“A matter of life and birth”

Health seeking experiences of HIV positive women in rural Malawi

Master thesis

by

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Temwa

A matter of life and birth

HEALTH CARE SEEKING EXPERIENCES OF HIV POSITIVE WOMEN IN RURAL MALAWI

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Abstract

Despite global commitment to the eradication of HIV/AIDS, the incidence of mother-to-child transmission of HIV in sub-Saharan Africa remains extremely high: about 390,000 children are newly infected every year. The low uptake of Prevention of Mother-to-Child Transmission (PMTCT) services in developing countries can be attributed to several sociocultural and economic factors, such as; lack of male involvement in maternal and reproductive health; gender disparities; and poor management of health care supply. Cultural beliefs and values regarding women's behaviour also account for the low uptake of PMTCT programs.

This study contributes to the academic debate surrounding HIV-prevention and empowerment. Women's lived experiences are frequently missing from gender and development policy, or pictured as oppressed. Gender roles and portrayals remain static, which is not always in accordance with women's own experiences and realities. This thesis seeks to uncover how women are agents in making health decisions, while also trying to be good wives, mothers and daughters.

Case study research has been done in rural Malawi, to illuminate the context in which health decisions need to be made. The purpose of this study is to identify barriers to the uptake of Prevention of Mother-to-Child Transmission services in Malawi through women's lived experiences and an assessment of the health system. The functioning of rural health care delivery to women is analysed, as well as women's agency in making health decisions within sometimes limiting conditions.

The results of the study reveal that gendered norms and cultural practices signficantly influence women's actual and perceived access to health care services. Male partners frequently do not lend their emotional and financial support. The lack of room for disclosure of HIV status within the marriage contributes greatly to this. Ultimately the research argues that PMTCT services should be placed a broader health perspective, and help women develop tools to make decisions regarding their own reproductive health.

Key words: HIV/AIDS, gender, empowerment, vulnerabilities, agency, maternal health

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Abbreviations and acronyms

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
ARVs	Antiretroviral (medicines)
CPT	Cotrimoxazole Preventative Therapy (Prophylaxis)
DBS	Dried Blood Spot (testing)
DNA-PCR	DNA Polyasmere Chain Reaction (initial infant HIV test)
DHO	District Health Officer
DHS	Demographic and Health Survey
DPT	Triple vaccine containing Diphtheria, Pertusis and Tetanus
EBF	Exclusive Breastfeeding
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
KABP	Knowledge, attitudes, beliefs and practices
MA	Medical Assistant
MDGs	Millennium Development Goals
MoH	Ministry of Health
MTCT	Mother-to-Child Transmission (of HIV)
NAC	National AIDS Commission
NB	Nkhata Bay
NVP	Nevirapine
PMTCT	Prevention of Mother-to-Child Transmission (of HIV)
PLHIV	People Living with HIV or AIDS
SRH	Sexual Reproductive Health
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
RA	Research Assistant
TB	Tuberculosis
TBA	Traditional Birth Attendant
TH	Traditional Healer
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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1. Introduction

1.1.1 HIV AND PMTCT IN MALAWI

Globally, more than 1,500 unborn or newborn babies are infected with HIV every day. Most of these babies will die before they reach their fifth birthday (Kasenga et al., 2010, p.28). The majority of these infections are coming from mother-to-child transmission (MTCT) during pregnancy, delivery or breastfeeding. With the proper interventions, an HIV-positive woman in a high-resource country like the United States has less than a 2% chance of delivering an infected baby. However, the epicentre of the HIV epidemic is located in sub-Saharan Africa, where the implementations of prevention programs face many challenges. Even when interventions do exist, it is not always guaranteed that people will find themselves in a position to utilize them. For this reason and more, a positive woman in sub-Saharan Africa has a chance of up to 50% of giving birth to an HIV positive baby (AVERT, 2014).

Malawi has one of the highest HIV infection rates in the world. According to Kasenga *et al.* (2010, p.28), in 2003 over 520,000 women of childbearing age were infected with HIV. It is estimated that amongst pregnant women who attend antenatal care in Malawi, HIV prevalence hovers around 36%. In comparison, up to 21% of men in rural Malawi are infected with HIV (Government of Malawi, 2012, p.16). The epidemic clearly impacts (young) women more than men of any age, because of biological and social factors.

It is a very unfortunate thing for anyone, to become infected with HIV and to have to live with this disease for the rest of your days. However, women often have to deal with the added burden of how their sexuality and moral status will be redefined by society and their peers. The idea that a positive woman is 'spoiled' or 'promiscuous' still has a place in Malawi's society, even though stigma and discrimination that surround HIV are said to be slowly diminishing (Krokan & Christiansen, 2010, p.39). Positive men are equally stigmatized by being regarded as 'womanizers' (Duffy, 2005, p.16), but they are not the ones who are directly responsible for passing on the disease to their offspring. Therefore, a woman's experience with being positive and having children is likely to be very different from a man's. It is this experience that this research seeks to

uncover, with the aim of understanding how HIV transmission from mother to child could be better prevented.

1.1.2 Relevance of the research

While the subject of Prevention of Mother-to-Child Transmission of HIV (PMTCT) has been widely researched, a knowledge gap can still be identified. Very little in-depth research has been done in women's experiences of the obstacles and opportunities they are presented with, and how health decisions are made in such contexts. Each individual navigates the intersections between medical systems, social traditions, cultural customs, gender relations, economic constraints, and personal preferences differently. The large-scale surveys that are usually done to identify barriers to PMTCT do not capture the contextual factors and subjective experiences of women. Many studies also place an emphasis on the vulnerability of women and their lack of power over their own sexual and reproductive health because of gender inequalities. While this is highly relevant and will be discussed in the findings as well, a counterbalance should be given on how women deal with such adversities by displaying agency in their choices. The findings of this study aim to assist in stimulating awareness for researchers and policy makers alike, with regards to the social fabric in which their policies should be implemented, and how these can be made best suited to everyday realities.

1.2 Research questions

1.2.1 Main Question

This thesis is based on extensive fieldwork, done over a period of four months in the lakeshore area of Usisya in Malawi. A tiny village such as Usisya is like a microcosm in itself; self-contained and mostly self-sustaining. There is not much physical or immaterial traffic in and out, due to its geographical inaccessibility and remoteness. This means that new ideas are having a hard time getting in, and old customs and traditions, however harmful at times, continue to guide marriage, gender structures, and health seeking behaviour. This research aims to find out how women can balance adhering to medical advice, with conforming to their traditionally ascribed roles as wives, mothers and/or members of society at large. Both the supply- and demand-side of health care are analysed to find where they meet, impact or clash with one another.

Ultimately this should lead towards an analysis of what makes an environment conducive or obstructive towards full participation in PMTCT programmes (Eide et al., 2006, p.146). Using a holistic approach that envelops both perspectives has allowed for a deeper understanding of the situation. In light of these objectives, the main question guiding the research is as follows:

> *Which sociocultural, economic and structural factors influence the supply- and demand-side of services aimed at preventing mother-to-child transmission (PMTCT) of HIV/AIDS, and how do women in Usisya, Malawi, experience these factors?*

The main obstacles towards full participation in PMTCT programmes that come from inside the health system, or supply-side, are generally well known; inadequate financial and human resources, poor implementation of national policies, low coverage of PMTCT, lack of integration of general maternal health care and targeted HIV care, as well as insufficient follow-up. The research will show that these are all issues that need to be dealt with on an institutional level (Agu, 2010, p.12). The cultural, or demand-side on the other hand, is responsible for some more complex and obscure barriers that impede access for women. These might occur on a more subconscious level. For example, it is a woman's culturally defined duty to provide her husband with children (Saidi, 2010, p.164), but since HIV is often equated with an 'unpleasant life followed by certain death', HIV positive women are basically 'giving life to someone who is doomed to die' (interviews with participants, 2014). This seems contradictory, but women could not stop getting pregnant since this would fundamentally affect their own position in society. In other words, women sometimes have to make concessions to their own health and that of their (unborn) children, in order to keep fulfilling their predefined roles as 'good women'.

1.2.2 Sub-questions

In order to answer the main question, several sub-questions have been designed to break down the different themes and areas of interest:

1. How do women's sociocultural, structural and economic circumstances make

them vulnerable towards HIV and/or influence their access to reproductive health services?

2. How and to what extent does gender influence women's attitudes and experiences of stigma and discrimination surrounding HIV/AIDS?
3. How do traditional and cultural (healing) practices surrounding reproductive health influence women's uptake of PMTCT?
4. How could women's participation in PMTCT programs be increased?

1.2.3 Research objectives

The aim of this research is:

- To explore the intersections of limiting structural factors such as gender inequalities and poverty, and women's agency and health care seeking behaviour, in order to understand which factors influence access to maternal health services, PMTCT specifically.
- To examine knowledge, attitudes, beliefs and practices (KABP) regarding HIV status, PMTCT, and health care seeking behaviour of pregnant women.
- To highlight the local context of reproductive health, related to HIV and stigma and discrimination, using ethnographic evidence.

1.3 Outline of thesis

The thesis is organized as follows: firstly, the theoretical model and conceptual framework utilized for the study is presented. Specifically, a gendered analysis of the subject is promoted. Following the academic context, the reader will be provided with insights into the regional and methodological context of the research. The characteristics of the research population are presented, as well as a reflection on the researcher's positionality. The first empirical chapter will go on to discuss people's general knowledge, attitudes and practices regarding HIV and PMTCT, in order to identify which social factors might influence the uptake of PMTCT programs. The second and third empirical chapters have been organized in line with a health systems theory, which distinguishes between a supply- and demand-side in health care delivery. Chapter eight considers the potential benefits of involving traditional birth attendants in increasing the coverage of PMTCT programs. The overarching discussion captured in

the last chapter places the findings in line with the theoretical framework, and brings us to a number of recommendations for further research and policies.

2. Literature and Theoretical Framework

2.1 Related empirical studies

Within the social sciences, an extensive body of literature has been written on the subject of obstacles and opportunities surrounding Prevention of Mother-to-Child transmission (PMTCT) of HIV in sub-Saharan Africa. The focus of this literature review is on the correlations between cultural forces, gender and power relations, stigma and discrimination and socioeconomic factors, which all play their part in shaping the context in which the battle against HIV takes place, and MTCT in particular. I will look at studies that were carried out in Malawi and other sub-Saharan African (SSA) countries, insofar as they are comparable for the purposes of this research. The factors outlined below describe the most common barriers towards achieving full participation in PMTCT programs.

2.1.1. Knowledge about HIV and PMTCT

Many HIV prevention programs and policies are based on the premise that changes in knowledge and risk perception can lead to behavioural change, such as safer sexual practices. Studies conducted in low-resource countries like South Africa and Tanzania do show that there is a positive correlation between the amount of knowledge women have of HIV and PMTCT, and better access to treatment and care (Petrie *et al.*, 2007). A woman who is aware of her status and of the medical implications of being positive, is better able to make an informed decision about where and how to receive health care. Bardon-o'Fallon *et al*. (2004) found that women benefit mostly from receiving their information from same-sex friends, and from health care workers. Men's first source of HIV/AIDS knowledge seems to be via radio or television, followed distantly by secondary education. Knowing someone with HIV/AIDS increases the odds of knowing about MTCT by 1.5 times for men, and 3.3 times for women. However, in their study in rural Malawi, Bardon-o'Fallon *et al.* (2004) also discovered that for men, more knowledge is not necessarily associated with increased risk perception. Rather,

cognitive and behavioural factors such as knowing someone with HIV, their number of sexual partners and having been treated for a sexually transmitted infection (STI) increase men's perception of risk. For women, their partner's risky behaviour is much more related to their perception of risk of contracting HIV, than factors related to their own behaviour (Bardon-o'Fallon *et al.*, 2004: 139). Chapter five on knowledge, attitudes, beliefs and practices (KABP) surrounding HIV, will also show how this can lead to gendered stigma and partner blaming.

2.1.2 Male involvement

Literature suggests that the perceived support and involvement of her male partner is one of the crucial, socio-cultural determinants of women's participation in a PMTCT program (Auvinen *et al.*, 2010; Brusamento *et al.*, 2011). Male involvement in PMTCT is usually operationalized as men accompanying their wives to antenatal care, delivery, etc.; providing socio-economic support; and using family planning as well as HIV prevention measures (Mukobi, 2012, p.vi), with the purpose of ensuring women's and children's wellbeing (Kululanga et al., 2012, p.145). In many settings, up to 75% of women report that their male partners make decisions related to the woman's health, such as participation in a PMTCT program, HIV testing and/or adherence to Antiretroviral (ARV) medications (Brusamento et al., 2011, p.3). Perceived or actual non-supportiveness of male partners, which includes lack of discussion, absence of permission, no sharing of resources, the threat of violence or abandonment, and/or lack of physical and emotional presence in the PMTCT process appears to be very challenging for women and leads them to forego participation.

The World Health Organization (WHO) has started promoting male involvement in maternal health and PMTCT programs, for the following reasons. Firstly, women who are accompanied to the hospital by their male partner, are much more likely to accept an HIV test, and subsequently to adhere to an ARV regimen (Brusamento et al., 2011, p.3). Dahl (2008, p.748) found that 82% of women who feared a negative reaction from their partner upon receiving a positive result, or for even considering to undergo an HIV test, would fail to receive HIV testing, counseling or medication. Since HIV testing is the entry point of the PMTCT cascade, it is extremely crucial that as many women as possible have, and also perceive access to it. A WHO study from 2004 reveals that between 16-86% of women in developing countries choose not to disclose their status

to their male partners, for fear of violence, rejection, abandonment or loss of economic support (Brusamento, 2011, p.3). Spousal communication about reproductive matters, including PMTCT strategies, is shown to increase women's commitment to such programs. However, pregnant women especially tend to keep quiet about being positive (Brusamento, 2011, p.6), thereby essentially limiting their access to a range of services that could protect themselves and their children.

2.1.3 Stigma and discrimination

One very important concept sustaining the HIV epidemic is stigma. Stigma, suffering, shame, and silence are mutually supporting concepts that challenge health promotion efforts, such as the prevention of mother-to-child transmission. Stigma strongly relates to the way individuals are viewed within their communities. A stigmatized person is seen as 'not quite human', because in peoples' minds they are marked as different and 'unwhole', which usually results in reduced opportunities for that person (Duffy, 2005, p. 14). Weiss, Ramakrishna and Somma (2006, p.280) define health-related stigma as "a social process or related personal experience, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem." The model below by Turan and Nyblade (2013, p.2530) effectively summarizes the severe impact fear of stigma and discrimination might have on the uptake of PMTCT. Women's use of HIV and maternity services is limited by anticipated, perceived, and experienced stigma from the community, family, self, and health care workers. This is significantly associated with disclosing their status to male partners and the expected violence that might follow; women are forced to choose between their immediate physical, emotional, and economic wellbeing, and the future health benefits for themselves and their unborn child of participating in MTCT prevention services (Turan & Nyblade, 2013, p.2539). Such choices will be discussed in the empirical findings on women's use of agency in limiting conditions, such as an environment that is prone to stigmatization and exclusion.

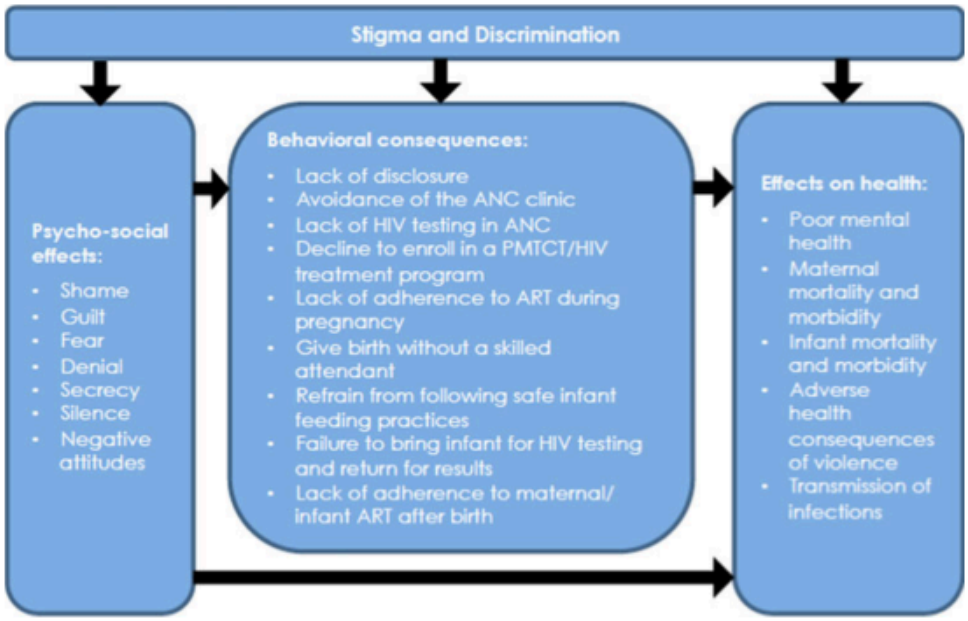


Figure 2: Framework for effects of stigma on maternal and chid health (Turan & Nyblade, 2013: 2530).

In developing countries, communities often depend on reciprocity and social capital to supplement the daily income. Stigmatizing behaviour can be seen as a way of dealing with the 'inevitable' loss of the infected person; they would be in need of support rather than be in a position to give it, making it unappealing to invest in maintaining the social relationship with that person (Verheijen 2013, p.180). Nombo and Niehof (2008) summarize similar findings from rural Tanzania as follows:

> *Different from the idealized view that social capital helps households maintain their livelihoods and strengthens their resilience to future shocks and stress, many of the HIV/AIDS-affected households were found unable to cope with HIV/AIDS impacts, because social capital itself is not resilient in a context of high HIV/AIDS prevalence and widespread poverty* (2008, p.241).

Resource-poor conditions only exacerbate the stigma placed on HIV-positive people: there is not enough food, money and time to help all in need, making them a burden to their social network. According to Bond (2006, P.192), people frame the difficult decisions they need to make regarding the distribution of resources, in terms of blame and exclusion. Conversely, Mak *et al.* (2007, P.1549) have found that self-stigmatization tends to dampen the level of (perceived) social support and leads to psychological distress among people living with HIV (PLHIV). They acknowledge that the prevailing sociocultural climate strongly influences the social perceptions of HIV/AIDS, but this study highlights the impact of self-stigma on PLHIV's mental health. Affected people

prefer to find support among others in a similar condition, rather than from friends and family, because of issues of disclosure and social acceptance. In light of this context, HIV positive women who often depend upon their families and husbands for social en economic support might take the well-considered decision not to disclose their status to others.

2.1.4 Traditional health care provision

Most villages in sub-Saharan Africa have at least one Traditional Healer (TH) or 'African doctor'. There are no reliable statistics on this, but qualitative research indicates that consultation rates seem to have remained quite constant at around 70% of people accessing THs, despite increasing coverage of orthodox medical care (Mills et al., 2006, p.360). Banerjee (2003, p.73) found that in Malawi, 57% of THs' patients are women, and that they usually come for natural diseases inflicted by God or bad luck (35%); bewitchment (30%); diseases caused by demonic spirits (18%); and breaking sexual taboos (17%). Interestingly, only 3% of visitors come for a question related to HIV/AIDS. However, the displayed symptoms suggest that at least one-third of patients seen by THs have an illness suggestive of AIDS.

As long as there is insufficient supply of medications and health professionals in low-resource localities, it is likely that the popularity of Traditional Healers will continue. Efforts at developing a collaborative relationship between traditional and biomedical health systems in the context of HIV/AIDS have not yet been very successful (UNAIDS, 2006: 5). The aim of this effort is to improve access to, and the quality of, health services for clients of both systems. Mills *et al.* (2006) argue that the concept of witchcraft in relation to health is pervasive in less-developed countries, and people often see HIV/AIDS as a punishment that may be curable. In such cases, Traditional Healers will often be the first choice of health care since they provide the needed spiritual interventions, and people trust in their abilities (Mills *et al.* 2006, p.361). While some herbal treatments might have a placebo or real therapeutic effect, it is important that efforts be made to engage THs in HIV prevention and treatment. For example, THs could be trained to recognise illnesses that need treatment they cannot provide (such as HIV, but also STIs and Tuberculosis), and refer patients to the nearest hospital. THs also need to be made aware of the risk of transmission to and from patients while administering herbal treatments, which is often done by making a cut in the skin with

an unsterilized razor.

Evermore researchers and policy makers are warming to the idea that modern and traditional belief systems are not incompatible but complementary (Mills et al., 2006, p.361). As described above, the battle against HIV could use all socially influential actors on its side. This does not only include Traditional Healers, but also Traditional Birth Attendants. (Hamela et al., 2014, p.27). As a primary entry point for maternal health care, Traditional Birth Attendants could play a valuable role in preventing HIV transmission from mother to child, when trained and supervised. However, SSA governments aim to stop their activities in order to stimulate more and safer hospital deliveries. The goal of reducing maternal mortality rates is unlikely to be reached due to the inability of current maternal and child health programs to reach marginalised communities and individuals. Certain steps of the PMTCT cascade could be strengthened by involving TBAs; they can accompany women to the hospital during delivery and assist them in case they do not make it there in time; inform women of the importance of receiving antenatal care and HIV tests during their pregnancy; and assist in administering Nevirapine (an antiretroviral drug) to the baby in case a positive woman has an emergency delivery (Hamela *et al*., 2014; Perez *et al*., 2008). One main concern is the confidentiality of TBAs as perceived by women; this should be assessed before giving them a more prominent role in PMTCT efforts (Kasenga *et al*., 2007, p.651).

2.1.5 Gender and health

It is well documented that in the Global South, gender often plays a determining role with regards to education, gainful employment and income equality, as well as the freedom to exercise one's agency (Filippi *et al.,* 2006). Gender can also be identified as a major determinant in maternal health outcomes (WHO, 2005). According to Khanna (2013, p.12):

> *Women's and men's well-being is determined by social, political and economic factors that shape their lives, as well as by their biological condition. Biological differences between women and men – that is differences related to their sex – affect their vulnerability to illness or disease. Differences in the roles, resources and status of women compared to men interact with biology to increase or decrease*

this vulnerability. These gender differences also affect access to health knowledge, self-perceptions of health needs and the ability to access services. Gender inequalities in the preconditions for health and in health information and services produce inequalities in health outcomes.

With this in mind, the research is grounded in an approach called 'Gender and Development'; acknowledging socially constructed differences by men and women, and advocating an analysis whereby the relational nature of women's subordination is seen as a consequence of power and control within gender relations (Razavi & Miller, 1995, p.12). In the study of maternal and reproductive health it is therefore important to take biological and sociocultural differences between men and women into account, and as well as gendered behavioural patterns, women's roles in production and reproduction, the availability and use of health services. The GAD approach serves as an umbrella for other, more specific paradigms used in this study; the transactional sex paradigm, the vulnerabilities approach and ultimately also the structure and agency approach.

2.1.6 Harmful cultural practices

The Malawian Human Rights Commission (2005) has issued a report on cultural practices and their impact on human rights in Malawi. The report does know certain limitations: it includes many references to practices that do not actually happen in the research region, is potentially outdated and is not based on academic research. However, it serves as an excellent baseline study to understand how Malawi is governed by a culture whose beliefs, customs, values and a host of other practices have a powerful influence on community life (MHRC, 2005, p.7). It rightly observes that a lot is done in the name of preserving culture, which erodes the physical and psychological health, dignity and integrity of certain individuals in society (MHRC, 2005, p.9). The report goes on to discuss a great number of cultural customs surrounding, among other things, pregnancy and maternal health. Some of them are detrimental for women's mental and physical health, such as food taboos during pregnancy that can lead to malnutrition, or cultural taboos that limit a woman's movements to such an extent that she might not want to participate in PMTCT programs, if necessary. Several of the cultural practices described in the report were also found in the case study area.

2.2 Theoretical Framework

The following chapter reviews the most important theoretical underpinnings of the research. Firstly, analytical frameworks regarding the interaction between supply- and demand-side of health systems in developing countries are presented. This will help to identify PMTCT barriers that are directly related to the care delivery system. Secondly, the vulnerability paradigm will be introduced to explain some of women's structural inequalities with regards to HIV. Lastly, the vulnerability approach will be countered with a discussion on women's agency and coping mechanisms within limiting structures. By placing the two arguments against each other, a balanced view is adopted – including both structural and institutional factors, and individual responsibility and decision-making.

2.2.1 Health systems

At least a billion people suffer every year because they cannot obtain the health services they need (WHO, 2014). The World Health Organization has stated that it is their aim to provide 'universal coverage – defined as access for all to appropriate promotive, preventative, curative, and rehabilitative services at an affordable cost. Health systems play an extremely important role in achieving the health-related Millennium Development Goals (MDGs). These include reducing the maternal and infant mortality ratio, as well as the delivery of interventions towards the burden of HIV/AIDS, malaria, and tuberculosis (WHO, 2014). A well-functioning health system can make all the difference in people's lives in terms of their livelihoods, longevity and personal wellbeing. While national levels of maternal mortality in SSA have declined in recent years, there is mounting evidence that health-related interventions are not necessarily reaching the most vulnerable sub-populations (WHO

> *Box 1: Definition of a health system:*
> "A health system consists of all the organizations, institutions, resources and people whose primary purpose is to improve health. […] The health system delivers preventive, promotive, curative and rehabilitative interventions through a combination of public health actions and the pyramid of health care facilities that deliver personal health care — by both State and non-State actors." (WHO, 2010: vi).

