majority of women from continuing with PMTCT services (Hardon, 2006), (Muchedzi, 2010), (Sprague, 2011), (Dillabaugh, 2012), (Kalembo, 2012a).

Drug burden

A systematic review and meta-analysis study on adherence to ART during and after pregnancy was conducted by Nachega (2012). The study reported that; majority of HIV^+ women were unlikely to take drug regimen that contains burden of pills, high frequency of intake per day and that with unpleasant smell. Furthermore; regimens that require frequency medical visits were also found to alter attendance and adherence to (Thompson, 2012).

ii. Social factors:

Stigma

Social stigma is associated with neglect, discrimination, blame, judgements and isolating a person from social life. HIV⁺ women who anticipate or have experienced social stigma tend to withdraw from the society and from health services in order to avoid stigma and discriminations. This situation hinder them from collecting medications, taking medications, deliver in health care facilities and also affects infant feeding (Moth, 2005), (Nyblade, 2005), (Hardon, 2006), (Muchedzi, 2010), (Turan, 2010), (Sprague, 2011), (Ekama, 2012), (Sasaki, 2012), (Kalembo, 2012a).

Beliefs and values

In Tanzania majority of women who are HIV⁺ feel shy, guilt and shame of being HIV⁺. This is because, HIV infection is associated with sexuality and promiscuity due to its predominance mode of transmission in general population. People who contract HIV are regarded as being promiscuity the state that is religiously and social-culture unacceptable. Additionally; in most of the religions, HIV is believed as a curse from God/gods. Consequently, HIV⁺ individuals are believed to be cursed due to their sins. Therefore; majority of HIV⁺ women become unwilling to disclose their status, which in turn hinder their adherence to PMTCT regimens (T-MARC, 2010).

Working conditions

Employed Women have demonstrated difficulties to obtain permission from their supervisors for drugs collections and breastfeeding. Likewise those who are self-employed also lack time for PMTCT services. Such working conditions therefore cause them to skip or default from PMTCT program including adherence to infant feeding options (Hardon, 2006), (Sasaki, 2012).

4.1.4. Social cultural environment factors

i. Social-cultural factors

Delivery practices

Women's choices on places of delivery are influence by traditional practices for child bearing. Traditionally, child birth had been conducted at home by traditional birth attendants or experienced elder women. A woman who failed to deliver at home was considered as cowered and not as strong as a woman should be. To avoid shame and losing traditional and social dignity; some women prefer home deliveries. For HIV⁺ women; home delivery by unskilled personnel increases risks for MTCT. Despite the fact that the government is advocating for institutional deliveries, still about 54% of all births take place at home. Preferences to traditional

delivery, inaccessibility and poor health services, and lack of transport are some of the factors facilitating home deliveries in Tanzania (MoH 2008), (T-MARC, 2010), (Kalembo, 2012a). Other factors are; availability of traditional birth attendants (TBAs), perceived good services and experience of TBAs, privacy and superpower to reverse curses against evils. For HIV⁺ women; majority do fear for stigma in health facilities (O'Gorman, 2010).

Infant feeding practices

Breastfeeding practice in Tanzania is a social-culture norm; non-breastfeeding is socially unacceptable. Infant feeding practices are not only mothers' decisions rather family and social concern. Non-breastfeeding women are regarded as irresponsive, abnormal or having mental illnesses. Usually complementary feeding starts when a child is aging 3 months and weaning is at 1.6-2year. In HIV era, non-breast feeding mothers, mothers who delay introducing complementary feeds or those who wean earlier are associated with being HIV⁺. Women who haven't shared their HIV⁺ status for the sake of avoiding stigma, discrimination and violence; fail to comply with safer infant feeding recommendations due to fear of disclosing their HIV⁺ status. Women also experience pressures from male partners and relatives especially mothers in law to follow traditional infant feeding practices (T-MARC, 2010), (Akarro, 2011).

Moreover; expressed breast milk is not a social-cultural practice for infant feeding in Tanzania. Employed and self-employed women have shown difficulties to maintain exclusive breastfeeding for the first six months as a mean for PMTCT. Therefore; mixed infant feedings are more frequently practiced (T-MARC, 2010).

Gender roles and responsibilities

Culturally reproductive and child health are regarded as women's roles while men resumes masculinity on family decisions and power. Gender roles limit men from accessing and participating in RCH services either at home or in health care facilities. These hamper them from participating in PMTCT programs. In turn; it hinders women from disclosing their HIV^+ status and therefore fail to adhere to MTCT regimens (Kirsten, 2011), (UNICEF, 2011), (Kalembo 2012b).

Cultural norms

Due to patriarch system in Tanzania; men assume power and decision making for the family while women assume femininity. Women tend to be submissive to men thus need to get permission on whatever family matters including their own health. This has affected women from adherence to PMTCT regimens especially when they encounter challenges on getting permission or when their spouses decide otherwise. Moreover gender based violence due to masculinity is another factor that hinders

women from adherence to PMTCT regimens (Feinstein, 2010), (T-MARC, 2010), (Belachew, 2012), (Kalembo, 2012b).

ii. Social and religious Beliefs factors:

Health belief about pregnancy and deliveries

In relation to cultural beliefs on pregnancy and deliveries; women are not allowed to communicate their due dates and labour because it is believed that they can be bewitched to make labour processes complicated in order to kill the woman, the child or both. In this kind of believes, due dates and labour must be secrecy and deliveries must be conducted traditionally. This norm has caused majority of women to opt for home deliveries assisted by TBAs and for HIV⁺ women, it facilitates MTCT. Consequently; failure to disclose due dates, hamper early arrangements for transport to health facilities for deliveries (T-MARC, 2010).