2010, v). Against the backdrop of existing inequities and unsustainability in maternal health services accessibility and utilization; several SSA countries have pursued a policy of free maternity care. This is premised on the notion that financial barriers are putting major constraints on equitable access to skilled maternal health services (Kuumuori, 2014). Indeed, the abolition of user fees is one way to ensure increased access to and use of maternal health services. On the other hand it has also led to crowded and over-extended staff in many public clinics, which ultimately compromises the quality of care. Even if all the required elements are provided, PMTCT program outcomes cannot be expected to be satisfactory, if the overall services are poor and users are not accessing and using them responsibly *(Ekouevi et al.*, 2012). Health service delivery depends as much on input of financing, a trained workforce, and effective managing of medicine and supplies, as on an understanding of health care seeking behaviours and patterns of utilization (Gerthnerova, 2011; Standing, 2004). The following sections are based on the framework by Jacobs *et al.* (2012) and discuss the dimensions of access barriers in terms of a supply- and demand-side of health services.

2.2.2 Supply and demand

Within the health sector, the different dimensions of health provision are usually divided into supply-side and demand-side mechanisms. Roughly, 'supply-side' refers to service delivery inputs such as human resources and supplies provided based on formal sectorial planning by technical planners and managers, or all factors inherent to the health system. 'Demand-side' refers to the behaviour and inputs of the (intended) recipients of these efforts: individuals, households and communities (Standing, 2004, p.6; Jacobs, 2012, p.289). Access to care, or the 'timely use of service according to need' (Peters *et al.,* 2008), is shaped by four dimensions: availability, geographic accessibility, affordability and acceptability (Jacobs, 2012, p.290). Three main delays influence access to care: delay in the decision to seek care, delay in getting to the facility and delay in obtaining the appropriate care once at the facility. The first one mostly relates to a lack of information and decisionmaking power within the household. The second delay is likely a consequence of lack of financial resources and available transport. The third delay can be classified as a supply-barrier, and includes lack of human and medical resources, health care workers' attitudes and lack of opportunity (Ensor & Cooper, 2004, p.75).

The supply- and demand-model is useful insofar that it focuses on interventions which can produce results in the short or medium term, and which can be applied at the dsitrict level. However, it does not include important barriers to health care such as females' lack of support or autonomy, because changing this would require societal and behavioural changes that are hard to bring about (Jacobs, 2012, p.289). Until recently, health service studies have tended to pay more attention to the supply-side; academics and policy makers seek for interventions that can break down supply-side barriers and improve service delivery and quality of care. Health-seeking processes received much less attention and interventions are usually limited to information, education and communication campaigns (Obrist, 2007, p.1585). Development interventions increasingly pay attention to the demand side, since health outcomes can ultimately be measured within the households and improved through health service contribution (World Bank, 2004). Another motivation for this focus on the demand-side is that governments of low-income countries continue to fail to provide adequate basic public health services.

2.2.3 Supply and demand policies

The components of good service delivery, as described above, will have to be incorporated into sound policy, in order to strengthen a health system. Since Malawi's health system is the subject of this case study research, a brief review of the underlying policies and their implementation follows.

Malawi's National Health Policy boasts a system that should provide free and equitable care, regardless of age, gender, ethnicity and sexual orientation (Kemp et al., 2003, p.2). However, as will be demonstrated in the empirical portion of this thesis, women remain vulnerable to HIV and are often not receiving adequate care to prevent themselves and their children from being affected.

In 2003, Malawi developed the National HIV and AIDS policy, which states as its main goal: "to reduce infections and vulnerability; to improve provision of treatment, care and support for PLHIV; and to mitigate the socio-economic impact of the epidemic" (Government of Malawi, 2012, p.10). In 2005, the country also developed the National HIV and AIDS Action Framework, used to mobilize an extensive, multi-sectorial response to the epidemic. Nine priority areas were identified to mitigate the impact of HIV on the nation: (1) prevention and behaviour change; (2) treatment, care, and

support; (3) impact mitigation; (4) mainstreaming, partnerships, and capacity building; (5) research and development; (6) monitoring and evaluation; (7) resource mobilisation and utilisation; (8) policy coordination; and (9) programme planning (National Statistical Office, 2011, p.165). A policy review of the National Action Framework reveals that women's vulnerability to HIV is mainly considered in terms of prevention. The wider burden that disproportionately falls on women, such as providing care, lesser access to nutritious food and being more likely to be removed from school is not being recognised, nor are the large barriers that women can face in accessing treatment, care and support. On the other hand, the policy does acknowledge the link with harmful cultural practices and socio-cultural norms. Unfortunately, tight budgets do not allow for a full implementation of gender equity programs, as focus is placed on short-term HIV treatment rather than long-term structural plans to diminish women's vulnerability to HIV (Coonan, 2012, p.3).

While the existence of these policies has brought major strides forward in the battle against HIV, several challenges still lie ahead. Behaviour change programs have not had the desired impact, following the evidence that the population's comprehensive knowledge is still low and HIV incidence across the country has not significantly diminished. Secondly, weak supply chain management is a major barrier towards delivering a continuous, reliable flow of high quality, effective and affordable medicine and supplies to achieve HIV targets (Government of Malawi, 2012, p.50). With regards to women in vulnerable positions; programs do not specifically target them and are therefore not providing them with adequate access to treatment and care.

2.2.4 Analytical framework

So far, several perspectives on the main topic of barriers to health care access have been discussed. Firstly, women have been identified as a vulnerable subgroup in general, and in particular when it comes to how they are affected by diseases such as HIV/AIDS. Women are often seen as victims of patriarchal structures. They have limited access to health care, due to societal and institutional factors. Therefore, developmental schemes often have a gendered focus, which tends to emphasize women's agency and capability to change their own fates, if only they are given the proper tools. A main part of this is their ability to choose to participate in maternal health services, which should ensure a

brighter future for them as well as their children.

The analytical framework below is based on an evaluational tool for reproductive health indicators, and incorporates the previously mentioned theories. The framework specifically discusses pathways to health care, and places these two perspectives in terms of the supply- and demand-side of health systems (distinguishing between factors of accessibility, availability, affordability and acceptability). Individual and societal factors are then taken into account. Lastly, two of the main barriers were discussed, namely male involvement in PMTCT and stigma and discrimination.

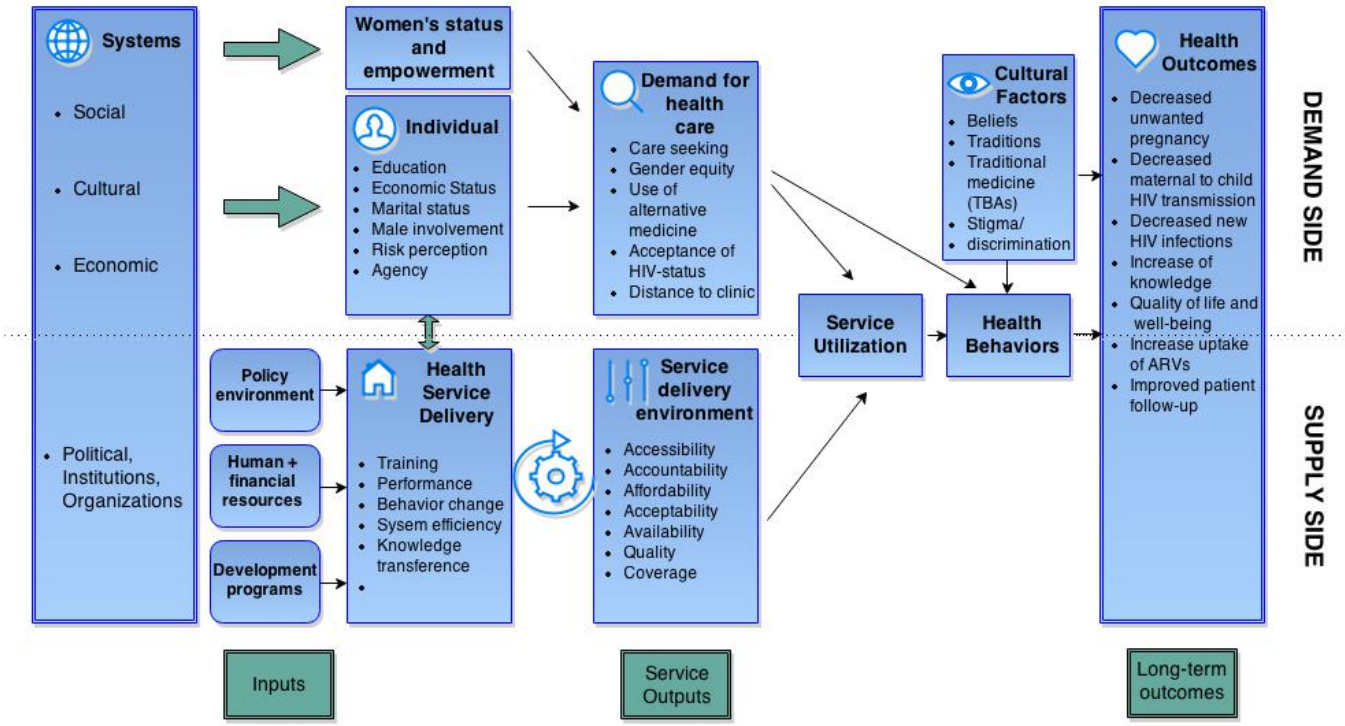


Figure 3: Conceptual framework, health corridors of maternal health and HIV-Prevention (by author, adapted from Measure Evaluation, 2014).

The conceptual framework illustrates the pathways by which HIV-prevention programs achieve their objectives, and simultaneously highlights where blockades might occur that could prevent people from obtaining health care. The systems column on the left lists the spheres in which a health system operates; socio-cultural and economic systems, as well as the policy-level. These can roughly be divided into the supply- and demand-side of health care provision. The top half of the flowchart represents the role of people's health care seeking behaviour and how individual characteristics influence their demand for health care, while being embedded in cultural systems. The discussion on agency and

structure will further examine the extent to which an individual is capable of making decisions about their health. The double arrow between the individual and health service delivery signifies the accountability mechanism, which is often absent in low-resource countries. Recipients of the services usually have little say about the quality of the services, and care providers are seldom held accountable for the (lack of) quality.

The box 'health behaviours' represents the behaviours that intended recipients of the services are encouraged to adopt, such as voluntary HIV testing, attending ANC, abstinence, being faithful and condom use for HIV-prevention, and most importantly acceptance and adherence of the PMTCT program. On the supply side of the health system, the first level of influence consists of the interest that policy makers and developmental organizations have in the health sector.

The strength of this framework lies in its encompassing of the interaction between health workers and service providers in a community, as well as community members in utilizing facility-based care and adopting preventive care (Abdella, 2015). The interplay between causal events on either side of the chain all lead to specific health care behaviours, which directly affect health outcomes in terms of maternal health.

Application of this framework to the research questions addressed here allows us to identify the different dimensions and aspects of barriers to health services, and to devise recommendations for specific interventions that can best address these barriers (Jacobs, 2012).

2.2.5 The Vulnerability Paradigm

UN Secretary Ban Ki-Moon made the following observation during a meeting of the Commission on the Status of Women, the Girl Child and HIV:

> *Thirty years into the HIV epidemic, psychological, sociocultural and structural factors, such as harmful gender norms, violence, poverty, legal inequalities and lack of education, continue to place women and children at risk of HIV infection and influence their inability to access health care and services, thereby having an impact on their ability to mitigate the consequences of HIV/AIDS* (Coonan, 2012, p.1).

A complete understanding of why babies in developing countries continue to be infected with HIV through their mothers requires a focus that envelops more than just pregnancies and the post-natal period. Which risk factors actually account for the higher rates of infections in women in the first place?

The 'vulnerability paradigm' helps to explain both what makes women more likely to get HIV, as well as why they might have less access to preventive and curative services. The contextual and empirical sections of this thesis will establish that women suffer disproportionately in the AIDS epidemic. This is partly because of their biological susceptibility, however is also related to gendered power dynamics that drastically disadvantage them in HIV-prevention programs.

Feminist groups introduced the 'vulnerability paradigm' to the social sciences in the early 1990s, to highlight women's disadvantages in their interpersonal relationships. A variety of definitions can be found, which is indicative of the broad applicability of the concept:

> *Vulnerability is the differential capacity of groups and individuals to deal with hazards based on their positions within physical and social worlds.* (Dow, 1992)

> *By vulnerability we mean the characteristics of a person or group in terms of their capacity to anticipate, cope with, resist and recover from the impact of a natural hazard. It involved a combination of factors that determine the degree to which someone's life and livelihood are put at risk by a discrete and identifiable event in nature or in society.* (Blaikie et al., 1994)

> *Vulnerability is perhaps best defined in terms of resilience and susceptibility including such dimensions as physical, social, cultural and psychological vulnerability and capacities that are usually viewed against the backdrop of gender, time, space and scale.* (Vogel, 1998)

Interestingly, vulnerability incorporates both the lack of power, opportunity and ability (or skill) to make and implement decisions that affect one's own life, as the ability to recover from such shocks. The opposite of vulnerability is empowerment; being able to make free and informed decisions, and to act accordingly (Tallis, 2012). Personal

conditions are thought to be exacerbated by external structures such as poverty, migration, lack of education and/or conflict (Higgins *et al.*, 2010).

Within this paradigm, gender inequality was appointed as women's main obstacle in achieving sexual autonomy and decreasing vulnerability to HIV. Such vulnerabilities decrease women's access to health services and information, and reduce their ability to prevent infection through affecting or negotiating behaviour change. Once they are infected, the burden of the disease is also greater for vulnerable groups, through stigma and discrimination, the effects of further impoverishment and malnutrition, and social rejection (Kemp, 2003, p.8).

On the one hand, the vulnerabilities paradigm helps to mobilize a prevention discourse that reframes women's biological and social risks in terms of gender inequalities, which are embedded in everyday heterosexual relationships, both inside and out of marriage. It no longer holds women personally responsible for their individual health, since structural influences that go beyond the individual's control disadvantage women in ways they can't control (Higgins *et al.,* 2010, p.436). These recognitions have been adopted by government policy makers and NGOs, attempting to suppress the spread of the epidemic by addressing women's realities, which goes hand in hand with policies on sex trafficking, child marriage and violence against women. Nonetheless, the number of HIV-positive women relative to men keeps growing, with fourteen infected women for every ten infected men (World Health Organization, 2012).

On the other hand, adopting the vulnerabilities approach in interventions and gender mainstreaming practices without taking local biosocial contexts into consideration might ignore women's agency and pleasure in the discussion on women's role in the epidemic. By only focusing on women, men are not seen as agents in the prevention of HIV and women are mostly seen as victims of gender power structures and male dominance. Combining this victim narrative with widespread stigma and discrimination could actually produce disempowerment, rather than challenge it (Higgins *et al.*, 2010, p.438). However, it is possible for women and girls to be vulnerable in certain aspects of their lives and at various times and different contexts, and empowered in others. As such, the term 'vulnerability' is best used in the context of 'lived realities' to explain individual and societal factors that may decrease or increase susceptibility to HIV infection, violence, stigma and other limitations to health and care. A gender analysis of vulnerability is essential to highlight the socially constructed

aspects of gender relations that underpin social behaviour in terms of driving the HIV/AIDS epidemic and devising solutions to it.

Three separate but interconnected sources of vulnerability can be outlined, namely societal, personal and programmatic. Personal vulnerability refers to biomedical, emotional and psychosocial factors, for example the stage of infection, gender of partner, access to birth control, sexual behaviour, number of partners, individual risk perception, etc. Programmatic vulnerability refers to the conscious or subconscious decisions of organizations to implement a specific program, such as one that impacts negatively on women's vulnerability without understanding the impact of their actions. Many organizations tend to have a 'one-size-fits-all' approach, which often does not reflect local realities. Societal vulnerability incorporates the processes through which contextual conditions and factors makes women, men and children vulnerable to the disease itself, as well as vulnerability to the social and economic impacts of the

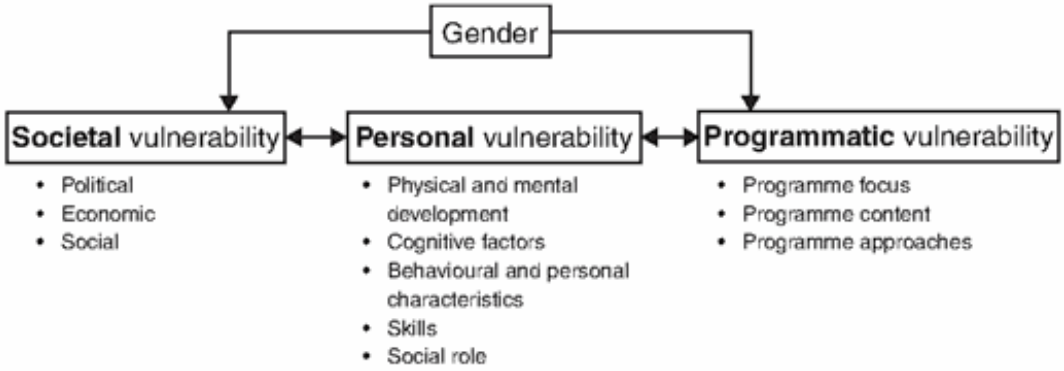


Figure 4: Vulnerability model (Tallis, 2012).

disease. The complex interplay between these dimensions of vulnerability has to be taken into account when assessing access to health care.

In the discussion of women's relation to HIV/AIDS and factors inhibiting their ability to make informed and independent decisions, it essentially comes down to a debate of structure versus agency. While adopting this model might prove to be useful in order to frame ways in which women might be vulnerable to circumstances and structures, one must not forget to account for women's agency and the active role men play in creating and reinforcing inequalities. Illustrate of women's role in actively perpatuating the HIV cycle and gender inequalities, is the transactional sex paradigm, which will be presented before moving on to the discussion on agency.

2.2.6 TRANSACTIONAL SEX PARADIGM

Feminist scholars have made great strides in their attempts to feminize the HIV/AIDS discourse (Higgins *et al.*, 2010, p.436) in a way that acknowledges women's vulnerabilities. They argue that heterosexual transmission accounts for more infections among women than men, because even if their follow the ABC commandments of abstaining, being faithful, and using condoms, they could be susceptible to HIV from their husbands because of a nearly universal sexual double standard and men's greater access to extramarital sex (Higgins *et al.*, 2010, p.436). Furthermore, harsh living circumstances lead women to engage in dangerous sexual liaisons with men, which creates a certain dependence and increased risk of HIV (Baral *et al.*, 2009, p.4). International scholars have begun to use the term 'vulnerability' in recognition of women's structural disadvantages related to gender inequalities. The outcome in terms of foreign aid and assistance was the conclusion that women should be economically empowered in order to reduce the need for them to resort to risky sexual practices for survival. The transactional sex paradigm, or the combination of gender inequality and poverty, has become one of the main explanatory models for the disproportionately high HIV rates in African women. However, Verheijen (2011) points out that this line of argument overlooks certain important cultural and socio-economic aspects of women's sexual choices. During her fieldwork in rural Malawi, she has found that the correlation between livelihood insecurity and sexual risk taking is not so clear-cut:

> *Factors that thus also play a role are the wish to conform to cultural norms, gaining or maintaining a respectable status, and averting suspicion, jealousy, and consequent community exclusion. Further reasons are longing for affection, sexual satisfaction, and offspring, and benefitting from other duties that husbands are supposed to perform besides providing money* (Verheijen, 2011, p.300).

Empowering women economically would therefore not necessarily reduce the number of HIV infections through promiscuity. Furthermore, "income generation is culturally considered a male responsibility, which in principle makes it unnecessary, inappropriate, and disrespectful for women to engage in" (Verheijen, 2013, p.300). In relation to PMTCT and women's health choices, it is important to note that the common

depiction of women as powerless victims of patriarchal structures and poverty does not do justice to their everyday lived realities, as will be shown in the empirical chapters of this thesis. Women sometimes have to make strategic choices which might negatively impact their health, but also allow them to continue living within the bounds of society as respectable women, able to take care of their children for another day.

2.2.7 Gender, structure, and agency

Women in the Global South are often depicted as powerless and subjugated under the weight of patriarchal structures, the outcome being that they have little or no control over their own sexual and reproductive lives (Van Hollen, 2013, p.12). I acknowledge that the sexual and reproductive health decisions of women I met in the field were constrained by sociocultural and gendered structures, as is true to different extents for women everywhere. However, by using Laura Ahearn's operationalization of 'agency' as the "culturally constrained capacity to act" (Ahearn, 2001), I draw attention to the ways women negotiate decisions regarding their own health and that of their children, in response to the previously mentioned contextual factors.

The structure-agency debate is central in the social sciences, and plays a major role in the theoretical underpinnings of this research. The main discussion often revolves around which of the two concepts best represents reality, or which one prevails over the other. The 'old' wave of HIV-prevention efforts, still widely practiced, builds on the assumption that human behaviour results primarily from individual agency, and can thus be changed by merely informing individuals about risk and protection. In reaction, the now widely called-for 'new' wave stresses that external structural forces – particularly gender inequality and economic deprivation – constrain human agency beyond individual will and must therefore be removed before behaviour change can occur (Verheijen, 2013, p.17).

The theories on vulnerabilities and structuralism both essentially transcend the individuals' responsibilities and possibilities for agency in their own health, but attribute it to inequalities in gender- and poverty structures. The victim narrative also disadvantages both men and women by assuming that HIV prevention is women's domain only (Higgins *et al.*, 2010, p.441). And indeed, it can be difficult to recognize women as agents of their own lives and health care, while simultaneously decrying the ways gender inequality threatens their autonomy and access to health care. Despite

these challenges, it needs to be acknowledged that the vulnerability paradigm can mask women's power and agency, while women in some way will display agency in any situation. So women's preferences and priorities need to be considered as potential influences on maternal health. Ultimately, it will be in the interaction between structures and individual wants and needs, where agency takes place. The question is not which one presides over the other, but how they interact (Higgins *et al.,* 2010).

2.3 Conclusion

In the theoretical underpinnings of the research, the two dimensions of health systems have been described, encompassing the the various dimensions of barriers to health care in low-income countries, in terms of geographical characteristics, availability, affordability, adequacy and acceptability. However, they do not yet explain what acually influences an individuals' health seeking behaviour. The vulnerability paradigm, transactional sex paradigm and structure/agency debate all focus on providing deeper insight into why, when and how individuals seek health care services, until they feel capable of living with their conditions (Obrist, 2007). They define numerous constraints on the individual, interpersonal, community and societal level.

Moreover, when examining the factors that influence spatial inequalities in health, access to health care might be less significant than environmental and social inequalities. Any analysis of health-related issues needs to adopt a bird's-eye perspective and acknowledge that "health" is more than the absence or treatment of disease, but is rather defined as a state of perfect physical, mental and social well-being (WHO, 2000). In other words, nearly every aspect of a person's life will contribute to his or her wellbeing, and consequently to how health behaviour is negotiated. The holistic framework developed by Jacobs *et al.* (2012) takes such contextual factors into account, and distinguishes between demand-side and supply-side barriers. They also acknowledge that universal coverage (defined as access for all to appropriate promotive, preventive, curative, and rehabilitative services at an affordable cost) could not only be achieved with financial interventions. Rather, it appears that community participation and community-based interventions are among the most effective ones, alongside culturally sensitive health care delivery, improved management, and social

marketing. Reducing barriers to access and participating and building the capacity of health care providers should enable greater access to health services for poor and vulnerable patients. The framework can be used to assess the appropriateness of interventions, or to design new interventions (Jacobs *et al.*, 2012).

3. Thematic, regional, and local context

3.1 AIDS AND AFRICA

The map below depicts the global distribution of HIV; Africa is obviously disproportionately affected by the epidemic. In fact, two-thirds of the 33 million HIV-infected people live in sub-Saharan Africa. 1.4 million women are currenly pregnant and living with HIV; 90% of them are in SSA (Besser, 2010).

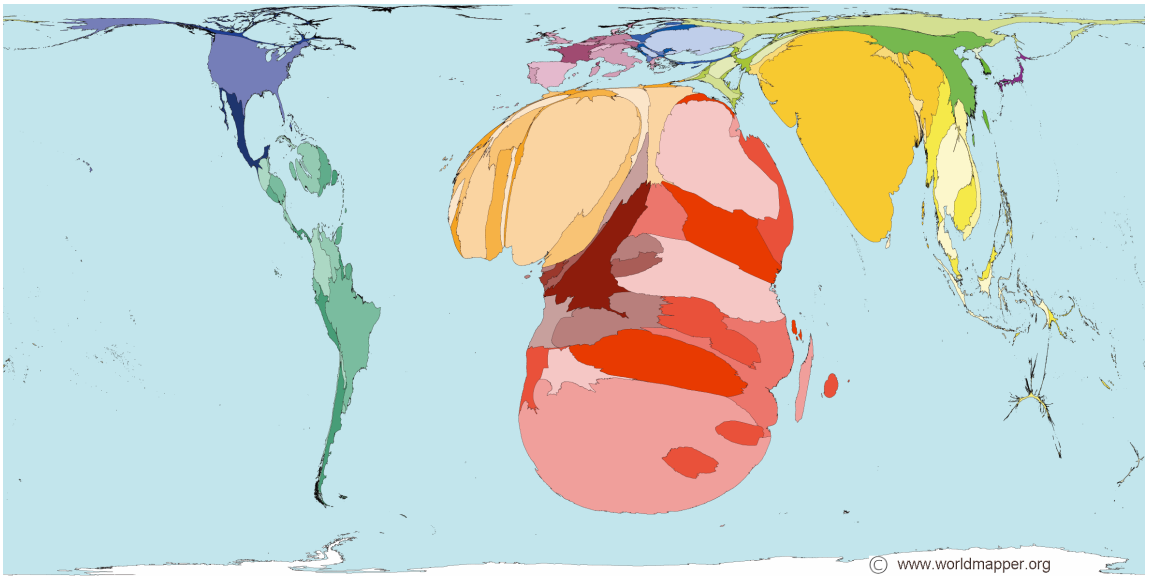


Figure 5: Worldwide inequalities in AIDS prevalence (Worldmapper.org)

To put the HIV-story in a global perspective, another map is provided. This one represents the number of doctors and nurses working around the world, relative to the size of the population. Sub-Saharan Africa only has access to three percent of the world's health care workers (Besser, 2010).

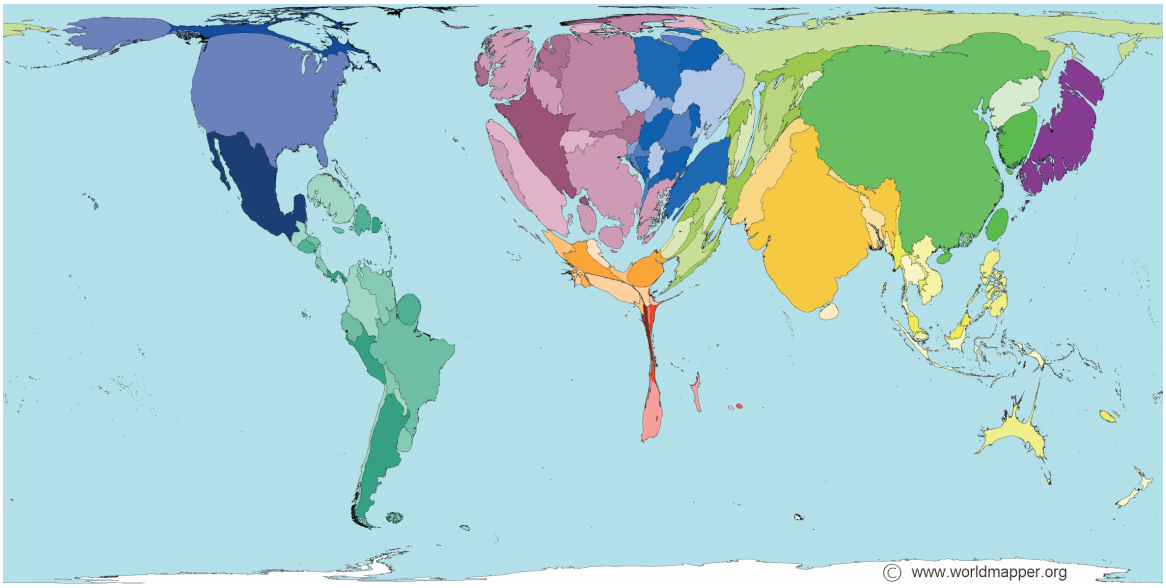


Figure 6: Proportions of physicians working around the world (Worldmapper.org)

This provides us with an initial clue as to why AIDS continues to spread, and what might account for women's low access to HIV-preventative measures.

In Malawi and most other sub-Saharan African countries, heterosexual intercourse accounts for about 88% of all new HIV transmissions, most of which occur in stable, long-term relationships. As in other high-risk and resource-low countries, over 60% of new infections are occurring in women, young children and infants. Around 14% of new transmissions worldwide come from mother-to-child transmission (van Lettow *et al.*, 2011, p.1). Out of Malawi's estimated 70.000 new annual infections, 25% can be accounted for through MTCT (Ministry of Health, 2012, p.11), meaning that 40% of children born from a positive mother end up being infected. In comparison, in resource-rich countries less than 2% of such babies will be born with HIV.

3.1.1. Feminization of AIDS

Since AIDS was first identified in the 1980s, in the academic world it has mostly been associated with minority groups such as men who have sex with men, and intravenous drug users. Heterosexual intercourse has only recently been acknowledged for its true role in HIV transmissions, currently accounting for about 90% of all new infections (Ministry of Health, 2012, p.11). It is thus affecting both men and women in the general population. Furthermore, in sub-Saharan Africa more women are infected with HIV than men, hovering around 65% in high-prevalence countries like Malawi (Akukwe, 2005). Scientists have sought rationales in biological and social causes for this apparent

divergence for why women seem to be more affected by HIV/AIDS than men. This attention to women signifies a shift in the academic debate, with the focus moving from gay men and drug users to women, as both victims and agents in spreading the virus. Visibility however, did not immediately mean that women had increased access to public health aid. The discourse from the 1990s featured two kinds of heterosexually infected women; pregnant women who could pass on HIV to their infants, and prostitutes who could pass on HIV to their male clients, and through these clients to the general population. Women's personal health was still secondary to that of their male partners or children. The initial feminization of AIDS thus mostly revolved around prostitutes of whom men needed to be protected. Male clients were not targeted in coercive testing practices and criminalization (Higgins *et al.*, 2010, p.435), thus held less accountable for their role in the epidemic.

3.1.2 Country demographic and epidemiological profile

Malawi is a small, landlocked country in sub-Saharan Africa. A major source of information on Malawi's population is the Demographic and Health Survey (2011). The nationally representative survey indicates that Malawi's population grows at a rate of 2.8% a year, currently counting an estimated 16.7 million people. About 84% of the population is living in rural areas, making Malawi one of the least developed countries in the world. Development challenges are great, since the agricultural base of the economy is unable to provide food security, and employment opportunities for the youth are rapidly diminishing (Mukherjee & Benson, 2003). Over 900,000 Malawians are infected with HIV/AIDS, about 58% of which are women (UNICEF, 2002). The direct impact of the disease in combination with famine has severely undermined household welfare over the last four decades (Bryceson, Fonseca, & Kadzandira, 2004). Furthermore, life expectancy has declined in the face of HIV/AIDS and remains static at only 54.7 years in 2012 (World Bank, 2014).

Figure 7: Map of Malawi (MoH, 2012)

3.1.3 MALAWI'S HEALTH INFRASTRUCTURE

Malawi's overall national health policy is to raise the health status of all Malawians by reducing the incidence of illness and death through developing a sound delivery system capable of promoting health; preventing, reducing and curing disease; protecting life and fostering general well-being and increased productivity (Chepuka *et al.,* 2012, p.26). However, the country's extremely low ranking on the Human Development Index, at no. 174, (HDR, 2014), is partially due to the health sector's inability to provide equitable, basic care for all. Challenges the health sector is currently facing include a heavy burden of communicable diseases such as HIV/AIDS, TB and malaria, as well as growing numbers of non-communicable diseases. Poverty reduction programs lack funding, human resources and medical supplies. While the World Health Organization recommends a minimum of 23 health workers per 10,000 inhabitants, Malawi only has 2 physicians and 3.4 midwives for every 10,000 people. The number of nurses has not increased since 2001, but advances in tests and (HIV) medicine mean that nurses now have to see more patients in less time than before, and provide them with more extensive care (Besser, 2010).

The financial component is usually not a main contributor to the lack of access to health care in Malawi. Studies show that in other low-income countries, health-related expenses are the cause of up to 85% of all cases of impoverishment. However, in all government public health facilities, almost all services are provided free of charge in Malawi. The government has issued a mandate which states that all available resources will be used to ensure that a package of basic health services (the Essential Health Package), will be provided to all citizens (Ntata, 2007). This includes ARVs, which are usually available and provided for free to all those who need them. However, receiving medications doesn't equal health care. Moreover, a woman can have her ARVs and perfectly understand that she needs to take them every single day, but she can still encounter problems at home if nobody knows or accepts the fact that she is HIV positive.

3.2 PMTCT

3.2.1 The medical process

Finding out you are HIV positive is a difficult experience for any person, in any country. However, modern medicine has made it possible for a positive person to live a very long and relatively healthy life, provided they have access to the right drugs. The prospect of a long life should bring back some sense of normalcy, which was initially taken away by the idea of having an incurable disease. People might start thinking again about having children, creating a family of their own. Luckily for them, it is entirely possible to give birth to an HIV negative baby, even if the mother is positive herself. Such an outcome does require full participation in a lengthy process of testing, taking drugs, giving birth safely and administering drugs to the newborn. This section will provide an overview of the medical and social steps that need to be taken in order to complete the PMTCT process. An understanding of this will later be helpful in identifying the challenges a mother or health care worker could encounter while going through it.

Mother-to Child-Transmission (of HIV) can take place during pregnancy, delivery or breastfeeding. Without preventative measures such as ARVs (antiretroviral drugs) and Nevirapine for the baby, there is a 15 to 45% chance the infant will become infected by its mother (AVERT, 2014). Figure seven presents the initial phase of the PMTCT cascade, which includes counselling from a trained health care worker before and after the HIV test, and three subsequent antenatal check-ups before giving birth.

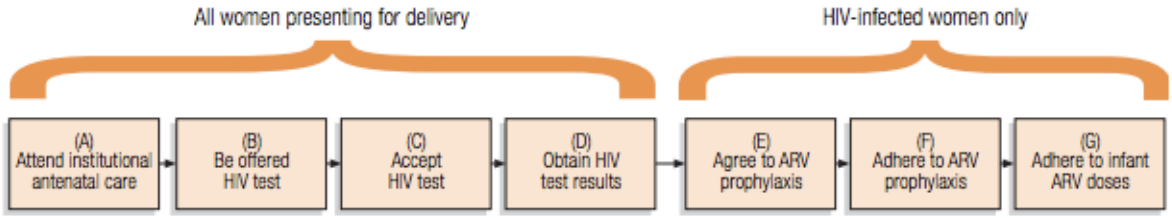


Figure 8: Series of events required for a pregnant woman to successfully receive full ARV treatment (Stringer *et al.*, 2008)

After a pregnant woman has been identified as HIV positive, she will immediately be started on lifelong ARVs, as recommended by current World Health Organization guidelines. With these drugs, the risk of transmission to the baby is reduced to less than 5%. Whether a non-pregnant woman needs to start taking ARVs depends on her CD4-count, which is a determination of the stage of the virus and

whether the body's immune response is still strong enough. However, in countries like Malawi, antenatal care is the key moment where HIV testing takes place, so most women will already be pregnant when they find out their status and therefore be started on ARVs straight away. Coincidentally, this means that HIV prevention programs are missing the opportunity to reach women *before* they get pregnant, unknowing of their health status. In my opinion, HIV prevention interventions should focus on testing women *before* they get pregnant in order to bring down the number of positive babies being born, and prevent infections in women as well. Generally, women are given drugs for a period up to two months and will have to collect them at their local health centre. This is the stage where the largest dropout of the PMTCT cascade takes place, *after* testing and receiving the results. The baby should be brought in for testing at 6 weeks, Depending on the quality of the information the woman was given, the perception of confidentiality and reliability of the health care providers and the woman's social environment, she chooses whether or not to adhere to the drugs, deliver at the clinic and bring her infant in for testing and medicine.

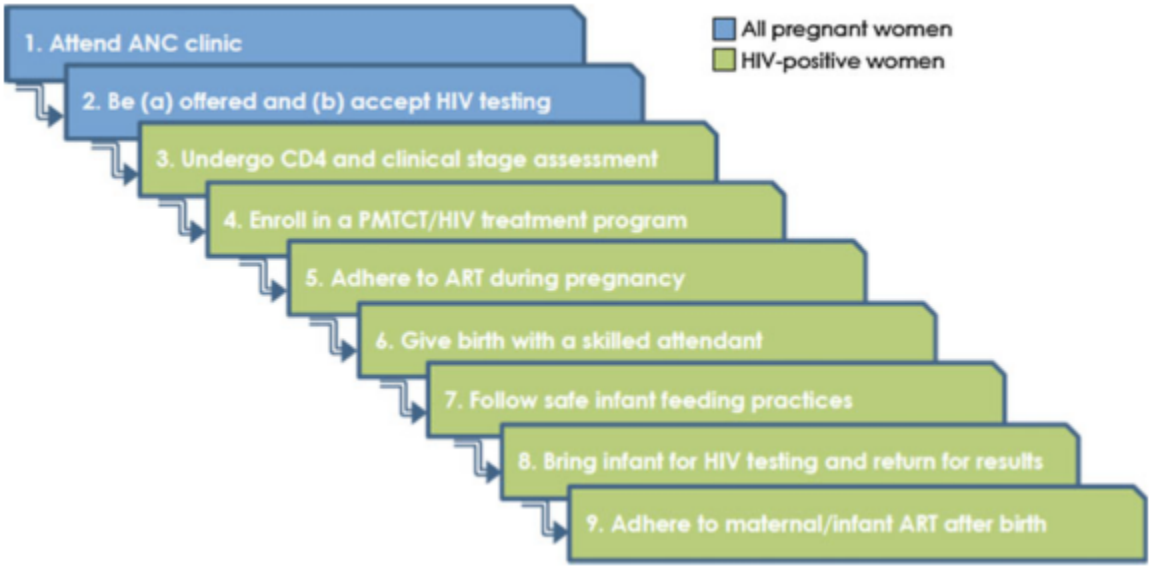


Figure 9: The PMTCT cascade (Turan & Nyblade, 2013: 2529)

The chance of transmitting HIV to the baby during vaginal childbirth is 25%, for a mother who is not receiving treatment. There should be no excessive vaginal examination, to prevent the ascending infections (interview with Munthale, midwifery expert, 11-03-2014), and no rupturing or tearing of the membrane. Therefore the delivery cannot be induced, and a skilled midwife in a hospital or clinic should perform

it. Within two hours of being born, the baby should be given a single dose of 200mg Nevirapine, and then daily doses for another six weeks. This is a crucial stage, as NVP reduces the risk of HIV transmission by nearly 50% in the first 14-16 weeks of life (Kasenga et al., 2010, p.28). After six weeks, the baby should be brought to the clinic for DNAPCR, or rapid blood test. Regardless of the result, the baby gets preventative therapy (CPT) once a day. Another test is done after one year; if the baby tests negative, he or she will continue with CPT. If the child is positive, it will be started on ARVs. After two years a final test gives the definitive result about the child's status (Munthale, interview, 11-03-2014).

Approximately 40% of mother-to-child infections occur through breastfeeding, which makes this the most widespread means of MTCT of HIV (Liamputtong, 2013, p.6). However, the risk of MTCT can be reduced significantly by breastfeeding exclusively (giving a child no other food or drink, including water) (Petrie *et al.*, 2007, p.72). Depending on the economic and social situation of the mother, she chooses whether she wants to breastfeed the baby or give formula feeding. If she is to breastfeed, it is recommended that she do so exclusively for six months. After this time, she can choose to introduce complementary feeding.

3.2.2 The PMTCT program in Malawi

Throughout the years, significant strides have been made on the medical front of the HIV battle. Malawi was one of the first countries in the world to implement the innovative Option B+ approach. Option B+ is the most advanced HIV regimen, providing the triple ARV drugs to pregnant women from the moment they are diagnosed in the antenatal clinic, to be continued for life. It also promises to include further simplification of regimen and integration of service delivery and synchronization with ARV programs, protection against mother-to-child transmission in future pregnancies, continuing protection against transmission to negative partners, and avoiding stopping and starting of ARV drugs (World Health Organization, 2012).

3.3 Description of sample population and case study site

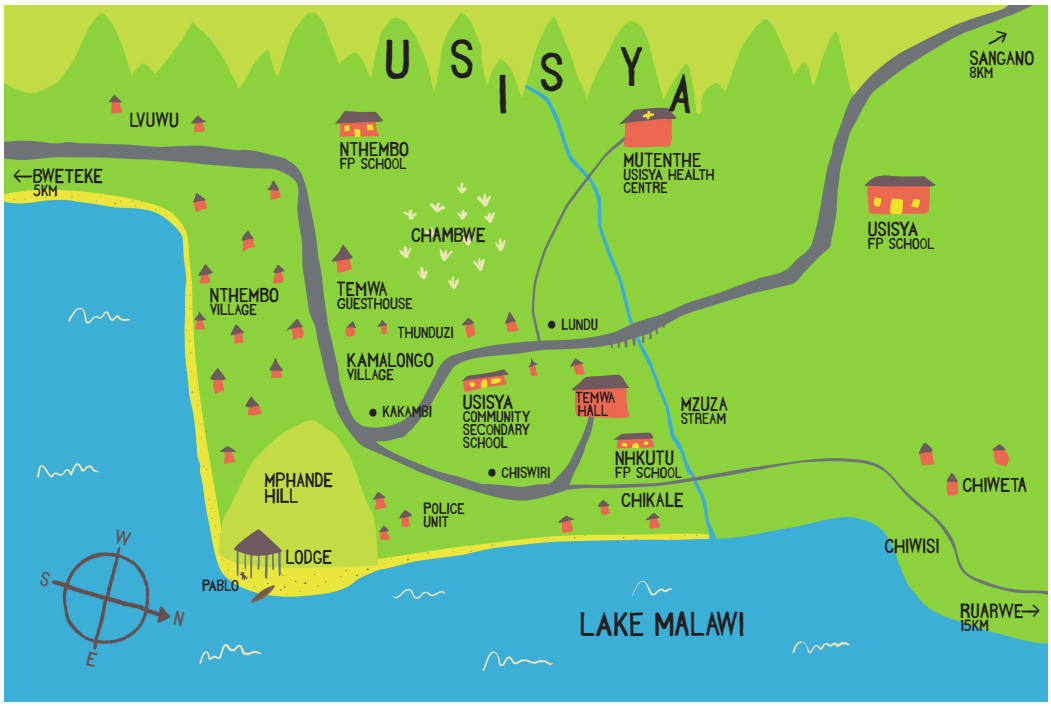
3.3.1 An introduction to Usisya

The four-month fieldwork was conducted within the boundaries of Usisya, a small, charming fishing village on the coast of Lake Malawi. An imposing mountain range hugs the western town borders, while the lake stretches out as far as the eye can see on the eastern side. Due to the geographical characteristics of the area, traffic in and out of Usisya is extremely difficult to manage. A passenger boat will make a brief stop there twice a week; once to go up the coast, and once back down south. Should someone be so lucky as to procure a car ride, they are a two-hour bumpy four-wheel drive ride away from Mzuzu, the nearest city. The most common form of transport for people and goods is an old truck that will usually drive during night hours, often with a drunk chauffeur, who is responsible for the loss of several lives along the steep and winding mountain roads.

This specific village was selected to be the research site by partner NGO, since this is the location of their field office and the main beneficiary of their development projects. Therefore, they would be able to provide support on the ground and the gathered data would be optimally useful for the organization (also see Appendix 5).

Figure 10: Satellite image of Usisya (www.flashearth.com)

The hand-drawn map below shows the different 'neighbourhoods' of Usisya, where the research was conducted. Most interviews took place in Nthembo, Mutenthe and Kamalongo village, which are coincidentally the most densely populated and central places.



F
Figure 11: Hand-drawn map of Usisya, by Temwa-employee Benson Chiumia

3.3.2 Community profile Usisya

People in Usisya are subsistence farmers, living off what their land provides and suffering if anything disturbs the delicate balance. Gainful employment is very rare, since Temwa, the small local lodge and the clinic are the only places where someone might find a job. Others small business owners run shops selling soap and Sobo, or they might sell some vegetables or fish on the street. A local market is currently being built, with the intention of increasing Usisya's commercial position amongst the other fishing villages along the shore. Piecework *(ganju)* is available; for men this can include construction work, whereas women might go farming on other people's lands in order to make some money. Transport, HIV and hunger are considered by the community to be their biggest problems (Philips, 2007, p.6). Because of its remoteness and lack of resources, Usisya is very vulnerable to natural disasters, exclusion from government programs and being closed off from 'civilization' when the road is inaccessible during rainy season. The government has also admitted to neglecting people's needs in

communities like these, and depends on NGOs like Temwa to cover some of their responsibilities. The town boasts three primary schools and one secondary school, which are all lacking in human and financial resources. The primary school dropout rate is extremely high, since many children or their parents see more benefit in them staying at home to help out, for boys to become fishermen and for girls to get married, than in getting a relatively 'useless' diploma (Cassie, 2014).

3.3.3 Local authority

In order of importance, the Usisya area is traditionally governed by a Paramount Chief, then a Senior Chief, a Traditional Authority (TA), a sub-TA, a Group Village Headman (GVH) and finally by village chiefs. They all act as different levels of intermediaries between the civil society and the government. Mostly, they are expected to resolve social conflicts by offering counselling and allocating resources to those in need.

4. Research design and methodology

4.1 My positionality as a researcher

In this study, I have attempted to find a balance between an *emic* and *etic* perspective on the research subject. While the research question demands insight into the participants' experiences, imagination and explanations regarding the world around them, I also realize that as a researcher I am too embedded in my own culture to ever claim a full understanding of a culture like a 'native'. The etic approach guided the focus of the research as per my own interests, and subsequently I would adopt an emic approach to document behaviours and beliefs coming from 'inside' the culture. I don't believe the two to be in conflict or mutually exclusive, but rather complementary, since it is in the interaction between the researcher and the subject that knowledge and understanding of each other are generated.

To some extent, I am aware of the impact my personal background, physique, nationality and ethnicity had on my collocutors. Being a young, white, European, highly educated female, mostly worked against me since there were not many shared experiences between me and my participants, or any other common grounds to relate to each other on. I do not believe that my gender gave me any advantage in talking to

women, since there were so many more factors that divided us, making most of my participants look at me with a mixture of suspicion and aloofness, rather than some kind of 'female solidarity'.

While this thesis aims to answer questions about women's attitudes and experiences, I do not wish to proclaim myself as an expert on these women's lives, since I do not have the right nor the experience to do so. Mohanty (1984) has warned feminist scholars about constructing 'Others' in their writings, about creating an image of the singular 'Third World Woman'. This would be produced by hegemonic, Western discourses and relations of power that deny the fundamental complexities which characterise the lives of women in different classes, religions, cultures, races and castes in these countries. Women in feminist literature are often represented as powerless, or as victims of patriarchal cultures without any agency to influence their own desperate situations. This image is henceforth used as a category of analysis, creating a skewed image. Even though this representation might, to some extent, be accurate for certain groups of women, there is more that divides women worldwide, than what unites them. The main lesson to be taken away from this is that we can never assume that women in any country or community are a homogeneous group, with the same interests and problems, regardless of class or social background. Therefore, this thesis is not written with the underlying assumption that the women in the target group are victims of their poor surroundings, or powerless slaves of a patriarchal system, but rather through some of their stories I try to create a heterogeneous image of what life is like within their particular environment. Obviously my choices as a researcher and a writer give the story content and direction; therefore in this sense I cannot claim to represent peoples' true experiences and lived realities. Rather, I would prefer to see myself as an interpreter and everything written here should be read as such – as my personal perception of reality in Usisya, and the meanings I ascribe to it. This is in line with the traditional anthropological idea that reality is not absolute and given, but there are multiple realities which are constructed and reproduced through culture, stories and symbols. The challenge is how to understand and represent the complexities of everyday life without undermining or reducing the native account. I believe the key lies in acknowledging my positionality as a researcher and showing the tensions and symmetries, which facilitated or impeded the dialogue between us. Ultimately, these encounters shaped the form and content of data that were produced.

4.2 Study design

The tools I used to shape the research to measure 'reality' in its closest approximation were designed to encompass the complexities of health issues, both medically and socially. Some quantifiable data was required in order to know what the scope of the problems was and which qualitative questions to ask to gain a deeper understanding. The data collection process was, at least in the beginning, rather unstructured and unrestricted, because I did not want to limit myself to topics that I presumed would be important for answering my research question, fearing this would lead me to miss out on unexpected explanatory factors. To some extent this has proven to be true, but the main themes have remained unchanged.

A mixed methods approach, including both quantitative and qualitative techniques, has been utilised for this research. Quantitative data from surveys inspires and supplements the qualitative data collected from key informant interviews, focus group discussions and participant observation. Semi-structured interviewing has become the most important technique, since participant observation was only possible to a very limited extent, as a consequence of my obvious status as an 'outsider'.