Social believe about HIV

HIV infection is traditionally believed to be caused by witchcrafts and can be cured through traditional medicines and spiritual prayers. The believe have motivated majority of people living with HIV and AIDS (PLWHA) including HIV⁺ women on PMTCT to seek traditional medications and prayers; thus affect the adherence to HIV treatment regimens (Roura, 2009), (T-MARC, 2010).

Beliefs on medicine

Negative myths and believes about ART have influenced majority of women and PLWHA not to take ART by fearing that, drugs weaken the body, accelerate the disease and make people die faster. The quotations below explanation what people in Tanzania and Uganda belief about ART:

"Those drugs make them ... They cut, they really cut ... I mean people are just dying. You just find yourself dying. You die while you are just fat" respondent from Tanzania (T-MARC, 2010).

"People say that drugs make you lose energy, and then you die. That's what people say." (Never enrolled in HAART) (Duff, 2010).

"Now you see that if you are taking drugs you can die there and then. I have to control myself and look after my kids to see that they've grown, work for them and build for them. Now you see my land is not progressing, we want to build. Do you want to kill me there and then?" (Never enrolled in HAART) (Duff, 2010).

Religion beliefs

Studies show that, women who have strong faiths and believe in super natural powers for healing of HIV are unlikely to enrol and adhere to PMTCT regimes. It was revealed that they don't believe on efficacy and effectiveness of ART and PMTCT regimens. This has influenced majority to fail to avail on PMTCT regimens (Zou, 2009). In a qualitative study about

religious and HIV that was carried out to identify health seeking behaviours among PLWHA; it was reported that; 80.8% of respondents believed that prayers could cure AIDS. Basing on their religious beliefs; more than 54.6% of respondents said they would feel ashamed if they would test HIV⁺ and 14.3% said that they wouldn't take ART if they would test HIV⁺ instead they would pray for healing (Zou, 2009).

Additionally; Roura (2009) in a follow up study to find out reasons for defaulting ART among PLWHA reported that; majority of participants believed that HIV is a curse and punishment from gods or witchcrafts. Therefore; it can only be cured through spiritual prayers and traditional medicines. Moreover; a cross sectional study that was done in Ghana to explore knowledge and perception about ART, PMTCT and adherence to ART among HIV⁺ women, discovered that; some respondents believed HIV can be transmitted spiritually/magically and can only be treated through spiritual practices and prayers (Boateng, 2013). The following quotation reveals:

"I believe the only means I might have gotten the disease was spiritual because I brought my husband and children to test after I was tested positive and none of them had got it. I have not committed adultery and I don't go to the hairdresser's salon. I believe someone bought it for me spiritually." (ARV user) (Boateng, 2013).

The results from the three studies above were associated with lack of knowledge about HIV, PMTCT and ART. Therefore individual's beliefs and inadequate knowledge about HIV were found to be factor that hinder women from adherence to PMTCT regimens (Roura, 2009), (Zou, 2009), (Boateng, 2013).

After describing factors that hinder HIV⁺ women from adherence to PMTCT regimens; the following section 4.2 will describe factors that enable HIV⁺ women to adhere to PMTCT regimens.

4.2. Factors that enable HIV⁺ women to adherence to PMTCT regimens

4.2.1. Individual factors

Perceived benefits

After being educated about PMTCT, its effectiveness and advantages; majority of pregnant women get motivated to accept HIV testing by knowing that their unborn and infants will be prevented from contracting HIV infections. Perceived benefits play a big role to enhance women to enrol on HIV testing and thereafter take ARV prophylaxis. This was revealed by Akarro (2011) in a case study that was conducted in Tanzania. Besides that; mothers who were previously involved in PMTCT

program and have babies who are HIV negative were also found to be motivated to adhere to PMTCT regimens (Nassali, 2009), (Boateng, 2013). The following quotation reveals mothers' motivations:

"When I tested positive, I was referred to this place to take ARVs. I know I need the drugs to prevent my baby from getting infected and this is very important to me so I make sure I come whenever I'm supposed to." (Boateng, 2013).

Self-efficacy

Women who are confident are unlikely to afraid of being stigmatized. The study that was done by Duff (2010) in Uganda to investigate barriers to accessing HAART among HIV⁺ women revealed that; majority of respondents (58%) declared to be confident to adhere to PMTCT regimens regardless communities' view on their HIV⁺ status. The following quotation states:

"What people think does not hinder me because this life is mine. Let them talk. I'm not the first one to have HIV." (Duff, 2010).

Physical health

As it was described in section 4.1, good health was a reason for defaulting from PMTCT services. Differently, Roura (2009) in a follow up study to find out barriers to adhere to ART explored that; good physical health especially improved after using ART is an enabling factor for PLWHA to adhere to ART regimens. The following quotation reveals:

"..Because these drugs are giving me hope so that I may live, I have only to drag myself although it is far....", "....Even if you get a problem today, you will go there the following day and continue with the drugs because that medicine is your life..." (Good adherent regardless health conditions) (Roura, 2009).

Social economic status

According to T-MARC (2010); infant feeding practices, hospital delivery and consistency medical follow up for PMTCT are associated with persons' social-economic status. Women with good social-economic status are more likely to adhere to PMTCT regimens. For example; they can afford formula milk for their babies and can afford adequate food to enhance exclusive breastfeeding. Moreover; they can afford transport fares and medical costs. Roura (2009) added that; women with good social-economic status are more likely to receive fair or good treatment in health facilities because of their abilities to buy health services, or can be favoured due to their economic status. Furthermore; they are unlikely to use traditional services e.g. home deliveries and traditional medicines due to their personality and ability to buy modern health care.

Knowledge/previous experience

According to Nassali (2009); women who have good knowledge or experience about PMTCT services are four times more likely to adhere to PMTCT regimens than those who have no knowledge/experience about PMTCT. Moreover women who used PMTCT previously and have children with HIV-negative status are also more likely to adhere to PMTCT regimens

4.2.2. Social network factors

Disclosure of HIV⁺ status and acceptance

In section 4.1 it was described that; women are confronted with stigma, discrimination and violence after disclose their HIV⁺ status, therefore hinder them from adherence to PMTCT regimens (Njunga, 2010), (Akarro, 2011). Surprisingly; in this section 4.2.2, the issue is different. Disclosure of HIV⁺ status to spouses, relatives and friends is found to be an enabling factor for adherence to PMTCT regimens. Male partners can be a source of adherence to PMTCT regimens for their HIV⁺ spouses who disclose their HIV⁺ status to them. This was discovered by Kirsten (2011) in the study about assessing adherence to combination prophylaxis for PMTCT in Tanzania.

Furthermore, male spouses who accepts HIV⁺ status of their spouses, play a big role of supporting them psychologically thus relieve their psychological and emotions distresses. Emotional calmness helps HIV⁺ women to further disclose their HIV⁺ status to HIV⁺ peers, friends and relatives therefore increases social networking. In turn it helps women to be widely supported both socially and psychologically to enhance their adherence to PMTCT regimens (Stutterheim, 2011).

The international conference on population and development (ICPD) in 1994 and the international (Beijing) conference on women in 1995; acknowledges the importance of men for the success of reproductive health services because of their influences on decisions making on family issues (UN, 1994, 1995). Male involvement in PMTCT programs was then adopted and introduced aiming to combat men's related barriers to PMTCT uptake and adherence among HIV⁺ women (Kalembo, 2012b). So far, in most developing countries that are doing well in PMTCT programmes in terms of increased adherence to PMTCT regimens among HIV⁺ women and reduced incidences of MTCT; they have already adopted male involvement model into PMTCT programs (Baek, 2010), (Akarro, 2011), (Busza, 2012), (Detekemena, 2012), (Kalembo, 2012b).

In Tanzania male involvement has increased adherence to PMTCT regimens among HIV⁺ women by three folds in uptake of ART, six folds increase in adherence to recommended infant feeding choices and four

fold increase in breastfeeding avoidance option (Nassali, 2009), (Peltzer, 2011). In other African countries; male involvement have helped to strengthen communication, disclosure and support between spouses thus increased adherence to ART, institutional deliveries and infant feeding options (Busza, 2012), (Detekemena, 2012), Kalembo, 2012b).

Therefore; Kirsten (2011) continued and concluded that; in order to support disclosure of HIV⁺ status among women to their male partners; male have to be involved in PMTCT program. They have to be informed and educated about HIV and PMTCT together with their spouses. Ultimately, they have to undertake couple voluntary counselling and testing (CVCT) for HIV together with their spouses. This idea was also supported by Madiba (2013) in South Africa while investigating HIV disclosure to partners and families among women enrolled in PMTCT program and the implications for infant feeding.

Peer influence

Apart from male being providing psychological support to HIV⁺ women as spouses; male partners who are HIV⁺ have shown great support to enhance their spouses to adhere to PMTCT regimens because of being "HIV⁺ peers". They remind each other on ART intake, provide social supports like adequate food and money for transport fares to collect ART drugs, reminding for follow up appointments, encourage for skilled birth assistance and adherence to infant feeding options. They provide all kinds of support as real models who experience the same and having the same goal of preventing their unborn babies or infants from contracting HIV infection. Moreover; family members and friends who are HIV⁺ were also found to be change agents to encourage, support and influence HIV⁺ women to adhere on PMTCT regimens (Roura, 2009), (Stutterheim, 2011), (Sasaki, 2012). The following is a quotation states:

"So we enlightened each other, we met those using it and they said "I used to be in a very bad condition but right now I feel better, you come here walking so you are better." I was satisfied because if you go to clinic you meet your fellow there so you exchange ideas." (Roura, 2009).

Cohesion and empowerment:

HIV⁺ women who join and participate in community groups of PLWHA had shown strong cohesion on adherence to PMTCT regimens. This is because; in the groups, PLWHA share their positive lives experiences, challenges and successes. Therefore, it encourages and empowers each other psychologically. Moreover; groups of PLWHA do receive capacity building workshops and trainings about HIV and AIDS and related issues from the government or NGO that improve their knowledge and capacities to overcome HIV and AIDS related stresses (Roura, 2009), (EGPAF, 2010). Additionally; the government and NGOs also support groups of PLWHA on different income generating activities to improve their economic status in order to meet their basic needs and PMTCT requirements (Roura, 2009).

Social support

According to Busza (2012); HIV⁺ women who expect and or receive social and psychological support (for example; care while they are sick, emotional encouragement etc) from family members, relatives or friends; were proven to improve their moral on adherence to PMTCT regimens. Family members including children were reported to be important sources of encouragement and support both physically and psychologically to make HIV⁺ women encouraged to continue with PMTCT services. The following quotations reveal:

"I was there with my sister. They kept on giving me courage ... At present I know I can do everything, I am able. I just decided to choose them ... because in case I have problems they can help me." (Roura, 2009).