4.2.1 Sample selection

A total of a 110 people contributed to the study, excluding the NGO staff. The sampling frame below provides some insights into the composition of the informant group.

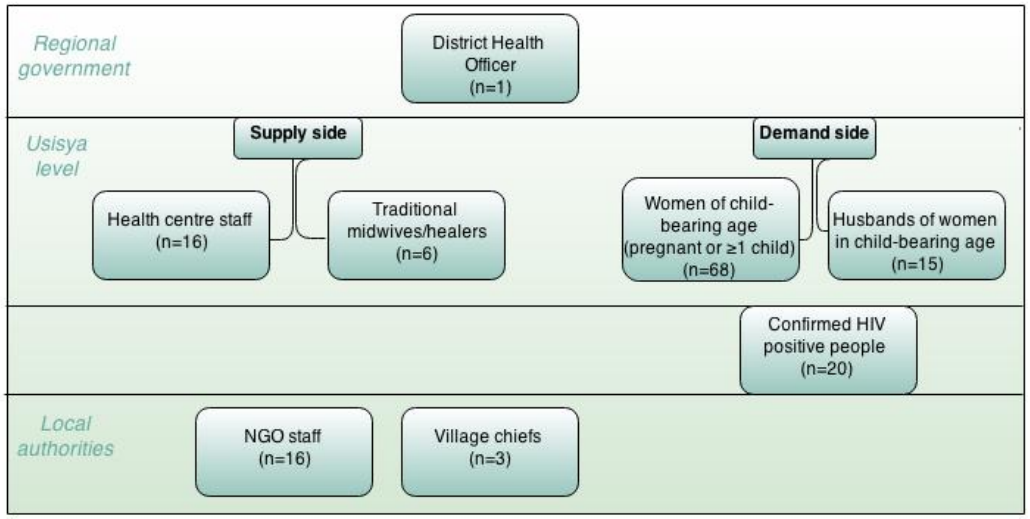


Figure 12: Sampling frame of research population

For the household survey, 72 people were successfully interviewed. While this number may not be entirely representative of the Usisya population, I have observed enough homogeneity in the area in terms of housing types, income, family organisation, etc., to be confident that the findings would approximate those of a larger sample.

4.2.2 Sample population

All empirical research data were gathered from interviews, informal conversations, surveys and focus group with a total of a 110 people. The sampling frame consists of 76 women and 34 men. 19% of female participants were in their twenties, and the men's ages are equally distributed between the age groups of 20s, 30s and 40s (see appendix 1 for a more detailed table). Women generally stop having children after the age of 35, for health- and cultural reasons, so most participants were under the age of 40. Nine older women were interviewed because of their status as 'respected elders' and as Traditional Midwives. Informants were selected based on the judgement of my research assistant, since she was acquainted with practically everyone in the village and knew the basics about their age, pregnancy and marital status, and likely HIV status. This made the process semi-targeted, but we also randomly asked people on the street or in the clinic to participate in surveys and/or interviews, especially in lesser-known areas.

The process of finding research participants who were, or had previously been involved in PMTCT, was very targeted. Names were acquired from the HIV counsellor at the clinic, but when I approached the woman in question I made it seem like a random encounter, in order for her not to feel like her privacy and confidentiality at the hospital had been compromised. It should be noted that this sample might be biased, since most of the women I spoke to have a social support system and were therefore easier to find and talk to. Women who lacked such a safety net tended to distance themselves from public events or groups and would not come to the clinic. Undoubtedly, talking to such women would be most illuminating for the research, but finding them seemed virtually impossible within the limits of this research.

4.2.3 Research assistant

Having a research assistant has proven to be an absolute necessity, most importantly as a cultural translator. Malawian culture has many unwritten but well-established social rules that are easily broken by the unknowing foreigner, sometimes making it hard to

uphold the image of a serious researcher. Because of the remoteness of the area, there are usually no other *azungu* (white people/Westerners) in Usisya. The unique event of having a European in the community stirs up much interest, but my research assistant Denas was able to deflect much of that (unwanted) attention simply by being present and/or explaining the purpose of my presence and research. She functioned as a social bridge, opening many doors for me that otherwise might have stayed closed much longer. On top of that, she has excellent social and linguistic skills, which made her able to guide me through complex social procedures and 'translate' cultural customs and traditions so that I could understand and act accordingly. For example, she was one of the few who are willing and able to openly talk about witchcraft, sexuality and traditional healing practices. This gave me different insights and ideas for subsequent areas of inquiry that might be useful for answering the research questions.

4.2.4 SURVEYS

During the first phase of the research, I dedicated a great deal of my time to designing and administering three different surveys. The first, main survey was aimed at measuring people's knowledge of HIV and attitudes towards infected people. The second one focussed on broader (maternal) health issues and sought information on where people go for health services and which issues they encounter which doing this. The third and final one was a 'patient exit survey', which was used to find out what people had learned during a health visit (for example ARV collection) and how they experienced it, as well as assessing the (perceived) quality of health services.

Administering surveys, especially with the use of a translator, can be a very time consuming and inaccurate method of data collection. Although participants were relatively familiar with answering questions for aid agencies, many had trouble providing the survey administrator with in-depth answers. Much probing was needed, no matter how simple the questions were. While the surveys were not designed to touch upon the core of the research questions, they do provide the research with a necessary and helpful baseline of information to build upon and have identified respondents that were worth revisiting for a follow-up interview. In order to use my time as efficiently as possible, I trained my research assistant to administer the remaining surveys on my behalf during the time that I was absent from the field, or when I did not need her services.

4.2.5 Semi-structured interviews

In my experience, interviewing is a more adequate way of building rapport with informants and talking about sensitive issues such as HIV. Hence, I have shifted my attention from doing surveys to doing semi-structured interviews with similar participants. The same themes were still discussed, but in a different format which was better suited to the local context and ways of conversing. The purpose of the interviews was to gain insight into community members' perceptions, knowledge, attitudes and practices regarding maternal health and HIV. Even so, doing in-depth during interviews remained a challenge because of certain enormous cultural differences that could never fully be bridged.

Initial interviews were conducted with HIV postive as well as negative childbearing aged women, health care workers, religious leaders, non-governmental organizations and community members. The HIV positive mothers were all identified through the local clinic in Usisya. The selection criteria included women aged between 16 and 45, either pregnant or having given birth before with knowledge of their HIV status. Eleven positive mothers were identified, all of whom agreed to participate in interviews or a focus group.

4.2.6 Focus groups

Five focus groups have been conducted with different target groups. Criteria for inclusion in focus groups were: age of 18 years and above, currently married, divorced or living in union and has given birth/fathered a child within the past two years.

The first one took place after a monthly gathering of church leaders, with six participating reverends from different churches. It was successful, but it would have been useful to have follow-up individual interviews with some of them in order to check more recent findings with their experiences. For example, one of the main conclusions points towards the importance of engaging community leaders in sensitization of HIV/AIDS issues.

The second focus group was a spontaneous one, with a group of women playing cards outside on the street. Because of its impromptu character it was somewhat chaotic, but all the more interesting because it made women feel in their element and free to speak within their own group of friends.

A third focus group discussion was supposed to be an integral part of an HIV teen

action club meeting, but had to be cut short because of lack of time and planning from the NGO's side. Some participants did come back a few days later for a continuation of the discussion, but this did not include the people from more remote areas who would have been interesting to hear from as well.

The fourth group consisted of five married men. The topics of discussion were general gender issues, marriage, sex and HIV. It should be noted that it was extremely difficult to get men to come to the focus group, and much probing was needed. Their reluctance can likely be attributed to the lack of compensation (even though drinks and snacks were provided) and their disinterest about the topics that were discussed. Generally such issues are regarded as 'women's talk', which men should not concern themselves with.

The last focus group was composed of six HIV-positive, pregnant women, all of whom were receiving PMTCT treatment. This is the only group that was compensated for participating (with some bars of soap and snacks), as advised by HIV counsellor Julie, who helped to organise it.

My main difficulty while conducting the focus groups was establishing interaction between group members, rather than having them answer my questions directly. People never really felt compelled to counter each other's responses. It was not supposed to be a group interview, but even in groups with already established social dynamics a proper discussion never seemed to really eventuate.

Recruitment of interview- and focus group participants has been done through the locally acceptable procedures. First, the support from the only active NGO in the area, Temwa, was sought. The District Health Office in Nkhata Bay was also approached for information and permission, which was granted. The health care workers in charge of the health centre and several group village headmen or chiefs were consulted as entry points into the community. Having a local research assistant has proven to be one of the most effective ways to gain entry into people's lives, since it inspires trust and curiosity. Aside from the necessary translation component, she also functioned as a bridge between me and the local population, who were more willing to interact and participate in the study because of my obvious association with 'one of them'.

4.2.7 Limitations and ethical considerations

A number of constraints that lay outside my sphere of influence had a big impact on the

success of all research undertakings. Most importantly, I consider it as a major weakness that I was not able to build much rapport with my informants, because of the language and cultural barriers. However, I experienced this rapport vicariously through my research assistant, who did not suffer from these restrictions, and was therefore still able to ask most of my questions to the participants.

Another issue relates to what is locally known as "African time"; trying to make plans was most often useless, as people will easily turn up 2 hours late to an appointment, or not at all, meaning that half a day has passed before anything has been accomplished.

Being a foreigner and outsider comes with certain expectations, since Malawi knows a strong aid culture. The government lacks the resources and sometimes the will to reach areas like Usisya, so this gap is somewhat filled by NGOs and foreigners bringing in money. It was a constant struggle to explain to people that I was not there for the purpose of giving handouts, but to gather information that might inspire some improvements in the health sector. Most people understood, but still the question 'what benefits will I get from participating?' tended to come up a lot. This might skew the research results a bit, since it influences the answers people gave as they were often aimed at exposing a need or lack or resources, which they hoped I might help with.

One example of how this impacted the research: one woman I interviewed was told by the clinic to go to the nearest bigger hospital because she was having a problematic pregnancy. She lacked the funds to do so, so she had to take the risk of staying in Usisya for the delivery. She asked me for help, but I had to explain that it would be unethical for me to give her money, but not all the other women who are experiencing similar problems. It would also negatively influence my research if word got out that people could get money from me for such issues. She was very disappointed and non-responsive after this, which made me lose a valuable respondent. Luckily her delivery went well, but it remained an issue that there was much purposive answering, and people's expectations of me continually had to be adjusted.

5. Knowledge as vehicle for change

5.1 Knowledge, attitudes and practices surrounding HIV

"One song won't keep you dancing throughout the night"

-Malawian proverb

As the above proverb suggests, just one sexual partner won't satisfy a person for their entire lifetime. This is an attitude frequently found in Malawi, especially among men. However, the undeniable and continuing presence of the deadly HIV virus in Malawi requires a second look at the common practice of having multiple concurrent relationships, and unprotected intercourse. The perceived need for a change in such behavioural patterns has led the Malawian government and local health services to try and inform as many people as possible about the 'ABC of HIV prevention': Abstinence, Being faithful and Condom use. People are being reached through campaigns, civic education, integrated HIV counselling into antenatal services, and incentives for HIV testing. The desired impact of these programs targeted at improving HIV knowledge, is that individuals will change certain behaviours that put them at risk for contracting the virus. This comes forth out of the realization that "any epidemic sustains itself largely because of the social organization that supports its propagation, not simply because of biological characteristics of the causative agent" (Bassett and Mhloyi, 1991, p.144). HIV is a highly socialized, gendered disease that required societal changes as well as medical solutions to eliminate.

Figure 13: Government campaign against AIDS (MoH, 2012)

This chapter discusses which particular behaviours and attitudes influence the continuing spread of HIV, how access to information can generate change therein. Ultimately, mother-to-child transmission of HIV cannot be halted without an understanding of which factors and behaviours make women vulnerable towards HIV

and subsequently to becoming pregnant without being aware of their status or of ways to have a safe pregnancy. Also, people with more information and knowledge about the existing health services and about their rights should be better able to represent their own interests and obtain the health services they are entitled to (Deininger & Mpuga, 2005, p.55). In order to create an HIV-free generation, people will have to adjust their sexual behaviour to make it more befitting of the local context in which they live. Socio-economic and cultural drivers of the epidemic of the research location will be discussed later in this chapter (Government of Malawi, 2012, p.5).

This chapter offers a perspective on maternal health and HIV-related issues through the voices of the research participants. After all, they are the ones who are immersed in the epidemic on a daily basis. Their experiences make them 'experts' on the subject; therefore it is only logical that their stories should be the center of the analysis.

5.1.1 HIV KNOWLEDGE AND MISCONCEPTIONS

Many Malawians still lack accurate knowledge about the ways in which HIV can and cannot be transmitted. Results of a survey designed to measure people's active knowledge of HIV in Usisya, indicate that all participants know that HIV can be transmitted through unprotected heterosexual sex. 38% of the female participants could correctly identify the three main strategies for preventing sexually transmitted HIV: abstinence, being faithful to one uninfected partner and using condoms. Young men appeared to be more knowledgeable of HIV, at 58%.

Women mainly gather their information on HIV and PMTCT from the health care workers at the clinic, especially when they have to attend a mandatory antenatal counselling session. When I conducted the knowledge survey at the clinic, a sizable proportion of (female) participants were not able to reproduce the information they had just received during such an educational session at the local hospital. When asked about ways of transmitting or preventing HIV, many would simply say, "I forgot.". After probing and offering examples, the majority was eventually able to explain some basic information, but 40% of the women could not give a comprehensive explanation of how to prevent herself or her baby from becoming positive.

Partially due to people's lack of active HIV knowledge, a large proportion of the sample population continues to hold beliefs about HIV/AIDS that potentially put themselves or others at risk. The HIV-knowledge survey and interviews identified some major misconceptions; the possible HIV-transmission by the sharing of razors, earrings and toothbrushes. This is often mentioned as dangerous, as well as kissing a positive person with open sores in their mouth. At least 50% of interview and survey participants mentioned the sharing of razors when asked about which ways they knew of transmitting HIV, often even before mentioning unprotected sex. After probing, every single person said they were aware of this risk. People also tend to warn each other about the risk of exposure while cleaning or caring for a positive person with sores. While, in theory, these are all ways that HIV could be transmitted, they are not nearly as risky as having unprotected sex (Aidsmap, 2014). Only a few cases of transmission through shared razors have been documented in scientific history, making it closer to a myth than an actual risk. However, the HIV education and information that is provided in Usisya does not acknowledge the unlikeliness of such transmissions, making people think that the risk of being infected with HIV is everywhere around them. To illustrate, a typical HIV counselling session at the antenatal clinic will go as follows:

-Health Care Worker: What are the ways of transmitting HIV?

-Woman 1: *Having unprotected sex, sharing of razors, sharing of toothbrush.*

-Woman 2: *If you are kissing a person with sores in their mouth, you can get it.*

-HCW: *If you're sleeping with a person without condom, without protection, you can get it. The second way is through blood contact. Examples: using the same razors or toothbrush, blood transfusions, contact between two cuts with an infected person.*

-HCW: *How can we prevent HIV? The first way is with using condoms, having an HIV test before you start having sex with your partner, and be faithful to one another. And not using the same razors.*

-*Woman 1:* *And not using the same earrings, if both women have a cut you can get it.*

-Observation at antenatal clinic Usisya, 13-03-2014

The HCWs do not place any emphasis on the unlikeliness of such transmissions, and fail to tell their patients that nearly all HIV transmissions occur within the marriage or stable relationship. Instead, they will tell women:

> *So you have to make sure to prevent HIV through all these ways, cause you can't just get it through sex. So you can blame your husband for bringing the disease to you, but maybe you got it another way. So you have to look at yourself too.*
>
> - HCW, antenatal counselling 15-05-2014

Furthermore, some people fail to differentiate between sharing razors (meaning having blood contact) and sharing things like spoons and cutlery (meaning saliva contact). In some people's minds, every contact with a positive person becomes dangerous and therefore they choose to stay away from them altogether. This line of thinking encourages exclusion of affected people, decreases the strength of the social safety net they might rely on and impedes access to proper health care.

On the other hand, increasing the focus to non-sexual ways of transmitting HIV has had the (unintended) effect of diminishing stigma and discrimination. As Baptist church pastor Msisya commented:

> *Yeah like those days people were just thinking that you get HIV from sex. But these days, people are aware that you can get HIV from many ways. So these days people are coming out* – Focus Group Discussion, 11-04-2014

While it is advisable for hygiene purposes to refrain from sharing razors, earrings, towels, toothbrushes and the like, there is no reason to emphasize the risk of HIV transmission to the extent that is currently happening in Usisya. It might lead people to underestimate the influence they could exercise over their own health and wellbeing. One health care worker shares these concerns:

They don't fear the disease, they say HIV is like body lotion, each and everyone uses it and everyone can get it. So they don't fear it. And if they do get it, they will just get the ARVs, they say it's just the life – Male HCW, interview, 09-05-2014

While the sample size of the knowledge survey was not big enough to generalize the findings to the entire population, the numbers do indicate that knowledge about HIV is not widespread enough to generate the needed change in behaviour, and certain misconceptions are unquestionably still alive (see table 2 in the appendix).

5.1.2 Lack of information

Apart from a lack of information, there is also a lot of wrong information going around the community about health care, leading to misbeliefs and misconceptions about HIV and its medications. Rumors are extremely common in Usisya, influencing people's perception of risk. For example, some people claimed that they had read on the Internet that people in Tanzania were being cured of HIV with some newly invented drugs. As the rumor spread around town, with every interaction it changed slightly, so that soon enough, an HIV positive woman who had never missed a day of her ARV dosage, asked me:

People around town are saying that ARVs are now so strong that they can make the HIV disappear from your body, is it true? Do you think that I can stop taking them, maybe after 10 years? – Lia, 08-05-2014

I was able to convince her that until this day, no cure has been found for HIV. Unfortunately I have also encountered others who strongly held on to their misconceptions, since these stories were told for so long and so often, that they have become the 'truth'.

5.1.3 Gendered HIV knowledge and attitudes

There are significant disparities in the knowledge base of men and women. Generally, this can be attributed to the fact that men and women in Usisya move in different social spheres, according to cultural norms and the traditional job division. Commonly, women are seen as natural primary caregivers: responsible for the daily running of the

household as well as caring for ill children, family members and neighbours. In a context of HIV, this places an additional burden of care on their shoulders. A consequence of such social stratification is that men are very hesitant about going to the hospital:

> *Men, they are shy, they think the hospital is just a place for women. That is because women are always the ones who should be guardians. If I fall sick, a woman will take care of me or accompany me to the hospital, not a man* - Paul Mkewu – 22

Even a Malawian man who has spent much time with foreigners and therefore considers himself 'forward-thinking' and 'half-Mzungu', feels very uncomfortable when going to the hospital:

> *Other men were laughing, like one time I was carrying my firstborn and a woman was laughing, asking where my wife was. Malawian men don't want to do a woman's job, they take this as a woman's job. But it's a true story; some women bewitch their husbands so they do everything for them, but not for me* - Lenzo, 26

It appears to be mostly a matter of pride and personal status for men, that needs to be upheld by not engaging in 'trivial' women's matters. Men's reluctance to go to the clinic extends to the whole health care spectrum, from childcare to HIV testing. When asked if her husband would ever take their baby to the hospital, a young woman (17) sighs: "I don't think he can, he's very pompous and proud."

When asked why they don't come to the clinic, men usually laugh the question away and say: "I'm too busy, when can I find the time to go there? I am out fishing all night, and during the day I have to sleep." To some extent this is true - if you walk around town during the day, there is not a man in sight. But older members of society seem to think there is more to it:

> *Men are a big problem here in Usisya. Only when the problem is very big, is when they go to the hospital. They are ignorant. They are taking it like they are the masters and the women are the house workers. The health care workers should*

come into the village and talk to them about it – Focus Group Discussion, 25-04-2014

Aside from the added burden to women's already considerable household duties, this gender division has another consequence. Adult women in Usisya receive significantly more information on HIV and PMTCT than men, since the main source of reliable information are the health care workers at the clinic. Medical Assistant Paul concurs:

> *It's not that men don't believe in PMTCT. They have a lack of info, because all the information is given at the clinic, but 90% of all the patients are women. When men have health problems, they come to the hospital, but late. But women rush to the hospital when they are sick. So if you go and look at the female ward, they will always be full, the men's will be half empty but it will be more critical, more complicated.* – MA Paul, interview, 02-05-2014

Even policy makers such as the District Health Officer are aware of this issue:

> *We are always going to have males coming in later, more sicker. 'Cause they never get educated. A woman that is pregnant will get some semblance of education, on how to take care of her family, and how to take care of other things. So that is across the board, males present late. There are lessons that are taught daily. So the education that they get, for that woman, if you come today they are on the topic of family planning, STIs, HIV, all those things, so by the time you have had 2, 3 kids, you'll have a different area of different things. If you come to the hospital and deliver there, people will also train you on how to look after a child, how to breastfeed, danger signs, things like that, so the education is primarily about health. So they get educated in that, for you to find a man sitting, and listening to such… It's not happening. That's why I'm saying; we need to motivate the men, because with the women, we know. It's the man, the husband that can say: 'don't go to the hospital'* - DHO, Albert Mkandawire, 22-04-2014

Mkandawire's statement subscribes the need to involve men in women's health, since not only their lack of knowledge, but also the lack of interest and support are significant factors that are preventing women from accessing PMTCT services.

5.1.4 HIV STIGMA

The unique social environment in this research site directly affects the concealability of the individual's infected status, and therefore the perceived stigma (Colbert, Kim, Sereika, & Erlen, 2010, p.303). There is no anonymity since everybody is somehow related to, or acquainted with, every other person in town. Even if the health care workers were to keep the test results confidential, simply being seen at the clinic on the ARV provision day is enough to get the community talking about someone's status. People say that their family will know about their status, even before they make their way back home from the clinic. This is one of the main reasons that women feel 'shy' about coming to the clinic. Being related to one of the health care workers only exacerbates this feeling, rather than making someone feel comfortable by having a familiar face around in these testing times. However, even though there is much talk about HIV in everyday life, sympathy for affected people seems to accompany the expressions of stigma or discrimination:

> *At first there was a big discrimination to those people were positive, they were thinking bad about that person but now, because it is everywhere, in every home there is a positive person, so people are accepting this thing and are taking care of each other.* (Everyone in the group agrees, this is true)

> *Even still now, because of misunderstanding and lack of knowledge, people still have that feeling that HIV is the only killer disease. They still have that feeling in the community, they see a person with HIV, and think that person is already dead. But it's not like that, people who suffer from malaria can also die, people suffering from cancer. But that feeling is really still there, that people only die of HIV and not other diseases.*

Till now people are still thinking that if a person is positive, that person is a prostitute or a womanizer, but that's not the truth. There are other ways a person can contract HIV/AIDS, they just think that if you are positive, you have many partners, so when you hear that someone is positive, the first question you ask is; oh, was that person also going out with many girls?

Its really a painful thing to find out a relative is positive, because we depend on each other, within everything at home, but if you hear a person is sick, everything stops. If you hear a tacher is affected with HIV, we feel sorry for them, because we depend on these people for the development of the family and community (Teen Action club focus group, 26-04-2014).

I have never heard someone directly express stigmatizing comments toward PLHIV. Observations suggest that people take care of one another, but stigmatizing ideas remain deeply embedded in cultural interactions. Usually people will say that 'others' have a negative attitude, but it remains unclear to what extent these are actually expressed in interactions between community members.

5.1.5 PMTCT

With regards to PMTCT, a different set of knowledge, beliefs and misconceptions needs to be examined in order to understand why uptake of prevention programs is so low. In 'formal' interviews or surveys, people would rarely talk about their actual ideas and beliefs, and hide behind the information the hospital told them by replicating it to me. Through informal talks, overhearing conversations, rumors, gossip and 'secret' translations by my research assistant, I was able to piece together how some people's actions completely contradict what they know and say. This is illustrative of how knowledge of PMTCT and access to the medication are not enough to ensure adherence, and generate a change to less risky behaviour. Trivetowe's story below is no exception; other women have told me similar stories, about themselves or about friends.

BOX 1: TRIVETOWE

Trivetowe is only 27 years but has already given birth to 4 children. One of them has died of HIV at the age of three, because she was staying in Tanzania at the time where ARVs are extremely pricey. When she got pregnant again, Trivetowe decided to come back to her homeland Malawi, where she would be able to receive all the necessary care for free.

She is an intelligent woman - able to correctly reproduce any piece of information the health care workers have told her in the course of the PMTCT process. I leave her house after an interview about her experiences with PMTCT with a good feeling, thinking that the system appears to be working, even for single, poor and uneducated mothers like her. My research assistant Denas looks at me shyly, scrapes her throat and says: "Trivetowe told me to keep this a secret for you, but I thought you should know. She is not really taking her ARVs, she just collects them from the hospital every month to make them think she's complying, and keeps them under her bed. Even though she should have started during pregnancy, she said: 'my body is still healthy, my immune system is still strong, so maybe those people [the health care workers] just made a mistake, I don't need to take my ARVs now. I am also not giving them to my baby; her body is much too small to handle such strong drugs. I think if I give them to her, her whole body will just become ARVs, that's not good.'" Trive has claimed over and over that she trusted the health care workers completely, that she had never missed a day of drugs, and that she would do everything to stop her baby from getting the disease. I was present during the baby's first blood test at 2 months, which came back positive. If a woman is adhering completely to the PMTCT progam during pregnancy and breastfeeding, there is only a very minimal chance that the virus is transmitted to the baby. Trivetowe knew this, and yet deliberately did not give her baby the medication she had direct access to, because the idea that a healthy looking person or baby does not need ARVs prevailed over all the knowledge she had learned from the health care workers.