"While I was still serious he used to come daily ... He would help me even to look at my card. He would look at my return appointment date and say 'ahaa, it's not yet due.' So when the date approaches he comes to remind me: "don't forget to go." I said "I won't forget." That's how he was helping me, insisting to me: "the date is on the card. You can't forget it." We kept reciting it: "it's a certain date." (Roura, 2009).

Likewise, women who receive support from social institutions (for example faith based organizations (FBOs), NGOs, CBOs or social groups) are more likely to adhere to PMTCT regimens than those who are not supported. In Zambia; the study was conducted in 2012 to examine adherence to ART during early months of HIV treatment. By the time there were food shortage in the country and World Food Program (WFP) was providing support to families experienced food insecurity. Among other factors; the results showed that adherence to ART was high among people who had food insecurity and received food support from WFP than among those who had food insecurity but received no food support from either sources (Stutterheim, 2011), (Sasaki, 2012).

Adding to the above mentioned factors; support for house works (e.g. hygiene, preparing food, care for children, nursing of patients etc); observation and reminding for ingestion of ART; referral of PLWHA to health facilities and follow up; spiritual and psychological counselling; and support/assistance for birth preparedness; that are offered by home visitors, groups of PLWHA and FBO have shown improvement on adherence to HIV and PMTCT regimens among PLWHA who had received such supports (Nassali, 2009).

Moreover; in Uganda for example, the study was conducted to assess access to HIV and AIDS care for mothers and children after delivery. The results revealed that; among the study participants; women who were

Christian were three times more likely to adhere to post natal PMTCT services than non-Christians. This was because; in Uganda, Christian institutions do provide HIV and AIDS related teachings; care and support for social needs like house works (cooking, hygiene etc), provision of food stuff and care for infants including formula milk; spiritual and psychological counselling; and financial assistance to support PLWHA to access HIV and AIDS care including PMTCT. Social supports have proven to enhance and motivate women to continue and adhere to PMTCT regimens (Nassali, 2009), (Ware, 2009), (Sasaki, 2012).

Perceived quality of services

Quality of health services, health workers-client relationship and communication are some of the services that influence HIV⁺ women on adherence to PMTCT regimens. According to T-MARC (2010); women who perceived good quality of care in health facilities were more likely to adhere to PMTCT regimens than those perceived poor quality of care. Quality of services in this case was measure on; staff attitudes, communication and rapport, confidence of staff, confidentiality and privacy.

Affordability of PMTCT services

In Tanzania all HIV services including PMTCT services are provided free of charge in public health care facilities or in subsidized costs in private facilities (MoH, 2005), (TACAIDS, 2011). A follow-up study to understand attrition from ART program that was done in Tanzania found that; free HIV services motivates and afford majority of HIV⁺ women to access and use ART (Roura, 2009). The following quotation verifies:

"When I heard that the drugs were available and that were being given for free, honestly I felt very pleased, I was very happy. That is why I wasn't ashamed neither did I have a grudge of continuing to receive the drugs." (Roura, 2009).

Drug burden

As elaborated in section 4.1; ART drug burden do hinder adherence to drug regimens; the results from the same study by Nachega (2012) and from Uganda and Ethiopia by Gusdal (2011) explored that; use of ART regimens with few pills, with less side effects and with easier dosing requirements do increase adherence to ART regimen among pregnant women. Use of the new WHO ART regimen for PMTCT with 3 triple therapy (annex 3) to increase efficacy of ART while at the same time reducing drug burden (WHO, 2012a); may improve adherence to ART regimens among HIV⁺ women (author's views).

In summery; this chapter 4 described factors that hinder HIV⁺ women from adherence to PMTCT regimens (session 4.1) and factors that enable HIV⁺ women to adhere to PMTCT regimen (section 4.2). The following chapter 5; will explore and discuss interventions that found to improve adherence to PMTCT.

CHAPTER 5.0: INTERVENTIONS THAT HAVE BEEN USED TO IMPROVE ADHERENCE TO PMTCT REGIMENS AMONG HIV* WOMEN.

This chapter answers the fourth objective of this thesis. As seen in chapter 4; barriers to optimal adherence to PMTCT regimens are influenced by individual/internal factors, external factors or both. In order to address them and improve adherence to PMTCT regimens among HIV⁺ women; this chapter explored and discussed some interventions that have been employed in Tanzania to improve adherence to PMTCT regimens. Moreover strengths and weaknesses of the interventions were discussed basing on results from different studies. Studies from different developing countries were explored to find out interventions that address issues of adherence to PMTCT regimens. The aim was to find out how best the interventions are and if they are feasible and applicable for Tanzania.

The interventions that are used to improve adherence to medical regimens have been developed to address specific or general health conditions (Busza, 2012). Therefore; in this chapter, both interventions that focus to improve adherence to PMTCT regimens, improve adherence to general HIV and AIDS programs, RCH programs or other related long term conditions (e.g. Tuberculosis) were critically analyzed to find out how best they are and how they can be adopted to fit in and improve adherence to PMTCT regimens among HIV⁺ women. The following were interventions that were explored and discussed.

5.1. Involving male partners in PMTCT programs

Male partners are among the major obstacles that hinder women from adherence to PMTCT regimens as described in section 4.1. Most of the countries that have good outcome in reducing MTCT have already adopted and involved male into PMTCT programs in order to improve its uptake and adherence (Baek, 2010), (Akarro, 2011), (Aluisio, 2011), (Busza, 2012), (Detekemena, 2012), (Kalembo, 2012).

In Tanzania male involvement into PMTCT program was adopted in 2008. It is done by asking women to request their partners to attend ANC for the next ANC visit in order to get information about PMTCT and be involved in couple voluntary counselling and testing (CVCT) for HIV. This approach is unsuccessful because male participation in PMTCT program is as low as 5% (EGPAF, 2010), (Kalembo, 2012b).

Different studies suggest different ways of improving male involvement in PMTCT programs. According to Kalembo (2012b), the study that was done in Tanzania on male involvement in PMTCT program revealed that; there is an increase of 30% of male participation in PMTCT program when men are sent a letter of invitation to participate in PMTCT programs through their spouses. In South Africa, the same technique had the same results

(Busza, 2012). From these studies, it was concluded that; depending on couple communication and relationship; otherwise invitation letters may hamper male involvement because women may not deliver the letters or men may resist attending after knowing about the aims for the invitation (Reece, 2010).

Another different technique to involve male in PMTCT program was studied in Kigali and Lusaka through a prospective cohort study that was conducted to 3625 pregnant women. Male were invited to participate in CVCT during weekends. The CVCT started by group counselling, followed by couple or individual pre testing counselling, testing and post-test counselling. In order to reduce waiting time, tackle challenge of accommodation and increase privacy; only 10-15 couples were served per day instead of 50-80 clients saved in routine working days. Men showed interest to participate in PMTCT program on weekends because it does not interfere with their official works (Conkling, 2010), (Sherr, 2012).

Further studies were done in Democratic Republic of the Congo (DRC) and Tanzania to investigate men's interests in ways they would like to attend CVCT and how they would like to be invited. In DRC, men were invited to attend CVCT in any of the three different venues; in bar, at health centre or in the church. The results showed higher attendance in the bar (26.4%; P<0.001) followed by in church (20.8%; P=0.163) lastly health centre (18.2%). In Tanzania however; men were asked to give different ways to overcome their barriers for participating into PMTCT programs. The results were: to set different CVCT hours within ANC services (73%); to extend CVCT services during weekends (65%); to set special venue for men/couples (61%); to be invited by letters from the health facility through their spouses (47%); and official letters to be sent to their employers for excusing them from work for ANC attendance (43%) (Ditekemena, 2012).

To complement to the above Ditekemena's studies in DRC and Tanzania; Kalembo (2012b) found that; male participation in PMTCT program in DRC at Kingasani maternity department was increased from 2%-18% when men were invited to participate in PMTCT program after official hours (15:00-20:00 hours). Additionally, in South Africa, Uganda and Burkina Faso; male participation in PMTCT program was found to improve when male nurses were used to provide services in PMTCT clinics (Kalembo, 2012b).

The lesson learnt from the techniques used in the above studies is that; there was increased services accessibility and reduced costs for transport. Also services were convenient in time, privacy, confidentiality and men friendly services that favoured their participations (Kalembo, 2012b).

5.2. Use of peer counsellors and community volunteers:

As seen in section 4.1; psychological depression is a problem among HIV⁺ women. HIV⁺ peer counsellors who had undergone and overcome similar challenges, have shown successes in enlightening feelings of HIV⁺ women to cope with HIV⁺ related challenged and thereafter adhere to PMTCT regimens (Roura, 2009). Moreover, peer counsellors and home visitors assist women by reminding them on follow up appointments, observing drug ingestion, accompany them to access medical care when needed, tracking those who LTFU and continue providing counselling and guidance related to HIV and PMTCT recommendations. This system has also overcome challenges of missing appointments, interrupted ART intake, home deliveries and infant feeding options (Roura, 2009), (Busza, 2012).

In Tanzania; to the knowledge of the author, there is no official document that was published on how peer counsellors are involved in either PMTCT programs or any related program of long term conditions. But; according to Busza (2012) in a social ecological review study to explore community based approaches for PMTCT in poor resource settings, it was explored that; in Tanzania, TBAs are encouraged to promote pregnant women to undertake VCT for PMTCT, institutional deliveries, ingestion of ARV during home deliveries and refer postnatal mothers and infants to CTC.

Busza (2012) continued with the same study in Cameroon and found that; trained TBAs have been used to provide pre and post-test counselling, HIV tests and administering single dose nevirapine during labour for women who deliver at home since 2002. But both studies for Tanzania and Cameroon have not yet been evaluated to find out their effectiveness. Doubtful; in Tanzania, use of TBAs to encourage institution deliveries as part of PMTCT cascade might be in-effective because, still institutional deliveries is as low as 46% (MoH, 2008).