5.2 ACCESS TO INFORMATION

Participants were asked how they had gathered their HIV knowledge. Among men, the most common source of information on HIV was radio or television, followed distantly

by church and talking to their peers. Women overwhelmingly report their main source of information as health care workers, supplemented by church and other women. 21% of respondents replied that they learned about it in primary school. Secondary school classes actually pay more attention to health issues and to HIV specifically, but an estimated 90% of people drop out before reaching secondary school (Cassie, 2014). Therefore, the general population is largely dependent on NGOs, health care workers and government services such as radio programs to bring the information to them. Within the area of Usisya, it proves to be extremely difficult to independently find reliable information, should an individual feel the need to do so. There are little means of accessing the Internet, very few households have a television and visits to the clinic are impeded by a variety of geographical and social challenges. The only source of information is Temwa's community library, which has a relatively extensive collection of HIV folders, flyers, reports and books. However, in the five years since it has been built, the library has only managed to build up a clientele of about 20 people, which are all adult males, who come just to read the newspapers.

5.3 Awareness raising strategies

The findings indicate that a person's HIV knowledge does not necessarily translate into perceived risk and behavioural changes. In addition, there appear to be highly gendered differences in the influence of perceived risk on behaviour. In the case of the Usisya area, it is recommended that more be done to raise awareness of the prevalence and consequences of risky sexual behaviour. Health care workers should go into the village to talk to people, do door-by-door visits if necessary. Chiefs could also be more involved, since they are the ones with the power to gather people and disseminate important information. Temwa is already engaging in such activities with mobile video shows on HIV and maternal health, but their efforts should be greatly expanded in order to reach all the population groups that do not actively seek to gain knowledge by coming to the community meetings or the clinic's information sessions.

6. Women's reproductive and health-care seeking behaviour

-A demand-side perspective

6.1 Women and health

Several major health organizations indicate that women in Malawi generally take longer to report to health facilities than men, because of their supposed lack of decision-making-power and access to resources (World Health Organization, 2012). In this sense Usisya appears to be deviate from the norm set by 'typical low-resource countries'; women here clearly consume more health care resources than their male counterparts. However, it is unclear whether women also enjoy better access to adequate care in this locality, but they are definitely vulnerable to more and different health threats than men. In addition to the usual threats such as infectious diseases, malnutrition, poor sanitation and inadequate water supplies, women are also frequently confronted with multiple socio-cultural factors negatively affecting their physical and mental wellbeing, as well as their access to the necessary health care services.

This part of the analysis looks at aspects of how the population perceives and uses reproductive health services and it explicitly seeks to reveal why utilization rates of PMTCT programs are so low (Abdella, 2015). Firstly, we will establish which factors in women's lives contribute to their vulnerabilities, and then show how they adjust their health care seeking behaviour to them. Specifically, the second part of this chapter addresses the context in which pregnant women discover their status and their ensuing birthing experiences (Van Hollen, 2013, p.155).

6.1.1 Vulnerabilities

"*Women are vulnerable to HIV, men are at risk*" (CIDA, 2003)

The above quote refers to the reality that HIV affects both men and women; however there is a big difference in the ways the disease reaches and affects either gender. As has been established in the theoretical section of this thesis, HIV is a discriminatory disease, which disproportionately affects women for a number of biological and social reasons.

Often it is a combination of the two that leads to the higher infection rate of women over men. The main factors contributing to women's vulnerabilities in the case study area will briefly be discussed here, in order to understand the context in which health decisions need to be made.

During unprotected vaginal sex, the female is about twice as likely to be infected with the virus than the male, because of certain cells in the cervix, vaginal inflammation, STDs or ulceration which can all facilitate the entry of the virus (MoH, 2003, p.20). Additionally, in interviews women indicate that the practice of 'dry sex' is still used by young, single women to create the impression that they are still virgins. They do this by applying dehydrating herbals to their vagina, which often leads to vaginal tears during sex and consequently to a much greater risk of HIV infection (Denas, interview, 06-05-2014).

As was discussed in the theoretical framework, gender inequalities, poverty, low education, and lack of employment opportunities can sometimes force women to engage in transactional sexual activities in order to survive economically. In this case, the cultural practice of requiring a woman to be a virgin when she enters marriage, causing her to fake it by using dangerous herbals, only exacerbates a woman's biological vulnerability to HIV.

As for other social and cultural factors: the lack of proactive opportunities for women to discuss sexual practices and risks with their husbands is a big risk factor. Condoms are not popular in Usisya; only one woman reported consistently using condoms for the purpose of HIV prevention. Otherwise, condoms are mostly just used while a woman is pregnant (because of the common cultural belief that the baby will otherwise be born covered in sperm), or within the first year or two after a new baby, to allow for child spacing. In other situations, asking for condoms is seen as indicative of a lack of trust, or promiscuity:

> *I can't use a condom because this man is the father of my kid and my husband, so there is no way I can use a condom or those other ways. We are very faithful and it's hard for me to tell him that we should use a condom; he will think that I am going out with other men. But I am on birth control to prevent myself from taking pregnant because my kid is still young* - Female survey respondent

Furthermore, sexual behaviours of men may put women at risk, especially since HIV disclosure rates within the marriage are low and extramarital relations are common. One woman, Mtinkheni, is painfully aware of her husband's infidelity but does not feel like she is in a position to leave him or prevent him from doing it:

> *If he found me with another man, he would even kill me! But as a wife I have to respect him, not denying him what he wants. […] We are using condoms because our kid is still young, but I am very afraid that he will bring HIV into the house after that…* - Interview, 09-04-2014

Finally, the majority of female respondents identified their husband as the head of the household, which implies that he has control over the household's resources. This leaves a woman at her husband's mercy; whether he feels like spending the money on food for his family, or on drinking beer with his friends. Obviously there are also responsible, caring husbands who provide for their families, however many women do experience their dependence on their husbands as described above:

> *It depends on the husband, but there are many, many of those men who have money but don't give their wives, prefer to do other things like drinking beer, smoking cigarettes, they don't want to spend their money on the antenatal care and such baby supplies. Mine is also like that but I don't have any source of income, I have to wait for him to give it to me!* – Focus group discussion, 30-04-2014

The moment that the husband no longer allows her to use the resources, the woman is put in a very vulnerable position; especially when she needs money to obtain health care. Esther's story illustrates what might happen if a woman does not find herself in the financial position to obtain adequate assistance during her pregnancy.

Box 2: Esther

"Filtered sunlight streams through the cracks in the bamboo window shading and falls onto Esther's face, but she has averted her eyes in embarrassment. In her arms a small baby is sleeping, while two of her other children fall over each other excitedly. A *mzungu* in the house is definitely a new experience for all members of the family. Almost inaudibly, Esther tells me she is about to give birth to her fifth child but that the doctor has told her she is not allowed to give birth in the Usisya clinic, since she has been classified as a risk pregnancy. Not only has she been found positive, but a fifth delivery comes with more risks than the clinic could possibly handle. "But my husband is sick and he doesn't work, so we don't have any money to get transport to Mzuzu…" She looks up at me hopefully while I try to find the words to explain why I couldn't give her the money. A few days later I see her at the clinic, holding a tiny baby. I sigh with relief that both have survived the pregnancy, but now she has to face the doctor who is technically not allowed to give her a check-up, since she defied his orders and delivered her baby at home with the help of a Traditional Birth Attendant. After handing him a fraction of the sum the village chief has ordered her to pay as penance, she follows the nurse into the HIV counselling office. Esther is about to start the next phase of a long and arduous process, which will hopefully result in her baby testing negatively for HIV. She hasn't looked me in the eye again."

6.1.2 Power and gender stereotypes

"Akazi ndi maluwa sachedwa kulakatika"
Women are flowers that blossom nicely in the morning but
wither /die quickly in the afternoon
-Malawian Proverb

This well known Malawian proverb can be interpreted in a number of ways; firstly, men should not trust women and take their actions seriously. In that sense, it essentially portrays women as inferior and weak. Secondly, it can be taken as that women are there to shine and be admired, and then discarded when they lose their beauty/value. Alternatively, it could refer to people who lack confidence and do not take challenges and quickly withdraw, as flowers do by withering when the sun hits them. It finds the

defect in the victim, rather than looking at structural, contributing factors. Flowers are also important in procreation and fertility, as women are, but their work is undervalued (Kamwendo, 2014). In any case, the saying highlights disparities in gender and reinforces the stereotype of women as a subordinated group, whose main role in life is to serve her husband and reproduce. My research assistant observed that:

> *With men in Usisya, once they give you a child, you are basically a by-product to them, a waste product. You have lost your value to them, so they look for the newer, younger version. They may have a first wife who was beautiful but after she had a kid, she loses her looks and her value, so he finds a second one, and then does it again after she is used up. Women keep sleeping with the men because they see it as an opportunity, because they keep getting things or money from them.* –Denas, 05-04-2014

We find an interesting contradiction here: a woman has value so long as she can have a man's child and is desirable to him, and society requires it of her in order to fulfil her reproductive role. But to this specific man, she has essentially become worthless after they have reproduced. This cultural practice perpetuates the HIV-cycle and increases women's vulnerability to sex because of their unstable economic position and low bargaining power, but at the same time women choose to engage in transactional sex, which gives them opportunities. The question now becomes; to what extent are they being coerced? The fact that a man can easily walk away after the child has been conceived plays a major role in women's low accessibility to PMTCT services. The male often feels no sense of responsibility towards the child, and is not required to lend his resources or emotional involvement to the goal of preventing HIV infection in his offspring.

6.1.3 Motherhood as assertion of femininity

Despite the prevalence of the previously discussed stereotypes and language in Malawi, society can also be found to display a certain amount of respect and awe for their women's life giving abilities. In Usisya, evidence of this can be found in the rites of passage that women go through once they have had their menstrual period; the new status that is bestowed upon a woman once she has become a mother; and the

multitude of customs and traditions that surround pregnancy and maternity (MHRC, 2005, p.36). Procreation is as essential for the individual, as it is for her family and the community around her (Saidi, 2010, p.164). Unfortunately, becoming pregnant and giving birth does not come without risk in rural Malawi. As Box 2 illustrated, Esther became pregnant while she was HIV positive and already had four children, and she was lacking the resources to have the safest birth possible. She may have been one of the lucky ones in the end, but what causes a woman to take this risk in the first place?

6.1.3.1 To birth or not to birth

The consensus in medical communities in countries like the United States is that a positive woman should never choose to become pregnant in the first place, and if she does so accidentally, she should terminate the pregnancy (Besser, 2010). Malawian doctors have adopted a more nuanced view, taking into account the social pressures on a woman to provide her husband with a baby, regardless of her health status:

> *We tell them in counselling not to get pregnant but they do, they need a baby. She will need to; it's a family matter! So we counsel them to go for Nevirapine, so the baby will be born very well* - Msoya, HIV counsellor and living positively, interview, 05-05-2014

The doctors in Usisya do feel a sense of powerlessness, since they see no room to provide women with appropriate health care advice previous to becoming pregnant:

> *Women who have previously been found positive and want to have another baby, don't come to the clinic for counselling on how to have a safe pregnancy. They just come when they are already pregnant. It's up to the women to choose to become pregnant again, a matter of informed consent. We just inform them about the risks, but no discouragement is given* – Mnthale, informal conversation, 28-04-2014

Richey's (2011) study of HIV and reproductive health in South Africa found that women are often blamed and criticized for defying medical advice from the health care workers who are treating her for HIV, and having an "adherence problem" with respect to the counsellors advice to use condoms, even within marriage (Richey, 2011, p.280). She

argues for the need to add a gender dimension to such accusations; health care workers need to understand the context in which women elect whether to continue childbearing or not, after becoming aware of their status.

One such contextual layer pertains to the idea that women who are unable or even unwilling to have children, are often regarded as 'failed' or as 'not fulfilling their purpose in life' (MHRC, 2005, p.53). In this context, when a women becomes pregnant despite the fact that she is aware of their positive status (maybe from previous pregnancies), this can signal two things: either she feels pressured into having to fulfil her reproductive role in life, despite the health risks; or she can acknowledge the risks and decide that they outweigh the consequences of not adhering to the gender-assigned role of a woman of her age and marital status, and choose to get pregnant anyway. The outcome might be the same, but the subtle difference between the two is the *choice* that is made. This is a matter of representation and lived experience, which I will illustrate with two stories:

> *-Me: So why did you decide to have another baby?*
> *-F: Since I am married, the man needs a baby. I can't refuse that I don't want a baby, then the man can abandon me to look for another wife. Even if he loves me, he can have someone else.*
> *-Me: Why do men need a baby?*
> *-F: It's like sometimes, maybe they are chatting with their friends, they are laughing at them, 'you are just married, just staying there, why is your wife not pregnant up to now?' So that can cause a husband to try, to make his friends stop laughing at him, at me. If the woman is refusing, the man can look for another woman, not to marry but just to have his baby. Maybe this woman will not know the aim of the man, why he is going to her, a man can cheat her, or he says that he will leave his wife for her, say 'I love you so much'* - Farai, 23, pregnant and positive, informal conversation, 16-05-2014).

Farai felt like she did not have a choice and needed to put her own health on the line by getting pregnant through unprotected sex, thus risk multiplying the HIV virus in her body and possibly giving birth to a positive child, in order to prevent her husband from leaving her and not to feel stigmatized by the community as a childless woman.

One of her friends from a support group for PLHIV tells the story a little differently:

> *My husband left me last year, after he found out I was positive. But I managed to go to his house again and now I am pregnant. We are not staying together. But if I don't have my husband, at least I will have my baby. Who else is going to take care of me when I am old and sick? I will have this baby because it will be my remembrance, my legacy, people will say I got this baby when I was positive*
>
> *– Woman (27), interview, 02-05-2014*

The presence or absence of children before the HIV-positive diagnosis appeared to be a primary determining factor; all women who already had children said that these would be enough, and that they would try to prevent future pregnancies. In this case, the fear of transmitting HIV to child outweighs the cultural imperative to be a mother (of many). Childless women found this a much harder choice to make: "For a complete family you need a baby. Otherwise there is no reason for me to live" (Ida, observation at ANC, 12-04-2014). Evidently, this cultural imperative is so strong that women will sometimes knowingly put themselves at risk of infection by their (possibly) positive husbands, or would risk their own health as positive women, to become a mother.

Evidence of this last argument can be found, for example, in the fact that many parents in Usisya were pushing their daughters towards going out with a man named Moyo, who already had 24 children with many different women, but was able to more or less support them all because he was gainfully employed. The parents' main motive was evidently not to get their daughters into a monogamous marriage with this man, but for her to become a mother and to receive resources from the man that she would then be attached to by virtue of having his child.

In conclusion; vulnerable, poor women often cannot say no to sex because they need the resources and support to survive. They do not have the bargaining power to demand birth control, so there is a high risk of becoming HIV positive, especially because this man is likely also sleeping with many other women without protection. Simultaneously, the chances of getting pregnant are also high since she has to hide the fact that she is sleeping with (several) men outside of marriage, so she cannot go to the clinic for any type of birth control. This puts her at triple risk; being stigmatized for

being a prostitute and losing social support, becoming HIV infected, and becoming pregnant. Does this 100% make her a victim? Is she coming out better on the other end, even though her health might be compromised? The alternative is being poor and childless, it seems that being positive and a mother is better.

6.1.4 GENDERED STIGMA

Male focus group participants painted the following picture of a 'good woman': she should be patient, understanding, submissive, make the husband happy, caring, not gossip, cook for the husband, and give him children (FGD, 13-04-2014). As for what a 'good man' is; he should not drink and provide for his family. During this focus group, some women were listening outside and came in at this point, adding to the discussion that a good man should also be patient, love his wife, be faithful, not beat her, involve her in making decisions, and help her with farming. Besides taking health risks by getting pregnant, the stigma that are placed on childlessness can also lead positive women to hide their status from their husband and society, in order to uphold their status as a 'good woman':

> *I have been positive all of my life, I don't know where it came from. But I'm not telling my future husband, will he still marry me if he knows?* - Digna (24), interview, 29-03-2014

The fact that many women willingly and knowingly got married to HIV positive men, indicates that different standards are being upheld for men and women. Men's promiscuity was more easily accepted, as well as the 'positive' outcome of such behaviour. Women preferred to enter into the marriage and gain a respectable status while also benefitting from the duties a husband is supposed to perform. The additional risk of becoming infected and the burden of caring for a sick husband has to be taken for granted. Men find themselves in a much stronger bargaining position for rejecting HIV positive women, since they do not need to be married to earn the respect of their peers.

Women's choice to enter into such a marriage represents the exercise of their agency, in a way. The costs to their health are weighed against the benefits, and within the structural constraints society places on them, they decide what would be in their best (direct) interest.

6.2 Factors influencing the uptake of PMTCT

For argument's sake, let us assume that a pregnant, HIV positive woman's mother instinct tells her to do everything in her power to protect her unborn child, such as receiving the care that will protect the baby from having to start its life with an incurable, but preventable disease. In a perfect world, this mother would also have *access* to the care needed to do so. Unfortunately we do not live in such a perfect world, and women will encounter all kinds of barriers on their path towards giving birth to a healthy child. In this chapter, we will follow women on this path and gain an understanding of how barriers can either be overcome, or can stop a woman in her tracks.

Filippi *et al.* (2006, p.391) define 'health barriers' essentially as reasons which explain delays in receiving care in due time. The first delays are usually affected by socio-economic, legal and cultural barriers, as will be shown in the findings here. Health care seeking behaviour is also influenced by the particular characteristics of the disease and how the woman and her surroundings perceive these. The perceived quality and accessibility of care, especially regarding health workers' attitudes and behaviour, play important roles in deciding whether or not to utilize them. The second dimension of delays can be attributed to the physical and financial accessibility of the health services; geographical location, distance and road conditions, availability of transport and all related costs (Filippi *et al.* 2006, p.391). This is further discussed in chapter seven, but cannot completely be severed from the first dimension and is therefore also included here.

6.2.1 Antenatal check-ups

Women generally come for their first antenatal check-up in the fourth month of their pregnancy, and should have four subsequent visits until finally delivering the baby at the clinic. Within this nine-month process, and possibly longer if they are found HIV positive, there are multiple stages and reasons for women to drop out and not return to the clinic to receive the necessary care.

Eide (2006) identifies the antenatal stage as a first barrier, but the Usisya area does not have any major problems with women denying antenatal care or failing to show up for the test. In this respect, the system works well; no matter at which moment

the woman comes to the clinic for antenatal care, which the majority of them eventually do, the first thing she receives is an HIV test. Even if it needs to be done during delivery, the HIV test is always a priority.

Government policy prescribes that women should receive a compulsory HIV test during the first antenatal visit, after participating in a group counselling session with a trained health care worker. During this session, women are informed about the basics of HIV transmission, prevention and testing, in order for them to understand the importance of the antenatal test and how to protect themselves and their (unborn) children. They are also mentally prepared for the possibility of testing positive, within the next few minutes. Compulsory HIV testing is generally accepted by the community and by women coming to the clinic for antenatal care:

> *To us, getting tested when we are pregnant is a nice, good thing. Because we are just blind, not knowing our body status. But after getting tested we now know that we are like this and we are able to take care of ourselves. Maybe before you were negative but if you're found positive, you know it's from this person, so you are able to know all these things* - Positive woman, PMTCT focus group discussion, 13-04-2014

However, positive HIV tests among pregnant women have been known to cause conflict and fear within families, mostly between women and their partners. Observations at the initial ANC visit make it clear that women feel more than a little nervous about getting tested, since they know what it will mean for their own lives, their unborn child and possibly their marriage if they are found positive. As the moment of testing nears, the tension in the room grows visibly every time. When a woman is called into the testing room, the dread is written on her face as she tries to estimate the possibility of actually coming out of that room with a 'death sentence', as they sometimes call it. 'Has my husband really been faithful to me? Did I ever accidentally share earrings with a positive girlfriend? Or have I done anything to deserve punishment from God or from the spirits? What will I do when I'm positive?' These are questions a woman has to grapple with by herself, since 99% of the husbands will not set foot in that testing room with their wives. While women will initially express their feelings about this as 'this is the way it

is, we are used to it', some do admit that it is causing problems for them with regards to disclosure:

> *When you go there for antenatal check-up, you get a blood test. That's a very scary thing for a woman. It's good for the husband to hear his wife is affected, because if I go alone and hear I'm positive, I'll lie to my husband and hide my status. So if we're together, that couldn't happen. Some people are shy so they hide, they don't want others to know* - Alice, interview, 14-05-2014

Medical Assistant Paul agrees that male involvement during this testing phase would have a positive effect on adherence to PMTCT measures:

> *If men would be involved, it's like the ARVs default rate would go down. Because when the woman is tested, and the man is at home, the hospital policy now is that when a woman is tested positive, on the very same day, when she is going home, she needs to take the ARVs. She's started yet, right there. And if my wife is started on ARVs, whilst I don't know anything, she comes home, she breaks the news to me, that she is HIV positive and she's started the ARVs… to me, the acceptance won't be all that easy. Hm. Uhm, I'll think it's her that infected me, so I'll push the blame on her. And because I'm pushing the blame on her, she will be afraid to tell me. […] So in fear of that, she might even throw the drugs away, or she goes home without the drugs. As a result, the default rate goes up. So if these males were involved, like 'I'll come here with my wife, go in there and get tested, and hear the results together', no one will blame… There is no way to know who is to blame who. And that way the default rate will go down* – MA Paul, interview, 02-05-2014

As a rule, men don't accompany their wives to the clinic. Men and women give several reasons for the males' absence; men are too busy fishing to go to the clinic, health care is regarded as 'women's business', and men who go to the clinic will be laughed at by their friends, who will say that he has been bewitched by his wife and is no longer a real man. Generally, men don't really see the point of coming to the clinic and listening to antenatal counselling, after all, "we are not the ones who are pregnant". Literature shows that supportive male participation in the antenatal period, such as showing

willingness to get tested, and communication about reproductive matters, including birth control, can dramatically increase women's commitment in PMTCT programs (Auvinen *et al.* 2010, p.288). Women say that they would love it if men could become more involved, like one woman said: "If I found a man who would come to the antenatal clinic, I would have ten babies for that man."

Many hours of observations of antenatal counselling have made it clear to me that information delivery should be improved dramatically for it to have the desired impact, since many obstacles to PMTCT can be traced back to this first antenatal session. For example, no information is written down at any point during the counselling, nor are the women given any folders or pamphlets to take home. If these were made available, it could increase a woman's credibility when she talks about the information at home, and women would also be more likely to retain the information if they have a chance to see/hear it more than once.

6.2.2 MTCT DURING PREGNANCY

After receiving a positive test result, the woman will be brought into the counselling room to talk about her ARV adherence program. This is a lot of information to process, and she will be given a supply for one month, to start immediately. Many women said they felt overwhelmed and stressed at this point, and were not able to see the situation clearly. This is why about 40% of women refuse the drugs at this specific time: some feel like they need permission from their husband first; others are afraid to take the drugs home and being found out by family members. Another reason is that they might have trouble believing the diagnosis, since they do not feel sick or feel like they have been engaging in risky behaviour. Then there is the group that will quietly accept the drugs, only to later discard them somewhere in a field.

However, it appears as though most of the women eventually make up their minds to take the drugs during the pregnancy. Since PMTCT services and ARV provision are integrated into the antenatal check-up visits, they do not have to fear being seen by other women. Whether they also continue taking the drugs after the baby has been born is an entirely different matter.

Additional follow-up visits by health care workers would be very helpful in identifying the women who are not adhering to the prescribed regimen, and to convince them to reconsider. Unfortunately the clinic lacks the human resources to go into the

field, and they do not have access to transport to reach women in the more remote areas.

6.2.3 MTCT DURING DELIVERY

About two years ago, the government has implemented a new policy that states all women should deliver at the hospital, in order to promote safe deliveries attended by trained medical personnel. However, many Usisyan women continue to deliver at home or on the way to the hospital, because of distance to the clinic, lack of funds for transport, lack of support, or sickness. Some positive women would even deliver in a different town in order to avoid stigma from their fellow villagers. This is making it difficult for the health care workers to control whether positive women administer Nevirapine to their baby after birth, and if there has been no blood contact during delivery. Nevirapine is provided for the mothers by the clinic to be taken at the place of delivery, but many women fail to give it to the babies or do not come back after delivery since they haven't been counselled properly or do not see the need for a postnatal check-up.