5.3. Use of Health Monitoring Information System (HMIS)

Loss to follow up is reported to over 20% among patients who are on ART in one year and about 59% over 4 years in Sub Saharan Africa. In South Africa for example, >80% of women in PMTCT program LTFU before reaching the end of PMTCT program (Fraser, 2007). As seen in chapter 4; LTFU at every stage of PMTCT cascade is a big challenge and is mainly contributed by poor monitoring and follow up system from health care facilities. HMIS is an effective system that is recently used in developing countries to monitor progresses of patients on long term medical intervention, and to track LTFU at early stages in order to improve adherence to medical regimens and improve health outcomes (Fraser, 2007). Different HMIS are used in different countries to monitor patients on long term regimens and have different achievements as follows:

In Tanzania; monitoring and evaluation of PMTCT services is done through routine systems (HMIS, demographic and disease surveillance) and non-routine systems (household surveys and research). The MoH is the incharge for the HMIS and disease surveillance, while non-routine information systems are often done by other government or research units. The system used to monitor PMTCT activities include; daily registration of HIV⁺ women in register books during ANC, delivery and post-partum. Registration of women and infants given ARV prophylaxis and those referred to CTC (MoH, no Year).

Then all reports are summarized and compiled on monthly bases on summary sheets. The summary sheets from different health facilities within the district are sent to the district medical officer for verification and compilation. The compiled district report is then sent to the regional level for compilation and sent to the MoH (MoH, no Year). The achievement to this kind of monitoring system might be poor because of difficulties to access data on hardcopies.

In Zambia; an HIV treatment program evaluated 29,998 HIV⁺ patients from 2004 to 2005. Initially; 4,870 patients (16%) LTFU; among them 44% were eligible for ART. Nevertheless; 16,198 patients were initiated on ART and 3402 (21%) LTFU. By using HMIS; routine patients' reports were reviewed and patients who LTFU were identified. Then community health workers (CHW) were asked to trace them. 1,089 (32%) patients were tracked of whom 305 (28%) resumed their treatment. However; 1395 (41%) could not be traced and 919 (27%) patients were dead (Fraser, 2007).

In Central Plateau of Haiti; Partners In Health/ZamniLasante (PIH/ZL) runs nine hospitals that provide HIV treatment as well as general medical care. PIH/ZL has installed a Web based medical record system (HIV-EMR) in 9 health facilities. All patients who tests HIV+ are entered in the HIV-EMR and CD4 count results below 350cell/µl are automatically emailed to patients' physicians. In order to confirm the effectiveness of this monitoring system, a preliminary retrospective study was done to examine whether early entry of CD4 counts into the HIV-EMR was associated with prompt ARV treatment. The results showed that; for patients with CD4 counts between 101cell/µl-350cell/µl and their CD4 count results were entered into HIV-EMR earlier (early was defined as within 14 days) had an odds ratio of 3.2 (P = 0.008) for starting treatment early compared to those without early CD4 count results entered. Additionally; the study found that patients with CD4 counts <100cell/µl were almost all treated within 1 week after testing due to timely availability of CD4 results (Fraser, 2007).

Similarly to the HMIS workflow in Haiti; in rural Rwanda, Partners In Health (PIH) run a group of six clinics in and around Rwinkwavu. HIV data

for patients are managed with a newer version of *HIV-EMR* based on the *Open MRS architecture (HIV-EMR 2.0)*. The system automatically highlights potential related problems of the patient and emails the results to clinicians. This system has improved prompt availability of patients' results and effective management. The system has overcome the challenges of delayed or lack of laboratory results as seen in chapter 4.1. Fortunately; patients' appointment dates are also automatically recoded on a follow up page within the system. Patients who fail to meet their appointments are reported monthly. This has helped timely follow up of patients (Fraser, 2007).

Likewise; in Kenya, an EMR system was set up in 2002 to document clinic visits of HIV⁺ patients who receive treatment in Eldoret hospital. The *AMPATH Medical Record System (AMRS)* was installed in Eldoret hospital to monitor HIV patients on ART as part of the project called *Academic Model for Prevention and Treatment of HIV/AIDS* (AMPATH). AMRS tracks patients who miss their appointments; therefore helps prompt follow up. Luck enough; AMRS have been also linked to monitor HIV⁺ women in PMTCT program who receive treatment in Eldoret (Fraser, 2007).

Lastly but worth; in Malawi, the Baobab Health Partnership has developed a HMIS using an *innovative touch screen interface*. The system was launched in 2001 and has been used to issue unique patients' identities card to more than 500,000 patients across three urban sites. The identity cards allow patient to access VCT and ART services from any CTC national-wide. The system is also used for registering HIV⁺ patients including their medical information and for monitoring VCT and ART programs. It produces patients' reports that monitoring and evaluation teams use to identify patients who are yet to start ART and those who LTFU and make timely management accordingly (Fraser, 2007).

Use of mobile phone technologies

As discussed in section 4.1; some of the factors that hinder HIV⁺ women from adhering to PMTCT regimens are forgetting taking drugs that leads to treatment interruption; forgetting appointment dates leading to missing follow up visits; and unavailability of laboratory results that lead to delayed patients' medical care and increase LTFU.

Uses of mobile phone technologies has shown dramatic improvement in health care deliveries by enabling close monitoring and follow up of patients, prompt access to patients medical information, readily availability of medical information concerning care and management of patients etc. The technology is portable, accessible and convenient due to its wide coverage of mobile phone and accessibility of internet even at remote rural areas (Wang, 2009), (Koehler, 2012), (Eskandar, 2013). The following are studies that show how mobile phones can be used to improve adherence to PMTCT regimens.

In Rwanda and South Africa; Kalembo (2012b) reported that; several projects are using mobile phones to access patients' medical information and to contact patients. Databases for storing patients' medical information are installed in mobile phones. This enables easier access to patients' medical information that help timely care and follow up of patients who LTFU. Additionally; the same mobile phones are used to access patients by calling or sending them texts for follow up, encouraging them to comply to medical regimens and remind them to attend their appointments.

The same technology was applied in Kenya in a randomized control trial for 48 weeks. During the study; patients in intervention group were sent a weekly text reminder about abide to treatments and follow up appointments while the control group received other health information. After the study; the results showed that; 90% adherence level to treatment was achieved by 53% in intervention group compared to 40% in control group (P-Value=0.03). Much more; interruption to drug intake was 81% in an intervention group compared to 90% in control group (P-value=0.03) (Pop-Eleches, 2011), (Busza, 2012).

Again, in Kenya; a patient tracing system was installed in mobile phone to monitor HIV⁺ women who were in PMTCT program. All patients' medical information were filled in the system. Among other functions; the system highlights and sorts names of patients who miss their appointment. Health care workers accessed and used the information to timely make follow up of those LTFU. The phones also were used for tracing women who LTFU by calling them direct or contacting their contact persons (friends, relatives or home visitors). Within one year; 269 women were contacted, of whom 162 (60.2%) resumed into PMTCT program (Busza, 2012).

Furthermore; at Kibera hospital in Kenya, an *active defaulter tracing system* was installed in mobile phones. The system sorts patients who LTFU among HIV⁺ patients, women and infants in PMTCT program, patients with TB and patients with HIV/TB co-infections who receive treatment at Kibera Hospital. The information from the system are used by social workers to routinely contact patients who LTFU via telephone, home visit, or both immediately after they have missed their appointments. This system has helped to reduce LTFU among HIV⁺ patients from 21.2% in 2006 to 11.5% in 2009 (Busza, 2012).

5.4. Use of simple PMTCT regimens

Use of regimens with easier dosing requirements, reduced pill burden, and better tolerability; reduces ART defaults and increase adherence to ART during pregnancy (Gusdal, 2011). Tanzania has adopted the new WHO 2010 PMTCT guidelines (annex 3) Option A for treatment of HIV⁺

women and exposed infants (UNAIDS, 2010). Option A has a bit more complicated protocols than Option B^+ . Apart from other advantages; Option B^+ has a simplified treatment protocols and reduced pills burden to effectively improve the health of the woman meanwhile reducing the risks for MTCT. Therefore; WHO recommends for Option B^+ regimen (WHO, 2010*b*).

CHAPTER 6.0: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

6.1. Discussion

As it was presented in chapter three that, there is poor adherence to PMTCT regimens among HIV⁺ women and exposed children in Tanzania; the results from this study also revealed the same, and that might be an important factor for high MTCT of HIV among infants born to HIV⁺ women in Tanzania. Majority of HIV⁺ women LTFU from PMTCT program at every stage of PMTCT cascades. Both internal and external factors contribute to the problem. Stigma, discrimination as well as violence from spouses were found to be the most important factors for LTFU and poor adherence to PMTCT regimens. Men were found to be both negative and positive actors to influence adherence. Men who were not involved in PMTCT program were found to hamper adherence while those who were involved into PMTCT program were found to be positive actors to enhance adherence. However; male involvement into PMTCT program was found to be low and wrongly approached. Different approaches like extending PMTCT services after official hours, during weekends or setting the PMTCT venue aside were found to be feasible approaches for improving male involvement into PMTCT program; therefore improve adherence.

Poor health care system including inaccessibility of health facilities (long distance), lack or poor referral systems, poor follow up and monitoring systems, stock out of commodities and poor health services were other important factors that led to poor adherence. Use of peer counsellors, CHW or TBAs to provide some of PMTCT services e.g. ART and continuous counselling at household level can help to improve accessibility and adherence to PMTCT services. It was also found that; women's physical health can influence adherence both positively and negatively. Continuous counselling and health education can empower women's knowledge that can influence them to adhere to PMTCT regimens regardless their physical health. Moreover; improving referral, monitoring and follow up systems by use of HMIS can help to tackle the challenge of LTFU and poor adherence.

Poor economic status was among the strong challenges that impaired majority of women from accessing PMTCT services. Women who received social supports showed some improvement on adherence to PMTCT regimens. But this is not a sustainable way; women empowerment on economic issues e.g. employment and self reliance can be a sustainable way to solve challenges of poor adherence to PMTCT regimens related to poor economic.

Through analysis of the findings; the study found that; adherence to PMTCT regimens was influenced by perceived PMTCT benefits. Moreover;

the study found that, the internal factors were strongly influenced by external factors to effect. For a woman to be able to take an action of adhering to PMTCT regimens; perceived benefits for PMTCT and women's self-efficacy to take an action must exceed perceived barriers for taking action. However; the efficacy and ability to take an action (adhere to PMTCT services) must be enabled by cue of actions e.g. knowledge about HIV and PMTCT, social support, psychological support, etc as described in section 4.2.

6.2. Conclusion

Adherence to PMTCT regimens is still a challenge. Majority of women LTFU even before reaching the CTC while others soon after being initiated to treatment. Small proportion of women was courageous to continue with PMTCT without fearing of stigma and violence while majority these were major barriers to PMTCT adherence. Close follow up and male involvements into PMTCT program have shown great influence to PMTCT adherence although in Tanzania they are inadequately addressed.