In most cases it is the women's social network that allows her or prevents her from delivering at the clinic. A 15-year old girl recounts the events of her delivery:

> *I woke my aunt when I was feeling [labour] pain at night but she couldn't give me any attention so I had to go to a midwife but it was too late. I delivered by myself, outside, the midwife just found other people to carry me to the clinic. So it was not my choice not to deliver at the hospital, but because my parents didn't pay any attention to me. But my baby is okay, so I was lucky* – Female survey respondent

It is customary to enourage women to be 'strong and brave' during time of labour, not to scream and wait a long time before going to the clinic, otherwise they will spend a long time waiting there. This cultural custom accounts for the high number of women that deliver on the way to the clinic, usually attended by a Traditional Birth Attendant (TBA). Chapter eight further examines how these TBAs could play a role in PMTCT.

Currently, about 62% of all babies are born at the clinic, attended by a skilled birth attendant. For positive women this number is likely lower, since women fear that they will be forced to take the drugs which they declined earlier, or that other people

will see them there and find out they are HIV positive. In most cases, it is a matter of being physically unable to reach the clinic without the support of a husband or family member:

> *It hinders the objective of the PMTCT program: mothers are advised to have a clinic delivery, but they need to involve the partner for transport etc., so they would rather stay at home – MA Paul, interview, 25-02-2014*

6.2.4 MTCT DURING BREASTFEEDING

The hospital advises HIV positive women to breastfeed exclusively (EBF) for six months and if they feel it is possible, they can continue doing so until the child is two years old. A new type of prophylaxis reduces the risk of infection during this stage significantly, and has been introduced to the Option B+ regimen (WHO, 2010). Alternatively, a woman can choose to substitute the breastmilk for powdered milk, but this comes with additional risk of infection.

During my time in Usisya I have never observed, spoken to, nor heard of a woman who used bottled feeding for her baby. They simply do not have the resources to afford milk powder, and even if they did, they would have to go to Mzuzu to obtain it. Breastfeeding actually has a lot of advantages for the mother; it is free, hygienic, always available, socially acceptable, no preparations needed and healthy for the baby. Bottled feeding on the other hand, is likely to arouse suspicions of being positive, since there is no other reason a woman in rural Malawi would choose not to breastfeed.

Problems in the PMTCT process can arise when women are not aware of the possibility of continued breastfeeding. I have found that most women are still holding on to the old rules, which told them to stop EBF at six months. At this time they will start giving the baby solid foods, which will often give them diarrhoea and sometimes lead to malnutrition, which in turn increases the chance that the baby will still become HIV infected. Even the women who said they were told about the 'new rule' that they should continue breastfeeding, said they would prefer to stop at six months since that is when the baby develops teeth, and might become infected if it bites the nipple and ingests the mother's blood.

6.2.5 CHILD TESTING

Once the baby has been delivered, most women consider that to be the end of the road:

> *After delivery, they will completely stop. You don't see them anymore, you don't see them for collection of drugs, they will not come for the child or the baby to be tested for DNA-PCR* – Mnthale, interview, 11-03-2014.

Women's failure to come back for infant testing can likely be attributed to a lack of information which has evolved into widespread misconceptions:

> *They just tend to pull out after, after the nevirapine syrup. To them, they think this was the most risk part, and for the rest they think the baby is not going to contract HIV from them* – MA Paul, interview, 02-05-2014

Some positive mothers will only bring their baby in once, to see if he is positive or not. The health care workers emphasize several times that this test at six weeks does not show the definitive result, but this information does not seem to stick in women's minds:

> *I really made a mistake not to come back, when the baby was tested the first time they told me he's negative so I just thought everything is ok. He told me to come next time, but I just made a mistake. I did continue to take ARVs, here at the clinic. They were asking, 'where is the baby', telling me to bring him, but I couldn't. There is no other reason. To me, it feels ok to come here, no problem. I will be coming this afternoon with the baby, for testing. I will just accept it, if the result is positive. Even if other people find out, you just have to accept. I talk to my mom about it, she also told me to come here. There is no reason why I didn't listen* - Lynas, interview, 28-04-2014

In the case of Lynas, stigma also played a major role. She never upheld her promise to come back that afternoon, nor any day for that matter. When I saw her at her house a few weeks later, she quickly pulled me inside since there was a group of women outside, obviously talking and gossiping about her. Lynas' house was completely empty; she did

not even possess a straw mat to sleep on. She confessed that she was afraid to go to the clinic with her baby because people would then know for sure that she was positive.

> *Word spreads so fast… At least now they are sometimes giving me food and some clothes, after my husband died I have nothing. But if I am positive, I don't know if they will still help me.* – Lynas, 29-05-2013

Again, Lynas had to make a difficult decision, in which she prioritized maintaining her place in the social network and the benefits she could derive from that, rather than her child's health and her own.

6.2.6 Male involvement

Any analysis of women's gendered behaviour is not complete without including the 'other side of the coin'; men's perspectives and their role in shaping women's lives, and their sexual reproductive health in particular.

Most men do not feel very involved in women's pregnancies, and they especially do not feel like they are in a position to accompany their wives to antenatal checkups:

> *It's like… generally, our culture, discourages men from this pregnancy issue. Yeah. It's like, when my wife gets pregnant, I will leave everything concerning the pregnancy to my aunt, or to her aunt, and then she is the one responsible for everything. Like any problems, she decides when my wife starts antenatal, she decided everything on the pregnancy. Not me, I am to hear from my aunt and not from my wife. So that way our culture discourages men from participating. So when my wife comes here to antenatal, she comes here with my aunt, or her aunt* – MA Paul, interview, 02-05-2014

The Usisya clinic is running a campaign where women who bring their husbands will be served before all other women during antenatal or postnatal check-up. The clinic is notorious for long waiting hours, so this is the best non-monetary incentive that seems feasible within this low-resource setting. Unfortunately, in the three years since it was initiated, this procedure has not had the intended effect. The underlying rationale is that a husband will be bothered by the fact that his wife has to wait for hours (thus being

unable to perform her other duties as a wife), feel some kind of sympathy or responsibility towards her and escort her to the clinic and thus shorten her wait. This does not appear to be the case. Unable to convince their husbands to accompany them, some women have to get creative:

> *The women just go and hire the guy that is seated there, and bring them, say 'this is my husband'. And then the nurses say 'you are lucky', the woman tells the history of everything. But now we've realised, that oh, and at that time, for some are getting 500 kwachas (€0.90), 1000 kwachas (€1,78), but that means that when one woman gets 1000kw, she should give that man 200kw. And he wears another t-shirt, he wears a cap, comes with another woman* – District Health Officer, Albert Mkandawire, interview, 22-04-2014.

If men do ever admit to being involved in their wives' pregnancies, their support usually doesn't extend beyond buying the necessary preparations such as a basin and baby blankets. Some men do describe their role as one of offering support, "sympathy" and care for their pregnant wives, and making sure she goes to the clinic. Hardly any woman has confirmed that men actually fulfil this role, aside from being told by their husbands that she 'should go to the clinic because it is good'.

On the opposite side of the men that at least economically support their wives, are the men who meet their women with nothing but physical and emotional abuse, often followed by abandonment. Even for women who are in good health, it is extremely common to be left by their husband with several children and no form of child support. It is a cultural trend that is hard to ignore and seems to be related with the way casual relationships are formed and abandoned again. Even if men do not leave their wife altogether, not a single woman has been able to truthfully report that her husband is being faithful to her. All women I asked about this issue, complain that their husbands would rather spend their money on beer, cigarettes and other women than to help her and her children survive. Adultery cases regularly appear before a village jury, where a scorned woman gets to plead her case to her peers and a judgement on either the man, or the woman he is sleeping with, can be made.

The fact that it is relatively accepted for men to be sleeping with several women outside of the marriage, does not diminish the idea that women are the ones who

should be watched because they supposedly would not be able to control themselves. A man wanting to marry a woman first pays her parents a substantial sum of money so that they will keep her 'safe' until marriage, and make sure she does not go out with other men. There is no such arrangement to stop men from sleeping with other women, either before or during marriage.

Men like to refer to women's promiscuity, half jokingly, saying that women cheat more often than men, since men don't even have time to cheat because they are always busy fishing. I haven't been able to collect any definitive proof on this subject, but observations and informal conversations show that women are usually responsible for all the household chores, taking care of the children, farming and often doing additional business for some petty cash. Most men on the other hand, are indeed busy fishing or mending the nets on the beach, but have the freedom to spend their time as they see fit and usually do not feel much responsibility in the domestic sphere.

6.2.7 Birth control, HIV and PMTCT

One of the main findings from the field research is that PMTCT efforts are actually quite narrowly defined. PMTCT services are more than just access to medication. Ideally, it entails informing women and their partners of their status, emotional counseling and offering them the tools to live a happy, healthy life. There is a bigger issue at stake, extending far beyond the primary goal of ensuring a baby is born without HIV; empowering the woman so that she will have access to all of the information and resources, which she can use to make a decision about whether or not to become an HIV positive mother in the first place. It is not enough for the doctor to explain from a medical standpoint what the disease means and how drugs can help. HIV/AIDS is such a socialized disease that treatment needs to be embedded within existing sociocultural structures rather than a biomedical approach, but also be lifted out of problems that specifically derive from this context.

This also includes access to birth control, and community sensitization on the use of it. Currently, stigmatizing characteristics are attributed to women who are either HIV positive, or use birth control; they are seen as promiscuous and will even be called 'prostitutes'. During a focus group discussion, men and one woman expressed this very clearly:

-Woman 1: *There is a belief here, if you are getting condoms from the hospital, you are a prostitute.*

-Man 2: *That's what people feel.*

-Denas: *Even the contraceptive.*

-Man 3: *It's true to prove that they are prostitutes. It's easy for her to go and get some contraceptives. My sister goes, and she doesn't even have a husband.*

-Me: *What is your definition of a prostitute?*

-Man 2: *A woman who is selling her body for money.*

-Me: *It cannot be that she is just having sex with one man, but she doesn't want to get pregnant?*

-Man 4: *No, she's a prostitute.*

-Man 3: *The women who knows who is her… that's why we say if they get contraceptive while she is not married she is a prostitute.*

-Me: *Does it have to be for money?*

-Man 2: *Sometimes for money and sometimes for pleasure.*

-Woman 1: *The devil pushes us to be prostitutes.*

During an antenatal session, Denas pointed to a young girl of around 20 years. She said that she did not know who the 'owner' of this baby was because the girl is a 'sex-worker', and that 'many, many men go into her house, she probably does it for money'. People tend to use the term sex-worker or prostitute loosely, I suspect that it could refer what many in the Western world would define as 'slutty behaviour'. As discussed in the context, lack of resources could drive a woman to accept food or money from men in exchange for sexual favours.

With regards to birth control, some misconceptions are created intentionally to serve the interests of certain groups, such as married men. At the very least, many female participants believed that men would spread rumors about the side effects of birth control (such as infertility, fistulas, and decreased sexual appetite), so that their wives would continue to have their children and fulfil their reproductive role in life. Health care workers also warn women not to believe everything they hear from their peers:

All these stories are false stories. All these stories are from husbands who don't even know, they just want you to make children like a cat. You can put the pill in water and it disappears, if you put it in your body, do you think you can have fibroids? No. If you don't want to use birth control, then continue baring babies like a cat – Mnthale, antenatal counselling, 18-03-2014

Lack of decisionmaking power and autonomy are major factors inhibiting women's access to birth control, as well as adequate means to protect themselves from HIV such as condoms. However, even if they did possess the agency to do so, they might not want to do so since condoms are often culturally perceived as antithetical to love, trust, closeness and fidelity (Higgins et al., 2010: 436; Chimbiri, 2007), or because women feel it inhibits their own pleasure. This is yet another example of how structural inequalities are not always sufficient to explain women's vulnerabilities to HIV, but some of them might be perpetuated by their own behaviour and choices. Denas illustrated this point nicely:

Women in Usisya say: 'If my husband is not being faithful to me, I will also not be faithful to him. It's better if we both sleep around and bring HIV into the family, than him just bringing it to me'. -14-05-2014

6.3 Conclusion

This chapter has discussed the myriad of factors that can influence a woman's reproductive health and health care seeking behaviour. Cultural incentives often push them a certain way, but do not control women's actions alltogether. It depends on every individual's emotional strength, access to resources, social network, perceived stigma and active knowledge, to what extent she will be able to break through barriers. While some fail in this respect and fall through the cracks of the system, others have a very clear idea of what needs to be done:

I don't care what other people think, or if they don't want to be my friend anymore. If I am pregnant and they find me positive with this test, then I will take every medication the doctor gives me to protect that sweet, innocent life inside me. It's a matter of life and death, of course I will do it! Or maybe I should say, it is a matter of life and birth, haha! – Woman (23), interview, 18-05-2014

7. Health service planning, management and provision

-A supply-side perspective

"As a child, is a man wrapped in his mother's womb; as an adult, in tradition; comes death, and he is wrapped in earth"
-Malawian Proverb

INTRODUCTION

Remote, rural areas in developing countries often suffer from a lack of access to good health care. A variety of problems can be responsible for this gap in national service provision, but the outcome is usually the same; the poor (remain invisible, and therefore) suffer the most. This chapter firstly discusses which combination of factors is hampering the development of Usisya's health care provision channels. Secondly, these factors will be taken into account in an analysis of why PMTCT services are failing to reach all eligible candidates. Finally, we will look at the role traditional medicine still plays, how it interacts with the official system. Chapter eight is devoted to a consideration of how traditional healing practices could potentially be transformed into a useful addition to the (partially failing) official system.

7.1.1 CHANNELS OF HEALTH CARE PROVISION

In Usisya, only one clinic provides health care for about 18,000 people within the region. This clinic is located quite far outside of the town's centre, making it about a 30 to 60-minute walk for most people within the Usisya area. People coming from other lakeshore communities that the clinic is supposed to service, have to face an up to six-hour walk through the mountains and other treacherous terrain, or come up with the money to pay for a canoe or boat to take them there.

The facility is equipped with an in- and outpatient department (24 beds,) an antenatal group counselling area, maternity (2 beds) and postnatal ward (7 beds), malaria testing laboratory, and finally there are two HIV testing and counselling rooms. 23 members of staff run the clinic, but there is no actual attending physician, just a

Medical Assistant. Antenatal counselling and check-ups are done by a nurse, midwife, or any other health care worker who is available, but not necessarily with a proper training background. The motto 'all hands on deck' seems to apply to the service delivery process.

7.1.2 Attitudes towards the clinic and health care workers

On Wednesdays the clinic time is allocated to women with children under five years old, who are encouraged to come for a routine check-up every month. Nearly every childbearing aged woman in the village falls into this category; therefore the clinic is extremely busy on Wednesdays. Dozens of women with hundreds of crying, playing and sleeping children occupy the benches, floors, and stone-covered field in and around the clinic, displaying a kind of resigned patience. Most are breastfeeding their young children and chatting with their fellow women, others try to find a position near the health care worker that might get her higher on the waiting list. The truth is that the health worker's attention is distributed quite randomly, according to whomever catches his or her eye. Family members, friends and the wives of highly regarded males can be sure of quick treatment, whereas the women who were there first might very well be seen last.

People's opinions about the (quality of care at the) Usisya clinic differ greatly, but can roughly be attributed to the number of visits they have made, the type of service they come for and previous education and/or experience with other clinics they have had. Women tend to be much more positive about the clinic than men, which comes forth out of a sense of dependency and lack of material for comparison. The complaints that were mentioned most frequently are about the insufficient numbers of health care workers, a lack of resources and over crowdedness, which results in long waiting times. Women report that they will usually arrive at the clinic at 7am, but the health care workers don't get there until 8 or 9, and they might have to wait another 2 or 3 hours from then on. Health care workers will also randomly leave the clinic for personal reasons or 'holidays', leaving their duties to other, less qualified personnel or closing the clinic altogether without warning or message to the community. Several people have related stories like this one:

> *There are negative attitudes from the doctors, like this woman who had a very bad foot injury on Sunday, she went because there was no way she could wait till Monday but they told her, 'what are you thinking coming here on Sunday?!' They helped her but she was very disappointed about their attitude* – Male survey respondent.

One of the reasons for the lack of doctors is Usisya's remoteness; highly educated people who are not originally from the area simply cannot be persuaded to move there. The government is currently working on new policies to tie people to a certain area after training, with a contract (District Health Officer, A. Mkandawire, interview, 22-04-2014).

Interviews with people waiting to be treated indicate that nobody really blames the health care workers for the long waiting times and minimal amount of attention that is given to each patient. The prevalent attitude among patients is that they are grateful there is a doctor there in the first place, but also that they have no choice but to sit there and wait, so they just accept the situation.

7.1.3 Attitudes from HCWs

Literature suggests that HCWs attitudes towards HIV positive people are a major determinant for people's perceived access to health services. During my visits to the clinic I did not encounter any negative attitudes specific to PLHIV, nor have people told me about them.

Health care workers at the Usisya clinic did often express feeling that the lack of resources prevented them from doing their job correctly. The lack of human resources did not allow them time to leave the clinic to go into the community and engage in educational activities. The follow-up of HIV positive women also had to be sacrificed due to a lack of time and transport. Julie, the HIV counsellor who usually deals with PMTCT participants, frustratedly explains:

> *I should be going out into the field every week, to search for those who are not coming to the clinic. But every day I am also needed here, there is always a queue waiting for me, right here in OPD. I am running from a delivering woman here, to the people waiting for drugs there. We are*

> *understaffed, yeah, it's a nationwide problem.* – Julie, interview, 02-05-2014

Perhaps her failure to go out into the field has skewed Julie's perception of how many women are actually defaulting the PMTCT program:

> *We do not have any problems with defaulters here, no. They are all just coming here because they want a healthy baby, I can say that.* – Julie, interview, 02-05-2014

This should be considered a major issue; if health care workers are not aware of the high number of dropouts, they are also unlikely to make efforts to reach such women or perhaps approach them differently during the counselling sessions.

7.1.4 Environmental factors

The geographical location of the clinic greatly contributes to its inaccessibility, for people of any age or gender. During the rainy season the only path leading to the clinic is so muddy that it is nearly impossible to pass. The clinic's only ambulance regularly gets stuck on this road, sometimes for days. People will often use wheelbarrows to carry invalid or pregnant people to the clinic, but it takes extreme amounts of effort to push this wheelbarrow up the stone-riddled path. Furthermore, people from other lakeshore communities such as Ruarwe walk six hours through the mountains to receive health care – a great challenge if one is feverish from Malaria, or experiencing labour pains. The simple reality is that 'the further you live away from a health care center, the more difficulties (Nyambe, Temwa employee, 10-2-2014).

7.1.5 HIV testing

In 2013, 443 new antenatal clients have been registered at the Usisya clinic. They have not been keeping reliable data on the number of people tested for HIV, but in theory this means that 443 women should have been tested for HIV. Health workers at the clinic claim that virtually no one ever comes for voluntary testing and counseling, even though they do promote it. Additionally, men hardly ever accompany their wives to the antenatal clinic to get tested as a couple, even though this is strongly recommended and

encouraged by health personnel. Only 8 previously untested women were registered at maternity, meaning at the time of delivery, and tested at that moment. Therefore it is probably safe to say that the actual number of tested people in 2013 will be very close to the number of 451 (also see Appendix 4).

Temwa has recently launched the second phase of their Mobile Testing Clinic program. It was discontinued because of a lack of HIV testing kits, which is a very common issue in both public hospitals as well as for private health care providers. The MTC is an extension of facility-based health services, making it possible to reach (disabled, sick, old or pregnant) people who would otherwise not be able or willing to make the journey to the hospital. Aside from the practical convenience, it should also help to overcome certain social barriers towards testing; males do not have to feel embarrassed about coming to the clinic, and since everybody in the community is being approached, there is no reason for suspicion about who might be positive. During a sensitization meeting Temwa held for highly regarded community members such as chiefs and elders, a male primary school teacher said:

> *It helped many people to come, and be open and public about their status. But the site was not convenient; we had to rent a house. Next time we should use a church. And we who are here should also get tested, as an example!* - Male, community meeting, 26-04-2014.

Like Angotti *et al.* (2009, p.2286) have found in their study on why not more people are getting tested in rural Malawi; an HIV test should not only be free, but also convenient, confidential and credible, in order to increase utilization rates.

During the previous round of HIV testing in the community in 2012, many teens and children were found positive. Since then Temwa has set up the Teen HIV/AIDS Action Club, to provide them with social support and a platform to talk about living positively and healthily. The group sessions have exposed a need for more basic education on living with HIV, for both adults and children. One 72-year old grandmother emotionally explained how she was afraid to take care of her grandson because she might get HIV from the sores on his body, and that she gets an HIV test every months because she will never be at peace with her fear of the disease (Teen Action Club Guardians, Focus Group Discussion – 26-04-2014).

7.1.6 ARV PROVISION AND INTEGRATION

A major issue contributing to women's hesitance to continue with the PMTCT program after the baby has been born, comes from the lack of integration of ARV provision into general health services. While a woman is still pregnant, she receives her ARVs during her antenatal check-up visits. These take place in the same room for every woman; therefore she can blend in with her fellow pregnant women and feel comfortable about going. After delivering the baby however, the woman will have to come in on ARV provision days. The clinic lacks the human resources to have an ARV-provider present every day, so the government policy of integrating ARV provision with the OPD has not been implemented in Usisya yet.

Friday is 'ARV day' at the clinic, which means that all patients coming to collect their medications are exposed to the community. Most research participants who were not open about their HIV status, admitted to feeling very shy and uncomfortable when they sit in the waiting room, or to failing to go alltogether. Many will even go to a bigger city, in order to stay anonymous and avoid the risk of being seen by friends and family. For those women who choose to stop in order to protect their social status as a healthy, ordinary woman, the health risks increase rapidly; she will likely develop immunity for ARVs by taking them irregularly, and her health will deteriorate and make her more vulnerable to other diseases. Furthermore, if she continues to breastfeed and/or also withholds her baby's medicine, the child's chances of becoming HIV positive or even dying will increase every day.

7.1.7 COSTS OF RECEIVING HEALTH CARE

All health services at the clinic are free, including medications, so this should not form a barrier. However, since the clinic is far away and there is no shop or other way of getting food on location, most people carry their own food with them. Therefore most money that is spent on receiving health care actually goes towards buying food, which is a substantial spending post for families who normally rely on their own land and hardly spend any cash on food.

7.2 PMTCT defaulters

According to the clinic data, on average 71% of pregnant women with known HIV+ status come to ANC. 86% of HIV positive women have received ARVs to reduce the risk of mother to child transmission of HIV during ANC. This means that 14% has not received the proper drugs to protect the baby from getting infected during the pregnancy. In 2013, 10 babies have been born from HIV positive mothers. Out of these infants, 60% has completed 6 weeks of Nevirapine for PMTCT. Only 53% of infants born to HIV positive women have received HIV-PCR testing within 6-8 weeks of birth, which is the recommended period for the first test. This number only rises to 67% for infants tested within the first 3 months of birth. These data show that, however small the sample may be, some women don't come back for medication or testing of the baby after they have learned of their HIV positive status. Over the last three years (2011-2013), 27 out of 57 infants received Nevirapine to prevent transmission of HIV, which amounts to a default rate of about 50%. Reasons for this can mostly be found on the demand-side, as was outlined in chapter six.

7.3 Traditional Health Care

The presence of a clinic or district hospital does not automatically guarantee good quality health care. Often, like in Usisya, they are lacking in basic equipment, knowledge and trained personnel. It is therefore not surprising that these services remain underutilized, even if cultural barriers regarding allopathic medicine are lifted and physical access is increased (Foster, 1984, p.848). This is because clients are capable of making pragmatic decisions about when, where and from whom to receive health care. At times it can be that traditional curers fill the gap where allopathic medicine is lacking. This is partially due to the prevalent belief in witchcraft ailments; biomedical health practitioners could never provide treatment for this. Three local Traditional Healers were interviewed to gain insight into people's health seeking behaviour.

> *Sometimes, if someone goes to the hospital and the doctor says 'I can't find anything wrong, even though you're sick', I can heal that person with my herbals. If a person is bewitched and came here for help, I tell them to get a letter from the*

chief about what kind of help they want from me, saying 'this person is bewitched, can you see who did it?' I am able to identify them, they come here and bring those things rituals the witches used, and I can heal them - Vyanusi, interview, 29-04-2014.

While I was interviewing this woman, we were surrounded by about 40 of her patients; men, women and children with different ailments. My first impression was that the majority suffered from a mental disorder, but there were also pregnant women there, looking for protection for their unborn baby from the witches and wizards, which is a common practice. Aside from providing herbal medications and witchcraft rituals, Vyanusi claims that she can also recognise when someone is infected with HIV:

-V: Sometimes, when that person is here, people will be singing me music, spirits will enter and tell me many things, so I can know she is affected, and not bewitched. Sometimes I can't see anything, I tell them to get tested at the hospital and bring their results, then I'll help them.
-Me: In your opinion, what causes a person to get AIDS? Could witchcraft be a reason?
-V: No that can not happen, but the witches can make you look like HIV and at the hospital they tell you you're negative, but you look positive, they use worms and mix it with something and throw it at you - Vyanusi, interview, 29-04-2014

Surprisingly enough, people in Usisya do not believe that Traditional Healers have any substance or ritual that could cure them of the virus. The reason one might suspect otherwise, is that THs are accredited with healing other 'incurable' diseases such as mental afflictions, cancer, conditions caused by witchcraft spells, epilepsy and many others. In its current form, I do suspect that Traditional Healers are contributing to the spread of HIV by allowing people to believe that they can prevent getting infected by performing (anti-) witchcraft rituals and applying herbals after risky sexual contact. THs in Usisya in no way claim to be able to cure or treat HIV, but they do spread misconceptions about whether or not a healthy-looking person can be positive and vice versa, and that HIV can be a punishment from God or witches. However, the THs seem

to be well informed about how HIV needs to be treated and say that they will always refer a suspected positive person to the hospital.