6.3. Recommendations

- 1. The government of Tanzania through the Ministry of Community Development, Gender and children; should address issues of patriarchy norms that favours masculinity and femininity in the societies through advocacy for gender equity. This will help to reduce gender based violence against HIV⁺ women who disclose their HIV⁺ status to their spouses. Moreover; women should be empowered on self-efficacy and social economical capacities through universal education, vocational training and equal opportunities for employment in order to reduce dependence tendencies on men.
- 2. The government through the Ministry of Justice and Constitutional Affairs; should strengthen the implementation of HIV Act that prohibits all kinds of stigma, discrimination and HIV and AIDS related violence against PLWHA. This will enable women to freely access and adhere to PMTCT services without fear of stigma, discrimination or violence from health care workers, community or spouses.
- 3. MoH should improve quality and accessibility of PMTCT data to improve monitoring, follow up and implementation of PMTCT program. It should improve its data storage system by creating a software database system (HMIS) where PMTCT information can be stored and easily accessed both nationally and internationally rather than paper copies in use. Use of simple technologies e.g. use of phone software have shown feasibility for monitoring and follow up

- in wide coverage areas including in rural/remote areas. Moreover the data must be updated frequently.
- 4. MoH should improve the techniques for male involvement into PMTCT program. Setting time for CVCT hours after working hours, during weekends or using different venues for CVCT has shown improvement for male involvement into PMTCT program.
- 5. MoH has to fully integrate PMTCT package into RCH package in order to reduce LTFU that is caused by inability of women to follow PMTCT and MCH (for child monitoring) follow up appointments from different health facilities due to fear of stigma, lack of transport, fare and time. For the time being, MoH must strengthen referral and follow up system for women referred to CTC from RCH.

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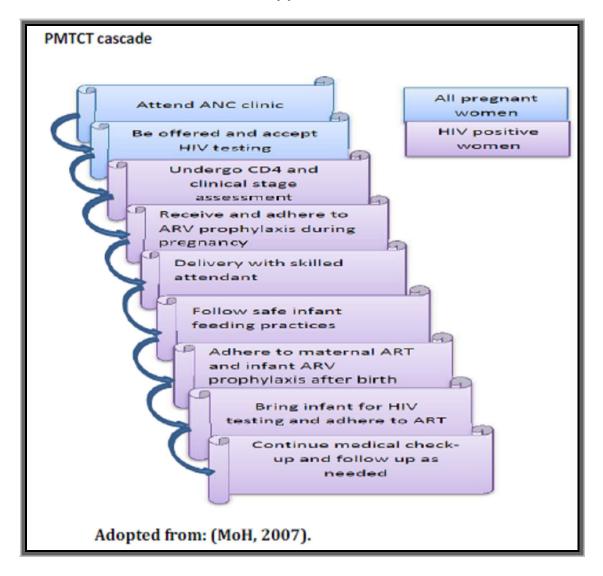
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Dedication:

I dedicate this thesis to HIV⁺ women and infants born to HIV⁺ mothers

Annexes:

Annex 1. PMTCT cascades as applied in Tanzania.



PREGNANT WOMEN ATTEND AND SERVICES GROUP HIV&PMTCT INFO.& GROUP/INDIVIDUAL HEALTH EDUCATION OFFERED PICT OFFERED Individual voluntary option for PMTCT enrolment Accept enrolment Denial enrolment Individual/couple pre-test Counselling counselling ANTENATAL Accept testing Denial testing **HIV TEST** Counselling Denial results Accept results HIV test Negative HIV test Positive Counselling Post-test counselling Post-test counselling Repeat test after 3 months Undergo CD4 and HIV clinical stage assessment HIV Positive **HIV Negative** Offer ARV during pregnancy Counselling Accept Denial Receive and adhere to ARV pre delivery DELIVERY Delivery with skilled health attendant DELIVERY CONTINUE WITH OTHER POST PMTCT CASCADE STEPS

Annex 2. PMTCT flow chart as applied in Tanzania.

Adopted from: (MoH, 2007).

Annex 3. PMTCT treatment regimens

Table 1. Three options for PMTCT programmes Woman receives:			
	Treatment (for CD4 count ≤350 cells/mm³)	Prophylaxis (for CD4 count >350 cells/mm²)	Infant receives:
Option A ^a	Triple ARVs starting as soon as diagnosed, continued for life	Antepartum: AZT starting as early as 14 weeks gestation Intrapartum: at onset of labour, sdNVP and first dose of AZT/3TC Postpartum: daily AZT/3TC through 7 days postpartum	Daily NVP from birth through 1 week beyond complete cessation of breastfeeding; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks
Option B	Same initial ARVs for both:		Daily NVP or AZT from birth through age 4-6
	Triple ARVs starting as soon as diagnosed, continued for life	Triple ARVs starting as early as 14 weeks gestation and continued intrapartum and through childbirth if not breastfeeding or until 1 week after cessation of all breastfeeding	weeks regardless of infant feeding method
Option B+	Same for treatment and prophylaxis ^b :		Daily NVP or AZT from birth through age 4-6 weeks regardless of infant feeding method
	Regardless of CD4 count, triple ARVs starting as soon as diagnosed, ^c continued for life		

^{*} Recommended in WHO 2010 PMTCT guidelines

Source: (WHO, 2012).

^b True only for EFV-based first-line ART; NVP-based ART not recommended for prophylaxis (CD4 >350)

^c Formal recommendations for Option B+ have not been made, but presumably ART would start at diagnosis.

Annex 4. Map of Tanzania



Source:

https://www.google.com/search?q=map+of+tanzania&hl=en&tbm=isch&tbo=u&source=univ&sa=X&ei=q6jxUf3OK16S0AXgq4GwCA&sqi=2&ved=0CC4QsAQ&biw=994&bih=636