7.4 Conclusion

The Usisya clinic suffers from many problems that are common in developing countries; understaffing, underfinancing, lack of equipment and no real prospects for improvement. However, the health care workers are dedicated to the wellbeing of their patients and will often do everything within their capacity to help them. Attitudes towards them are predominantly positive, indicating that perceived confidentiality and privacy at the clinic do not form an obstacle towards PMTCT participation. Any problem that does contribute to low uptake of PMTCT, such as failure to follow up on defaulters because of lack of personnel, could relatively easily be solved on an institutional and policy level. I would also like to refer to the final discussion, where the option of a community-based mentor program is outlined, in order to fill the gap left by the health care workers.

8. Traditional versus allopathic health care

"Insult the midwife, and who will help you next time?"
-Malawian proverb

8.1 Historical context and debate

Historically, Malawi's women have been giving birth at home with assistance from Traditional Midwives, rather than with trained, skilled birth attendants at hospitals. Since 85% of the population lives in rural areas and has limited or no access to formal health care, Traditional Birth Attendants (TBAs) used to be, and in many cases still are, a 'necessary evil' to fill in the gaps the government has left in health care provision. One side of the debate that international academics, health care providers and policymakers currently engage in, regards TBAs as harmful. On the other hand, there are those who argue that they do could do more good than harm, and should be tolerated or even trained (Perez *et al.*, 2008; Hamela *et al.,* 2014).

In 2010, president Mutharika lifted a two-year ban that had been placed on all traditional midwifery practices, since health indicators were worsening, and the maternal mortality rate only rose after prohibiting TBAs from doing their work (Mnthale, interview, 11-03-2014). Recently, the government has once again created a policy aimed at improving maternal health and reducing the number of deaths during childbirth, by means of excluding TBAs from the formal definition of skilled birth attendants. The goal is to have 90% of the births attended by a skilled birth attendant, at a health facility (Hamela *et al.,* 2014). Local village bylaws were designed to discourage TBAs and their clients, by penalty of having to pay a goat or the equivalent in Kwacha to the local chief. However, this rule is hardly ever enforced since chiefs claim that it mostly meant to deter rather than punish. They feel that asking people to pay such a steep fine would ruin most Usisyan families, so chiefs usually have mercy on those with a 'good excuse' for not delivering at the hospital.

Since the 1970s, the WHO has been researching and promoting traditional birth attendant training as one strategy to reduce maternal and neonatal mortality. Study results vary per locality, making it difficult to come up with universal guidelines regarding TBAs (WHO, 2013). This chapter will argue that Traditional Birth Attendants

are important players in the struggle against Mother-to-Child transmission of HIV, based on interviews and observations in Usisya.

8.2 Current usage of TBA services

Home deliveries used to be standard procedure for women in Usisya, because of traditional reasons, as well as for a lack of medical support at the hospital. In recent years, the number of hospital deliveries has increased and women are starting to see the benefits of being attended by a trained midwife with access to supplies. Female research participants generally agreed that a birth attended by a TBA, either at home or *en route*, is more dangerous and therefore less desirable. Several women held the opinion that:

> *The midwives, they don't have skills. All they know is when you deliver, but there is much more, maybe you can't breathe well or need blood, so the practice of delivering at home is not ok* – Female, focus group discussion, 18-03-2014

Unfortunately there tends to be a discrepancy between what women know, and what they do in practice. While many may truly intend to deliver at the hospital, they often end up giving birth in a field or roadside on their way to the clinic. The clinic nurse and midwife Mr Mnthale frustratedly explains the main problem with deliveries:

> *We do encourage women to come here at least at 32 weeks, that is eight months, to wait here for delivery, but normally women who are living just close to the hospital, they don't come. They would rather stay at home, unless the labour pains start, that's when they start coming here. Also in the village, when someone is in pain, they say no, don't go now, it's too early to go to the hospital. Just wait. 'I will go, we'll go.' And when they start to come to the hospital, it's too late and that woman ends up delivering, on the way here.* – Mnthale, interview, 11-03-2014

Another section of the female population lacks the awareness or appreciation for the allopathic health system. Those who think they are having a normal, or 'low-risk' pregnancy, usually have their baby at home. A TBA is consulted to see if it is a woman's

time yet and apply herbals in order to 'widen the way' and to intervene, in case the delivery is being impeded by witches or wizards. This is coincidentally a major reason for avoiding the hospital during delivery; some women say that they are afraid the 'witches and wizards will tie up the pregnancy, so they can't deliver'. Traditional Birth Attendants would be able to give them some herbal medication to prevent such an event from happening, whereas the clinic would not. Also, midwives at the clinic might get jealous and 'steal' or kill their baby, so they feel safer in their own home.

8.2.1 Deliveries for positive women

During antenatal counselling at the hospital, the women are imprinted with the importance of a hospital delivery, especially when they are positive:

> *Those women who have had an operation for their first or second baby should not be here, but in Mzuzu or Nkhata Bay, because we don't have the right equipment. Also if it's your first baby, you should not be here, but in Mzuzu. Those who already have children, come here as early as possible, 4 weeks before your due date. Signs and symptoms you are about to deliver: stomach pains, back pain, vomiting, diarrhoea, bleeding. If you see these signs, you are about to deliver. During birth, there can be a blood contact from mother to child, and HIV infection can take place. If you don't come here to deliver and get tested and take medication, you will find yourself at home with a baby who is positive* - HCW, ANC, 13-03-2014.

Traditional birth attendants themselves are very much aware of the importance of hospital deliveries, and would much prefer it if women did not come to them at the time of labour, especially when they are positive:

> *Sometimes the mother is bleeding, and if the baby has a cut, and they touch, the baby can get it. Also the baby can drink the blood from the mother, because at home delivery the process is very slow, but at the clinic the baby won't even have a chance to drink the blood* - Vickness, TBA, 06-04-2014

To some extent, they also agree with the government policy that women should deliver at the hospital, despite the fact that they are being prevented from doing what has been their profession for decades, in some cases.

> *The government, by coming up with this thing, sees something wrong with women delivering at home, so there is no way we can oppose the rule. Because you can see if the woman doesn't have the way for the baby to pass, if it's very small, or if there's a cut, we wouldn't be able to tie a cut. So it's the hospital who has that kind of equipment to do so - Liyema, 12-05-2014*

8.3 Using TBAs to fight MTCT

Temwa employee Calvin observes that maternal health services are lacking in his hometown:

> *What they do, they force people to go to the health centre if you are pregnant. In time, they discourage people to give birth at home. But it's not active to tell people the importance of delivering at the hospital. They need to tell me of that importance before I get pregnant, the importance of visiting the health centre and giving birth there. But if they teach when I'm already pregnant, that means they have already missed a point, someone will not come because she has not heard the information, she needs to hear it before.* – Calvin, interview, 16-05-2014.

The Usisya clinic does not have the luxury of being a facility that is specialized in anything in particular. Health care workers have been trained selectively, for an ideal situation where midwives only occupy themselves with maternal health and nurses don't have to leave for several days to pick up drugs in the city. Rather, it is all hands on deck and every person has to take on cases they might not be equipped to handle.

Traditionally, community midwives *do* only occupy themselves with maternal health, and have a lot of time on their hands to practice their duties. However, usually they have received no formal training and are even actively excluded from the health care delivery system. The well-meaning policy designed by the government has so far only resulted in more unattended deliveries on the way to the hospital. Women are culturally encouraged to 'be strong' and wait as long as possible before moving to the hospital,

while they are already in labour. They are scared to call the help of a midwife and they in turn are also reluctant to assist because of the steep fine that awaits those engaged in such practices. Christopher Blair, a Malawian clinician working with a local NGO that is aiming to facilitate health corridors in the Northern region, argues:

> *This is not a good rule. Because there are instances whereby the government has failed the community in terms of the supply, in terms of the human resource. (…) Some hospital nurses are no better than Traditional Birth Attendants. The only thing I think that the government could have done, is to empower TBAs, train them, and give them the capacity and all the resources. I think that's the best way."*

He, and other civil society actors, such as church leaders and NGOs, advocate the use of established community-based actors like TBAs to address health issues that suffer from social stigma and harmful cultural practices. In their view, TBAs are suitably placed intermediaries to contribute to sensitization and communication initiatives. They advocate the idea that TBAs could be engaged in a more controlled, formal way and play a vital role in reducing maternal and child death during labour, as well as prevent mother-to-child transmission and promote safe sex.

This movement goes to show that harmful cultural practices do not always need to be cut out of a society in order to be made less damaging. In this case the problem actually provides an opportunity for improvement, without requiring as much time and resources to accomplish. Ideally there would be more doctors, Medical Assistants and specialists that could apply their time and knowledge and get the problem under control. However, it takes 8 or 9 years to train doctors and typically they do not feel themselves particularly drawn to a career at a small rural clinic. Even formal training for midwives takes 4 or 5 years, and Malawi does not have that kind of time since the crisis is *now,* so a solution needs to be imminent. While there is no 'quick fix' for HIV or major maternal health issues, targeted training for traditional birth attendants is cost-effective, efficient, and they do not get 'stolen' to work in other facilities because they are embedded in their own community, and will remain in midwifery.

It has been established that women in Usisya have limited access to formal health care for a multitude of reasons, some stemming from a lack of resources, others from cultural barriers. Traditional birth attendants are the neighbours, aunties and

sisters of exactly those women that need their assistance. This is where their main strength lies; embeddedness in the community.

Such mobilization of midwives goes hand in hand with community sensitization and education. Unless the community is brave and confident enough to use the health facilities available to them, the battle against HIV will continue to be a losing one.

Most women in Usisya recognise the problems their small town is facing. It doesn't go unnoticed to anyone that HIV is still rampant but that nobody really talks about it. Everyone has a neighbour, cousin, brother or child that somehow suffers from the disease. This awareness means that Usisyans are already halfway to a solution. There is no need for sensitization on the 'what', only on the 'how'.

8.3.1 Achieving TBA engagement

In order for TBAs to be an integral part of health care provision, the District would have to keep records of the following; who is practicing and where; the number of (emergency) deliveries; their distance to the nearest maternal health care facility; if they have previously been trained; whether they provide antenatal, postnatal and referral services; whether they take measures to prevent HIV transmission, and if they accompany women to the hospital at the time of birth or for antenatal visits.

8.3.2 Points of caution

The cultural belief in witchcraft remains strong in rural communities of Malawi, forming a main component of women's motivation to get an antenatal check-up from a TBA. A women is believed to be more vulnerable to witches and wizards during pregnancy, the so-called 'danger zone', because she is 'between death and life', so she could easily die in the labour room because of bewitchment. For this reason, women often receive herbal medications from TBAs as a preventative measure. Sometimes these drugs can be so strong that they cause foetal distress, followed by a miscarriage or infant death, or rapid delivery that causes a woman to lose much blood and die. In this sense, TBAs are perpetuating harmful cultural practices. This should however provide all the more reason to provide them with professional training. Awareness of the harmful properties of herbal drugs and other practices would likely result in a dramatic reduction of their usage.

8.4 Community-based reproductive health and HIV prevention services

Although a hospital birth with a skilled birth attendant for all women is obviously the ideal, it may be many years before this is a feasible option in rural areas of Malawi. Even if all cultural barriers were lifted, there are insufficient numbers of such health workers, as poor rural areas do not form attractive employment opportunities. With the proper training and supervision, TBAs can be extremely valuable in identifying risk pregnancies and referring and accompanying women to the hospital. Specifically for women and babies who are in need of HIV services, TBAs would be able to identify, monitor and assist infected women. This would not only increase social control and support for people living with HIV, it will contribute to the much needed support in this area.

From the woman's perspective, seeking out a TBA for advice or birth assistance can be seen as a decision that is usually not driven by necessity, force or ignorance. Rather it is the expression of a woman's agency over her own body that allows her to choose where to find health care and which approach suits her best. Though it may go against hospital and government advice, traditional and cultural values upheld by the (female) population continue to determine standards of sexual and reproductive health. The consensus within the medical community is that using traditional birth attendants is not in a woman's best interest health-wise, but this knowledge does not lead women to stop seeking their guidance.

If TBAs could be trained to serve as counsellors to pregnant women in the community, they would be able to disseminate the message about having proper antenatal care and a safe delivery and encourage women to seek official health care. Women's decision to go in for health care depends on a myriad of factors, but one stands out; the encouragement they are receiving from people they respect. This can be from clinic staff, husbands, mothers, or community midwives. Since the health care workers are not really going out into the community to educate women and do follow-ups, many don't make the effort to ensure a hospital delivery. With such training, TBAs would retain their respectable position and serve as guardians for pregnant women, rather than physically helping them with their deliveries.

9. Discussion of findings

The empirical chapters of this thesis have covered a wealth of information and a broad scope of topics. It was the intention to provide the reader with a more nuanced analysis of culture, one that is observant of the multitude of ways agents navigate the multiple, contested meanings attributed to human behaviour. Overall, it has been demonstrated how specific semiotic axes intersect in particular cultural contexts (Tavory & Swidler, 2009).

It is widely acknowledged that gender inequalities and stigma have a perpetuating influence on the HIV epidemic, which in turn aggravates cycles of poverty and underdevelopment. Understanding the relationship between gender, culture, poverty, agency and the continuing HIV pandemic is crucial if this cycle is to be broken. This thesis has set out to examine the individual, psychological dimension of shaping people's experiences with HIV/AIDS. The way in which this sets the context for social identities and agency is central to how health care seeking behaviour is stimulated or resisted (Campbell & Gibbs in Boesten & Poku, 2013: 29). The basic assumption presented throughout the theoretical framework is that health decisions in low-resource settings are usually limited by structures such as gender inequalities, unsupportive social relations and cultural norms. However, reality is fraught with ambiguities.

Part of this psychological dimension that was researched, consists of people's exercise of agency in the way they deal with adverse circumstances and develop coping mechanisms when difficult choices need to be made. While literature often depicts women in patriarchal structures as victims of circumstance, the evidence of this thesis suggests that people, or women, can perpetuate some cultural habits and customs that might cause some of their own that suffering. Examples of this can be found in the way work is divided, what women allow their husband to do and know, and when and why they choose to seek health care at the hospital. We have also seen that some of such 'limiting' or harmful cultural traditions can actually be turned around to help improve women's circumstances and access to better care; traditional midwifery has the potential to play a major role in improving general maternal health, as well as contribute to women's uptake of PMTCT services.

One of the main conclusions we can draw from this fieldwork, is that women, in some circumstances, are agents of their own 'oppression'. Too often, women themselves hold beliefs that can hold them back, like how to behave during a pregnancy. Men do not control this behaviour; it's women who control each other. Women make change, but not in circumstances of their own choosing. They have to negotiate. They have to subvert tradition that once silenced them in order to give voice to new aspirations. And they need allies from their communities. Maybe this is because feminism, unlike almost every other social movement, is not a struggle against a distinct oppressor - it's not the ruling class or the occupiers or the colonizers - it's against a deeply held set of beliefs and assumptions that women, far too often, hold themselves (Ramdas, 2009). Ultimately it's not about changing a culture, it's about changing how you behave within that culture.

Women do not usually make cultural rules, but they do perpetuate them with their behaviours and continue to shape their own opportunities and restrictions. Men are affected by those rules as well. There might be men who would like to come to the clinic with their wives, support her and get tested together, but feel bound by stigma and stereotypes. Will this man still be able to have friends, and do his work in a tightly knit community like Usisya, if he is regarded as 'weak' or 'whipped' for being involved in his wife's pregnancy?

IMPROVING WOMEN'S ACCESS TO PMTCT

This research on maternal and reproductive health provides a glimpse into the subjective experiences of living with HIV in a context where health care provision is constrained. Health workers and antenatal patients in and around the Usisya health center have offered various perspectives on how their lives are affected by having limited access to resources that could prevent their children from being born with a deadly, stigmatized disease.

Despite increasing coverage of HIV testing of women and subsequent PMTCT treatment programs, over 60% of women are getting lost to follow-up. The reasons given by women for their failure to comply were found to be associated with issues at the facility and community-level. While women were generally satisfied with the structural delivery of PMTCT services in terms of counselling and availability of medications, they often complained about the lack of confidentiality and privacy at the

clinic because of a lack of integration of PMTCT services, and also identified distance to the clinic and other responsibilities as major obstacles.

The case study research offers contrasting opportunities through which women might be helped to protect themselves and their children against HIV/AIDS. Firstly, the uptake of birth control and especially condom use should be stimulated and sensitized around the community by influential social actors, such as elders, health care workers and chiefs. Information dissemination over the radio could also be increased. The promotion of female condoms could reveal a new arena for women to take control over their reproductive lives; they can use them regardless of the man's approval (to some extent), as it pertains to their body and not the man's (Susser, 2000).

Men's lack of involvement in women's pregnancies and SRH is such a deeply engrained aspect of Malawi's gender relationships, that positive women hardly ever identify it as an obstacle to their health. 'It's her responsibility', is often heard in Usisya; this quote sums up men's attitude towards women's health decisions. It can be seen as disinterested and unsupportive, but also as an opportunity to take ownership of one's health interests. It is only when this decision interferes with a man's interest that problems arise. Interviews revealed that men are usually the decision-makers with regards to women's health, in terms of how resources are used, but they do not physically get involved in obtaining the services. This is simultaneously a limiting and enabling factor for women; health issues and the hospital are their domain, where they can obtain knowledge and care if they choose to do so. However, they are not free to bring this knowledge and their personal health issues into the marriage and discuss them with their husband, in order to negotiate safer sexual practices, protect their health and that of the unborn child together. Breaking through these stigma and gendered boundaries can only be done if men are physically brought into the women's domain. For example, a hospital policy such as in Rwanda, where women cannot obtain antenatal care unless she brings the father of the child with her, could accomplish that.

Thirdly, a completely undiscovered source of support for women living with HIV, are, surprisingly enough, other women living with HIV. A mentor system such ones that are already being used in other, similar localities (Besser, 2010), could encourage women to share their experiences with others and carry the burden together. The most important issues that women are dealing with seem to be lack of disclosure of their status and perceived stigma. Women who have previously gone through the PMTCT

program and are the living proof that it is possible to have a negative baby while living a productive and positive life, could inspire hope and determination in women who feel like they have to deal with their disease all by themselves. Assigned mentor mothers could accompany newly diagnosed women to the clinic for ARV collection, child testing and check-ups. Additionally, they could be asked to explain the drug use and side effects to the mothers, as well as educate the women about safer sexual practices and infant feeding. These are issues the nurses at the clinic simply don't have time for. That way, the care does not stop after the baby has been born, but women can utilize their strong social networks and social capital to ensure that they live happy, healthy lives (Besser, 2010).

Children will continue to be infected with HIV by their mothers, if both men and women do not drastically start changing their risky sexual behaviours. Overall, the implementation of Option B+ has achieved a lot in Malawi, in terms of providing access to health for women and increasing coverage of PMTCT services. However, the huge number of women dropping out because of sociocultural and economic reasons is overshadowing the efforts of this policy. Implementing progressive policies is not enough if the social environment has not been sensitized on the direct benefits that can come from utilizing them. Besides the continued need to expand and improve the supply of services, there is also an urgent need to respond to demand-side barriers in women's lives that can affect the uptake and adherence to PMTCT programs.

BROADENING THE PMTCT DISCUSSION

While the intended outcome of a successful PMTCT treatment is a healthy child, the benefits of the program do not end there. Women themselves and society at large also have interests at stake. For one, it will give a woman immediate, lifelong access to ARVs which give her a better chance at a long, healthy life. Secondly, if she is healthy and physically capable to provide and care for her children, it relieves the community of the care for the enormous orphaned population. It will also create a strengthened female workforce, which have a positive impact on a country's development, especially when women are more empowered and increasingly occupy the role of primary financial decision maker within households. PMTCT is a sound investment in a country's

sustainable development, and will ultimately lead to less spending on medicine and health care.

In order to expand the impact of PMTCT services, we should be viewing them as something that is broader than just testing women for HIV and providing them with the right drugs and information. Broadening the definition and reach of HIV preventative services would be a major step forward in empowering women to be more equipped to make such choices. Every time a woman makes a difficult choice, such as whether or not to become pregnant, to be open about her HIV status or whether she should talk to an HIV counsellor or not, she is empowering herself as well. She may not be able to change the social fabric or even change the behaviours of people around her, but she can find a way to create the best possible situation for herself within that context. Health care workers need to be more aware of the fact that women often do not seek out health care, because they have made a decision that does not allow for their health to be a priority.

Some of the vulnerabilities that women experience have been outlined in the empirical chapters. In order to fully understand why HIV positive children are still being born every day, further research is needed to investigate what drives a woman to become pregnant in the first place, either without being aware of her status while living in a high-risk environment, or while she already knows she is positive. Most PMTCT literature and policy interventions focus on the stage where a positive, pregnant woman is in need of medication and social support. However, a more effective, well-rounded PMTCT approach should take into account what precedes that; the pressures on women to fulfil their reproductive role, and how such social contextual factors could be incorporated in interventions to reduce the number of positive babies being born.

10. Conclusion

"*Mutu umodzi susenza denga*."
"One head cannot carry the roof."
-Malawian Proverb

We looked into lived experiences of PMTCT clients and other women living with HIV, to gain a deeper understanding on how they make health decisions, while dealing with the challenges they face (Chinkonde, 2012). What I hope to have demonstrated with this thesis, is that it is not enough to present one single 'story' of a person or a place. When writing about other people and cultures, or even one's own culture or country, it is all about representation. In the words of Nigerian writer Chimamanda Ngozi Adichie:

> *Stories have been used to dispossess and to malign, but stories can also be used to empower and to humanize. Stories can break the dignity of a people, but stories can also repair that broken dignity* (Adichie, 2009).

Indeed, some women I encountered did display the submissive demeanour sometimes ascribed to African females in the literature. More than a few women also expressed a sense of cultural limits in their approach to sexual and reproductive health negotiation. However, I found that the prevalent attitude was one of awareness; women were by no means passive or incapable of taking control over their lives. Rather, they were well aware of their vulnerabilities to HIV infection (Susser, 2000, p.1048). Most participants saw themselves as active contributors to the search for a way to protect themselves from illnesses, inequality and injustice. Their cases give a sense of the dynamics between men and women, and the open-mindedness, concern and knowledge of women who might at first appear to be mostly constrained by family and tradition/church, and suggest areas for mobilization for PMTCT (Susser, 2000, p.1046). Different storylines are intertwined here, representing the choices that sometimes need to be made between a healthy life, and retaining resources and social status that pertain to being a respectable, married woman or mother.

References

Abdella, D. (2015). Understanding "Health Corridors": A case study on social & spatial inclusiveness of reproductive health services in Magu District, Tanzania. Unpublished research, University of Utrecht.

Adichie, C.N. (2009). The danger of a single story. [TED talk]. Retrieved from http://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story/transcript.

Agu, V.U. (2010). The development of harmonized minimum standards for guidance on HIV testing and counselling and prevention of mother-to-child transmission of HIV in the SADC region: PMTCT country report. Retrieved from https://www.k4health.org/toolkits/zambia-hivprevention/development-harmonized-minimum-standards-guidance-hiv-testing-and.

Ahearn, L. M. 2001. Agency. *Journal of Linguistic Anthropology 9*(1), 9-12.

Aidsmap. (2014). Estimated risk per exposure. Retrieved from http://www.aidsmap.com/Estimated-risk-per-exposure/page/1324038/.

Akukwe, C. (2005). Feminization of AIDS: Ten unavoidable choices for African leaders. *Body 19*(1), 1-2.

Auvinen, J., Suominen, T., & Välimäki, M. (2010). Male participation and prevention of human immunodeficiency virus (HIV) mother-to-child transmission in Africa. *Psychology, Health & Medicine*, *15*(3), 288–313.

AVERT.org (2014). Preventing Mother-to-Child Transmission of HIV. Retrieved from http://www.avert.org/preventing-mother-child-transmission-hiv.htm.

Baral, S., Trapence, G., Motimedi, F., Umar, E., Iipinge, S., Dausab, F., & Beyrer, C. (2009). HIV prevalence, risks for HIV infection, and human rights among men who have sex with men (MSM) in Malawi, Namibia, and Botswana. *PloS One*, *4*(3), 1-8.

Besser, M. (2010). Mothers helping mothers fight HIV. [TED talk]. Retrieved from https://www.ted.com/talks/mitchell_besser_mothers_helping_mothers_fight_hiv.

Blaikie, P., Cannon, T., Davis, I. and Wisner, B. 1994. *At Risk: Natural Hazards, People's Vulnerability, and Disasters.* London: Routledge.

Bond, V. (2006), Stigma when there is no other option: Understanding how poverty fuels discrimination toward people living with HIV in Zambia. In: S. Gillespie, ed., *AIDS, poverty and hunger: Challenges and Responses*, pp. 181–97. Washington D.C.: International Food Policy Research Institute (IFPRI).

Brusamento, S., Ghanotakis, E., Tudor Car, L., Van Velthoven, M.H.M.M.T., Majeed, A., & Car, J. (2011). Male involvement for increasing the effectiveness of prevention of mother-to-child HIV transmission (PMTCT) programmes. *The Cochrane Database of Systemic Reviews*, (11), 1–22.

Bryceson, D., Fonseca, J., & Kadzandira, J. (2004). Social pathways from the HIV/AIDS deadlock of disease, denial, and desperation in rural Malawi. CARE Malawi. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.198.7456&rep=rep1&type=pdf.

Campbell, C., Gibbs, A. (2009). Stigma, gender and HIV: case studies of inter-sectionality. In: Boesten, J., Poku, N. (eds.). *Gender and AIDS: critical perspectives from the developing world.* Palgrave MacMillan, London, pp 29–47.

Cassie, B. (2014). Primary school drop-outs: breaking the vicious cycle. Unpublished research, Utrecht University.

Chepuka, L., Taegtmeyer, M., Richards, E., MacPherson, E., & Theobald, S. (2012). *Assessment of the capacity of the health sector to respond to violence against women and children in Malawi* (pp. 1–71).

Chinkonde, J.R., Sundby, J., Martinson, F. (2009). The prevention of mother-to-child transmission programme in Lilongwe, Malawi: why do so many women drop out. *Reproductive Health Matters, 17*(33), 143-151.

Chimbiri, A. M. (2007). The condom is an "intruder" in marriage: evidence from rural Malawi. *Social Science & Medicine (1982)*, *64*(5), 1102–15.

Canadian International Development Agency (CIDA). (2003). Gender Equality Tip Sheet: HIV/AIDS. Retrieved from http://www.oecd.org/dac/gender-development/44896348.pdf.

Colbert, A. M., Kim, K. H., Sereika, S. M., & Erlen, J. a. (2010). An examination of the relationships among gender, health status, social support, and HIV-related stigma. *The Journal of the Association of Nurses in AIDS Care : JANAC*, *21*(4), 302–13.

Dahl, V., Mellhammar, L., Bajunirwe, F., Bjorkman, P. (2008). Acceptance of HIV testing among women attending antenatal care in south-western Uganda: risk factors and reasons for test refusal. *AIDS Care, 20*(6), 746-752.

Devarajan, S. (2004). Making Services Work for Poor People. *Journal of African Economies* (13), 142–166).

Deininger, K. & Mpuga, P. (2005). Economic and Welfare Impact of the Abolition of Health User Fees: Evidence from Uganda. *Journal of African Economies, 14*(1), 55-91.

Dow, K. 1992. Exploring Differences in Our Common Future(s): The Meaning of Vulnerability to Global Environmental Change. *Geoforum 23*(3), 417–36.

Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, *16*(1), 13–20.

Eide, M., Myhre, M., Lindbaek, M., Sundby, J., Arimi, P., & Thior, I. (2006). Social consequences of HIV-positive women's participation in prevention of mother-to-child transmission programmes. *Patient Education and Counseling*, *60*(2), 146–51.

Ekouevi, D. K., Stringer, E., Coetzee, D., Tih, P., Creek, T., Stinson, K., … Dabis, F. (2012). Health Facility Characteristics and Their Relationship to Coverage of PMTCT of HIV Services across Four African Countries: The PEARL Study. *PLoS ONE*. Retrieved from http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0029823. [Accessed 10th November, 2014]

Filippi, V., Ronsmans, C., Campbell, O.M., Graham, W.J., Mills, A., Borghi, J., Koblinsky, M., Osrin, D. (2006). Maternal health in poor countries: the broader context and a call for action. The Lancet, *368*(9546), 1535-1541.

Foster, G. M. (1984). Anthropological Research Perspectives on Health Problems in Developing Countries. *Social Science & Medicine*, *18*(10), 847–854.

Gerthnerova, E. (2011). *Knowledge as a Vehicle for Change in Reproductive Health and HIV/AIDS Prevention*. M.A. Dissertation, University of Utrecht, Utrecht.

Government of Malawi. (2012). Global AIDS response progress report. Retrieved from http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/MWI_narrative_report_2014.pdf.

Hamela, G., Kabondo, C., Tembo, T., Zimba, C., Kamanga, E., Mofolo, I., Hosseinipour, M. C. (2014). Evaluating the benefits of incorporating traditional birth attendants in HIV Prevention of Mother to Child Transmission service delivery in Lilongwe , Malawi. *African Journal of Reproductive Health*, *18*(1), 27–34.

Human Development Reports. (2014). Human Development Index Data. Retrieved from http://hdr.undp.org/en/data.

Higgins, J. a, Hoffman, S., & Dworkin, S. L. (2010). Rethinking Gender, Heterosexual Men, and Women's Vulnerability to HIV/AIDS. *American Journal of Public Health*, *100*(3), 435–45.

Jacobs, B., Ir, P., Bigdeli, M., Annear, P. L., & Van Damme, W. (2012). Addressing access barriers to health services: an analytical framework for selecting appropriate interventions in low-income Asian countries. *Health Policy and Planning*, *27*(4), 288–300.

Kasenga, F., Hurtig, A.-K., & Emmelin, M. (2007). Home deliveries: implications for adherence to nevirapine in a PMTCT programme in rural Malawi. *AIDS care, 19*(5), 646-652.

Kasenga, F., Hurtig, A.-K., & Emmelin, M. (2010). HIV-positive women's experiences of a PMTCT programme in rural Malawi. *Midwifery*, *26*(1), 27–37.

Kamwendo, J. (2014). Malawi proverbs in Chichewa language: Empowering or disempowering for girls/women. University of Botswana. Retrieved from http://www.seameo.org/languagemdgconference2010/doc/presentations/day1/julietkamwendo-sn.pdf

Khanna, R., 2013. Training manual on maternal health for CommonHealth, RUWSEC, and SAHAJ. Retrieved from: www.commonhealth.in.

Kuumuori, G. (2014) Barriers to accessing and using formal antenatal, delivery and postnatal care services in Ghana in the context of a free maternal health policy. The Ethox Centre. Retrieved from http://www.ethox.ox.ac.uk/research-1/global-health-ethics/barriers-to-accessing-and-using-formal-antenatal-delivery-and-postnatal-care-services-in-ghana-in-the-context-of-a-free-maternal-healthcare-policy.

Krokan, S. H., & Christiansen, C. S. (2010). *Preventing Mother-to-Child Transmission of HIV. A case study in the Lindi region, Tanzania*.

Kululanga, L. I., Sundby, J., Malata, A., & Chirwa, E. (2012). Male involvement in maternity health care in Malawi. *African Journal of Reproductive Health*, *16*(1), 145–57. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22783678.

Liamputtong, P. (Ed.) (2013). *Women, Motherhood and Living with HIV/AIDS*: *A Cross-Cultural Perspective.* Springer, Dordrecht.

Manzi, M., Zachariah, R., Teck, R., Buhendwa, L., Kazima, J., Bakali, E., … Humblet, P. (2005). High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling-up requires a different way of acting. *Tropical Medicine & International Health: TM & IH*, *10*(12), 1242–50.

Malawi Human Rights Commission. (2005). *Cultural Practices and their Impact on the Enjoyment of Human Rights, Particularly the Rights of Women and Children in Malawi*. Retrieved from http://www.medcol.mw/commhealth/publications/cultural_practices_report.pdf.

Measure Evaluation Population and Reproductive Health (PRH). (2014). Conceptual framework. Retrieved from http://www.cpc.unc.edu/measure/prh/rh_indicators/overview/conceptual-framework.html. [Accessed 12th October 2014].

Mills, E., Singh, S., Wilson, K., Peters, E., Onia, R. & Kanfer, I. (2006). The challenges of involving Traditional Healers in HIV/AIDS care. *International Journal of STI and AIDS, (17)*, 360-363.

Ministry of Health. (2012). *Malawi National Plan for the Elimination of Mother to Child Transmission 2012*. 1–120.

Mohanty, C. (1984). Under Western Eyes: Feminist Scholarship and Western Discourses. *Boundary 2, 13*(1), 333-358.

Mukherjee, S., & Benson, T. (2003). The Determinants of Poverty in Malawi, 1998. *World Development*, *31*(2), 339–358.

Mukobi, P. (2012). Assessing the approaches to male partner involvement in PMTCT in Uganda. Research report, MakSPH-CDC Fellowship Program. Retrieved from http://musphcdc.ac.ug/files/pdf/Assessing%20the%20%20approaches%20to%20male%20partner%20involvement%20in%20PMTCT%20in%20Uganda%20by%20peter%20mukobi.pdf. [Accessed 26th September 2014].

National Statistical Office. (2011). *Malawi - Demographic and Health Survey*, pp. 1–603. Retrieved from http://dhsprogram.com/pubs/pdf/FR247/FR247.pdf. [Accessed 27th September 2014].

Nombo, C., & Niehof, A. (2008) Resilience of HIV/AIDS affected households in a village in Tanzania: Does social capital help? *Medische antropologie, 20*(2), 241-257.

Ntata, P. R. T. (2007). Equity in access to ARV drugs in Malawi. *SAHARA J : Journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA , Human Sciences Research Council*, *4*(1), 564–74.

Obrist, B., Iteba, N., Lengeler, C., Makemba, A., Mshana, C., Nathan, R., Alba, S., Dilip, A., Hetzel, M., W., Mayumana, I., Schulze, A. & Mshinda, H. (2007). Access to health care in contexts of livelihood insecurity: a framework for analysis and action. *PLOS Medicine, 4*(10), 1584-1587.

Perez, F., Aung, K. D., Ndoro, T., Engelsmann, B., & Dabis, F. (2008). Participation of traditional birth attendants in prevention of mother-to-child transmission of HIV services in two rural districts in Zimbabwe: a feasibility study. *BMC Public Health*, *8*, 401.

Petrie, K. E. M., Schmidt, S. D., Schwarz, C. E., Koornhof, H. E., & Marais, D. (2007). Knowledge, attitudes and practices of women regarding the prevention of mother-to-child transmission (PMTCT) programme at the Vanguard Community Health Centre, Western Cape - A pilot study. *South African Journal of Clinical Nutrition*, *20*(2), 71–78.

Philips, K. (2007) Usisya profiling project. [Personal communications].

Ramdas, K. (2009) *Radical women, embracing tradition.* [TED talk]. Retrieved from http://www.ted.com/talks/kavita_ramdas_radical_women_embracing_tradition/transcript?language=en. [Accessed 9th November 2014].

Richey, L.A. (2011) *Antiviral but Pronatal? ARVs and Reproductive Health: The View from a South African Township.* In Sargent, S. & Browner, C. (eds.) (2011). *Reproduction, Globalization and the State: New Theoretical and Ethnographic Perspectives,* 68-82. Durham, NC: Duke University Press.

Standing, H. (2004). Understanding the ’demand side' in service delivery, *44*(0), 1-41.

Stringer, E.M., Chi, B.H., Chintu, N., Creek, T. L., Ekouevi, D., Coutzee, D., Tih, P., Boulle, A., Dabis, F., Shaffer, N., Wilfert, C.M., Stringer, J. (2008) Monitoring effectiveness of

programmes to prevent mother-to-child HIV transmission in lower income countries. *Bulletin of the World Health Organization, 86*(1), 1-80.

Susser, I., Stein, Z. (2000). Culture, Sexuality and Women's Agency in the Prevention of HIV/AIDS in Southern Africa. *American Journal of Public Health, 90*(7), 1042-1048.

Tallis, V. (2012). *Feminisms, HIV and AIDS : Subverting Power, Reducing Vulnerability* (p. 242). Retrieved from http://reader.eblib.com.proxy.library.uu.nl/(S(urmx4hlnyy4a50ctsxwi1wjr))/Reader.aspx?p=912212&o=998&u=kBvyHDjrQ9QPRV51NB7kyg==&t=1390208168&h=550A2D672460831B5A53B7F921986AF9CC869BE6&s=20725078&ut=3282&pg=1&r=img&c=-1&pat=n#

Tavory, I., & Swidler, A. (2009). Condom Semiotics: Meaning and Condom Use in Rural Malawi. *American Sociological Review*, *74*(2), 171–189.

UNICEF. (2002). The situation of women and children (Malawi). Retrieved from http://www.unicef.org/malawi/children.html. [Accessed 8th October 2014].

United Nations. (2008). Caregiving in the context of HIV/AIDS. Retrieved from http://www.un.org/womenwatch/daw/egm/equalsharing/EGM-ESOR-2008-BP.4%20UNAIDS_Expert%20Panel_Paper_%20Final.pdf. [Accessed 12th November 2014].

Van Hollen, C. (2013). *Birth in the Age of AIDS: Women, Reproduction, and HIV/AIDS in India.* Stanford University Press

Van Lettow, M., Bedell, R., Landes, M., Gawa, L., Gatto, S., Mayuni, I., Chan, A., Tenthani, L., Schouten, E. (2011). Uptake and outcomes of a prevention-of mother-to-child transmission (PMTCT) program in Zomba district, Malawi. *BMC Public Health*, *11*(426), 1-8.

Verheijen, J. (2013). *Balancing men, morals and money. Women's agency between HIV and security in a Malawi village*. African Studies Centre: Leiden.

Vogel, C., 1998. Vulnerability and global environmental change. LUCC Newsletter 3, 15–19.

World Bank. (2014). Life expectancy at birth, total (years). Retrieved from http://data.worldbank.org/indicator/SP.DYN.LE00.IN/countries/MW-ZF-XM?display=graph. [Accessed 6th November 2014]

World Health Organization. (2010). Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. pp1-93. Retrieved from: http://www.who.int/healthinfo/systems/monitoring/en/. [Accessed 12th November 2014].

World Health Organization. (2012). Programmatic update use of antiretroviral drugs for treating pregnant women and preventing HIV infections in infants. Retrieved from: http://apps.who.int/iris/handle/10665/70892. [Accessed 2nd November 2014].

12. Appendices

APPENDIX 1

Gender	Age groups						Total
	1-19	**20-29**	**30-39**	**40-49**	**50-59**	**60-69**	
Female	9	26	22	11	2	1	71
Male	1	10	10	3	5	2	31
Total	10	36	32	14	7	3	102

Table 1: Gender and age distribution of research population

APPENDIX 2

Misconception	**% that holds this belief**	**Answered 'I don't know' (%)**
You can tell whether a person has HIV by looking at them	24.8	0
Prayer or witchcraft spells can cure people or protect them from getting infected	10.6	15.8
HIV can be transmitted by mosquito bites	28	10.5
HIV can be prevented by washing the private parts after unprotected sex	31.1	21.1
ARVs can cure HIV if they are taken for a long period of time (i.e. 10 years)	11.5	35.8
ARVs stop transmission to other people	10.6	15.3

Table 2: HIV knowledge and misconceptions

APPENDIX 3

Table 3: Usisya antenatal clinic, data over last three years

Indicator	2011	2012	2013
# of newly registered ANC clients	401	398	443
% of women with known HIV status in ANC			15%
% of positive HIV tests at site			5%
% of HIV positive, pregnant women who received ART to reduce the risk of MTCT during pregnancy			86%
# of HIV positive, pregnant women who received ART to reduce the risk of MTCT during pregnancy	21	20	16
# of previously untested women who were tested in Maternity			8
# of infants born to HIV positive women	3	15	9
% of infants born to HIV positive women who received HIV-PCR testing within 6 weeks of life			53%
Women (16+y) given ART drugs in general	40	29	29
# of women tested for HIV	635	767	806
# of women tested positive	44	35	34
Babies born in the clinic	243	304	314
Women receiving voluntary testing and counseling, before pregnancy	208	343	364
Age distribution of women coming for antenatal care	10-14: 2 15-19: 49 20-24: 94 25-29: 182 30-34: 34 35>: 29	10-14: 1 15-19: 69 20-24: 103 25-29: 167 30-34: 28 35>: 21	10-14: 0 15-19: 101 20-24: 153 25-29: 142 30-34: 33 35>: 14

APPENDIX 4

Standard interview questions for women

General

1. Name
2. Age
3. Number of children
4. Marital status
5. Occupation
6. HIV status

Socio-economic status

7. Who do you consider as the head of the household?
8. Does any member of your family have an income?
9. What do you spend money on?
10. If you had a little more money, what would you like to spend it on?
11. Do you discuss money issues with your husband?
12. If you want to make a purchase, do you have to get permission from anyone?

About gender roles

13. How old were you when you got married?
14. How did you find your husband?
15. Did you and your husband ever discuss how many children you were going to have?
16. Does your husband consult you about important issues that have to be decided for the family? Can you give some examples?
17. Do you consult your husband for important decisions you have to make?
18. Do you feel like your husband respects you? Does he love you? And how do you feel about your husband? Is there anything you would like to change about him?
19. Can you tell me about your duties as a wife?
20. How do you divide the work between you and your husband?
    a. Would you like it if your husband did more work in the household, or with the children? Why, or why not?
    b. Would you prefer to fish instead of work on the land or do housework?
21. What happens if a man does something that women normally do (such as fetch water?), or a woman does a man's job? What would other people say or think?
22. What does it mean to be a good husband?
23. What does it mean to be a good wife?
24. How much time do you spend together with your husband? What kind of activities do you undertake together?

25. What would happen if these things changed, and men and women started mixing their tasks a bit more?
26. What kind of future do you see for your children? Would you like anything for them that is different from your own life?
27. Have you ever been involved in some kind of initiation ritual? An event where you 'became a woman'?
28. What happens if a man or a woman is found to be infertile, incapable of having children?
29. Do you use any birth control?

Health care

30. How is your health at the moment?
31. If you start to feel sick, what do you normally do?
    a. Nothing
    b. Consult Traditional Healer
    c. Go to hospital
32. Do you ever do self-medication?
33. How much knowledge do you have of health issues? Where did you learn about these things?
34. Do you usually believe health care workers if they tell you something? What if they tell you something different from what your family or your Traditional Healer says, who would you believe?
35. If you think back about the last couple of times you were sick, what were the causes of your illness?
    a. Have you ever been sick because of witchcraft?
    b. Do you know anyone who has fallen sick because of witchcraft?
36. Are there any health issues you would like to learn more about? Where could you go for more information?
37. How does religion play a role in health care? For example, do you discuss health issues at your church, do you get advice from religious leaders, do they come and visit you in the hospital if you are really ill?
38. Do you keep a record of your hospital visits or medication you have received? Would I be able to see it?
39. When you go to the clinic, do you have to ask your husband for permission, or at least tell him you're going? Does he ever tell you not to go?

Clinic perception

40. How do you feel about going to the clinic? Do you easily go or would you rather postpone until you feel that you are so sick that there is no choice?
41. How do you feel about the health care workers at the clinic? Who do you prefer to have as your doctor? Anyone you really dislike? (This information will not reach these people)
42. Have you ever had any problems at the clinic?

a. People being rude to you
b. Long waiting times
c. Doctor refused to see or treat you
d. Having to go to another hospital, because this one did not have the resources
e. Something else?

Pregnancy

43. How does your life change when you are pregnant?
44. Did you plan any or all of your pregnancies?
45. If you wanted to stop having children, would that be possible for you?
    a. Would your husband agree?
    b. Would you have access to birth control?
    c. Would you feel comfortable taking birth control?
46. What is the first thing you do when you find out you're pregnant?
    a. Tell your husband or family?
    b. Go to clinic?
    c. Go to traditional healer?
    d. Nothing, keep working
    e. Buy baby clothes etc.
47. Have you ever been to a Traditional Healer or midwife when you were pregnant?

For HIV positive women

48. Did you know you were HIV-positive before the birth of your last child?
49. If you were aware of your HIV-positive status, did you use PMTCT services?
50. During pregnancy, did you receive medicine to reduce the risk of passing the AIDS virus to your baby (single-dose nevirapine)?
51. During labour, did you receive medicine to reduce the risk of passing the AIDS virus to your baby (single-dose nevirapine)?
52. Did you take a daily dose of ARVs when you were pregnant?
53. Did your baby receive Nevirapine after birth?
54. How much trust do you have in the medications the hospital is giving you? And in the ones your baby receives?
55. How much trust do you have in traditional healing methods?

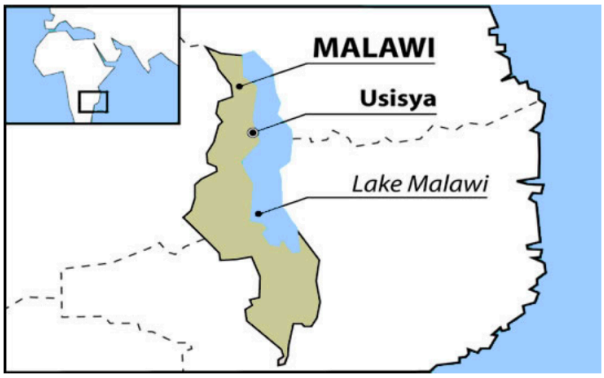
'Coping strategies'

56. How long have you known you were HIV positive?
57. How did you feel when you first found out you were HIV positive?
58. Did you tell anyone about your status?
    a. If yes, how did people react?
    b. If no, what did you fear in their reaction?
59. Do you take ARVs?
60. Do you collect them yourself?

61. Do you, or did you, ever feel shy about going to the clinic to collect drugs?
62. How has your life changed since you found out about your status?
63. Have you ever felt like people treated you differently because of your HIV status?
64. Do you think there is a difference for HIV+ men and women, in the way they are treated by other people in this community?
65. How do you deal with people's opinions of you? Does it matter a lot? Do you still talk to them, ignore them, run away, confront them, etc.?

APPENDIX 5:

Host organization: Temwa



Temwa is a British non-governmental organisation, founded in 2000. They only serve the remote region called Nkhata Bay in rural Northern Malawi, which has been neglected by the Government and other NGOs, due to its difficulty of access, and remote and rural location. It consists of 89 villages with a population of 39,000, and suffers from all the major rural development issues including poverty, malnutrition, high levels of HIV & AIDS and a lack of basic infrastructure1. One of the main catchment areas is Usisya, which has a population of 18,000.

Temwa believes that whilst the knowledge and resources exist for all areas of sustainable development, many rural communities lack the basic social capacity to enable change. As such their approach is twofold: to build social capacity and to stimulate the social action needed to realise change (Lewin, 2013, p.16). In the local language, 'Temwa' literally means 'community love'. This reflects their core effort to focus on community engagement and fight poverty, hunger and disease. All of Temwa's projects are run by the communities they serve, meaning that a fulltime staff of 34 locals manages the projects, giving the organisation the unique opportunity to fully understand the needs of the communities they serve, whilst providing much-needed employment to those who live locally. Meanwhile, a team of volunteers in Bristol is responsible for running Temwa's fundraising events, communications and the schools engagement programmes. Funds come from three sources; Events, Corporates and Trusts, and Foundations.

Projects

Current on-going projects include: HIV and AIDS education; support and testing services; interest-free microfinance loans; community agroforestry and tree planting to address malnutrition and deforestation; sustainable farming initiatives to promote organic

growing and environmentally friendly farming techniques; school building & bursary schemes; and the running of a community centre and library.

Temwa's main fundraising appeal is called 'Trees for Life', which aim to plant 250.000 trees a year in Northern Malawi. This gives companies a chance to offset their carbon footprint, while supporting Temwa's efforts to educate the communities about the care and importance of trees and sustainability. The communities are in dire need of a solution against deforestation, since it has been causing droughts, floods, displacement and soil erosion, which have in turn lead to poverty and hunger.

Health Education

Temwa believes that one of the main ways of overcoming the region's extremely high prevalence rate of HIV/AIDS is to talk about the issues with the community members, in order to empower them with knowledge and awareness. Since February 2009, Temwa has provided an extensive HIV & AIDS Mobile Counselling and Testing (MVCT) project throughout the region. The MVCT clinics aim to reduce the spread of HIV and improve the health of those people living with HIV & AIDS through providing mobile testing clinics that visit rural communities in their catchment area. Many people would not be able to access testing services without Temwa's project – 11,000 people live over an hour's walk away from the only clinic in Usisya, with some people living up to a nine hour walk away. In addition to providing testing clinics, the project also works to empower communities with the knowledge and understanding about their sexual health through advocacy and support activities.

Temwa uses film as a participatory educational tool, by going to remote villages with a projector and educational films about HIV/AIDS, among other things. The aim is to reduce the stigma against those infected with HIV as well as communicate information about the disease itself including the various ways of transmission and methods of treatment. In addition it also encourages people to go to testing clinics organised by Temwa.

Source: www.temwa.org